# Development of a Family-Based Care Model to Enhance Successful Living With a Permanent Colostomy Among Chinese Patients

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## ABSTRACT

The purpose of this action research was to develop a family-based care model to enhance successful living with a permanent colostomy among Chinese patients. It was conducted with 21 patients having a permanent colostomy, 18 primary family caregivers, nine nurses and the researcher, at a university hospital in a southwestern province of China. The major findings were presented in three parts: reconnaissance phase, spiral action research process, and final evaluation.

The reconnaissance phase revealed the main problems in the patients' situations of living with a permanent colostomy. Before discharge at hospitalization, bodily and mental suffering, inadequate discharge preparedness of the patients and their family caregivers, and issues on communication between the patients and their family caregivers were found. After discharge at home, the additional problems were: fewer social activities, insufficiency of continued nursing support for the patients and their family caregivers, and inappropriate family caregiving. Moreover, the meanings of successful living with a permanent colostomy perceived by the patients were extracted including: living with independence, living without suffering, and living without self-inferiority. These findings were used to determine further actions.

During the spiral action research process, three concepts (successful living with a permanent colostomy, family-based care, and empowerment) and the tendency of critical social theory to pursue emancipatory knowledge, were used to guide the development of a model which included two distinct stages in helping the patients to: (1) accept the reality of colostomy formation and learn colostomy care; and (2) adapt to living with a colostomy and return to a normal family life.

In the first stage during hospitalization, eight nursing strategies were employed, e.g. facilitating mutual goal-setting and decision-making among the dyads (patients and their family caregivers) and the nurses; empowering the dyads to perform colostomy care by providing information and inspirational support; providing preoperative ostomy site marking and education, and postoperative skill training and education. In the second stage, after discharge at home, seven nursing strategies were adopted, e.g. encouraging the patients to improve awareness and ability in colostomy self-care; encouraging the family caregivers to provide the patients proper assistance/support and gradually withdraw from colostomy care; providing continued nursing support by telephone follow-up, counseling, ostomy clinic visit, and home visit.

As a result, the components of this model were refined under the Chinese sociocultural context composed of: self-care with a proper degree of independence, proper family caregiving, active empowerment, and successful living with a permanent colostomy. Chinese beliefs in responsibility/obligation and interdependence between the patients and their family caregivers may improve the harmony between the two through a balancing of self-care actions of the patients and caregiving actions of family caregivers to a proper degree. Nurses should take this into consideration during the process of empowerment in order to enhance the patients' successful living with their colostomies.

A final evaluation about this model revealed significant improvement of skills in using ostomy appliances among the dyads. Moreover, both ability of self-care and awareness about life situations were improved, and this enabled the patients to proactively overcome restrictions in living with a colostomy and return a normal family life. During the action process, an equal partnership was built up among nurses, patients and family caregivers with mutual understanding and collaboration. All 14 dyads expressed satisfaction with the provision of overall nursing service in this model. The nurses felt satisfied with this model and were committed to continue using it. However, some factors must be considered, such as the patients' belief in self-care as their own responsibility, independence in using ostomy appliances, physical and emotional status, available family support, and continued nursing support.

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Hui Tao

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# Introduction

## Background of the Study

A colostomy is the most common type among abdominal ostomies, which can be temporary or permanent. A temporary colostomy is generally reversed after three months since the first surgery, while a permanent colostomy brings the lifelong impacts on the person with it. A permanent colostomy is mostly formed following an abdomino-perineal resection of the rectum for treating low rectal cancer. To be estimated, there are about 1,000,000 patients with a permanent colostomy in China, and the number of new cases is approximately 100,000 each year Wan (2007). With the change of Chinese lifestyle, the incidence of rectal cancer among Chinese people manifests a growing trend, and correspondingly the population with a permanent colostomy is continuously increasing.

The creation of a permanent colostomy has the lasting and multidimensional impacts on the patients and their lives. They confront numerous problems and difficulties which influence their successful living with a colostomy. Firstly, the colostomy-related surgery brings obvious physical changes, such as altered bodily appearance, incontinent defecation, sexual dysfunction, and complications related to colostomy. Secondly, the patients experience a chain of psychological reactions. Anxiety and depression are the most common emotional disorders frequently reported (Cotrim & Pereira, 2008; Nugent, Daniels, Stewart, Patankar, & Johnson, 1999). Other responses involve loss of personal control and autonomy (McVey, Madill, & Fielding, 2001); sense of less self-esteem, lower value and self-inferiority (Honkala & Berterö, 2009; Li & Zou, 2008); feeling of distance from body (Thorpe, McArthur, & Richardson, 2009); fear of leakage, odor, noise and come-off related to ostomy appliance (McMullen et al., 2008; Popek et al., 2010); and some negative emotions, e.g. shock, disgust, embarrassment, helplessness, insecurity and uncertainty (Andersson, Engstrom, & Soderberg, 2010; Salter, 1992). Thirdly, both physical and psychological changes cause many restrictions in life involving eating, dressing, working, travel, physical exercise, leisure activity, social gathering and sexual life

(Grant et al., 2011; Honkala & Berterö, 2009; Manderson, 2005). Moreover, the patients usually encounter social stigma, discrimination, refusal and isolation (Annells, 2006; Tappe et al., 2005; Williams, 2008).

Studies reported that rectal cancer survivors with a colostomy had poorer quality of life (QOL) than those without a colostomy (Engel et al., 2003; Fucini, Gattai, Urena, Bandettini, & Elbetti, 2008), and the patients with a colostomy encountered more problems on body image, sexuality, bowel function, and psychosocial function (Cotrim & Pereira, 2008). Moreover, in China, recent studies revealed that the adaptation score of individuals with a colostomy was low compared with the ostomy patients in developed countries (Hu et al., 2010; Xu, Cheng, Dai, & Yang, 2010). Hence, these studies suggested that the current ostomy care needs to be improved for achieving better patient outcomes, e.g. increased QOL and higher adaptation level.

Successful living with a permanent colostomy is affected by a number of factors. Correlational studies have discovered that variables associated with nursing support, family support and self-care by patients can contribute to positive patient outcomes (Ito & Kazuma, 2005; Marquis, Marrel, & Jambon, 2003; Piwonka & Merino, 1999; Wu, Chau, & Twinn, 2007). More health care professionals have recognized that the care plan should be provided jointly to the patients and their family caregivers in order to accomplish the best care for patients. Considering the caregivers' needs and maintaining their health can guarantee that they deliver the quality care for patients (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Northouse, Katapodi, Song, Zhang, & Mood, 2010). Additionally, the perspectives of caregivers on self-care can influence the patients' actions of self-care. According to Orem (2001), nurses can also contribute to the patients' self-care through doing for, teaching, guiding, supporting, and providing good environment for them.

However, most nursing service for patients with a colostomy is delivered at hospitalization, and there is insufficiency of continued nursing support after hospital discharge. The patient needs on continued support from enterostomal therapist (ET) nurses remain unmet because most activities of ET nurses are implemented in the inpatient/acute-care units (D'Orazio & Ozorio, 2008). Also, community nurses lack adequate knowledge on ostomy care to provide quality service for patients with an ostomy at home or in community (Skingley, 2004), Studies found that the main problems and difficulties faced by the patients with an ostomy happened in the first month at home after discharge involving fatigue, issues on diet and bowel function, usage of ostomy appliances, ostomy-related complications, access to ET nurses and peer supporters, and adapting to personal and social life (Burch & Taylor, 2012; Zhang, Wong, You, & Zheng, 2011). Moreover, their family caregivers often lack the preparation of giving care at home (Cameron, Shin, Williams, & Stewart, 2004) and experienced the difficulties of involvement (Persson, Severinsson, & Hellstrom, 2004). Studies reported that the caregivers of ostomy patients presented high level of anxiety and depression, which was not only due to worry about their sick relatives but also owing to their own inadequate preparation of knowledge and skills on ostomy care (Cotrim & Pereira, 2008; Persson et al., 2004).

In China, several issues on ostomy care involved a limited number of ET nurses, lack of routine ostomy home visit or follow-up, and task-orientated and nurse-directed nursing service delivery. The details of these issues were as follows.

Firstly, a small number of ET nurses are available. Xu (2009) reported that there were only 152 ET nurses until November 2008. To take an example, there are only four ET nurses until 2012 in a province of southwestern China (Q. X. Wang, personal communication, June 24, 2012). Hence, perioperative ostomy care is mostly conducted by ward nurses rather than ET nurses.

Secondly, community nurses hardly provide home visit for ostomy patients after discharge. Except for periodical medical check-up, the patients are scarcely acquired to have regular follow-up by hospital nurses. In Chinese community health service system, the connection and collaboration between hospitals and community health service units is still incomplete with lack of two-way referral system.

Thirdly, nursing service delivery on ostomy care remains task-orientated and nurse-directed. The ostomy nursing is centralized in the period of post-operation for accomplishing routine nursing tasks, e.g. infusion, medication, changing ostomy appliance and simple postoperative education. Liu, Mok, and Wong (2005) reported Chinese patients’ perceptions that nurses were always busy in task-orientated work and had no time to communicate with patients about their psychological problems. Therefore, the interaction of nurses with ostomy patients and their family caregivers is commonly nurse-directed with paucity of communication and mutual understanding. In fact, Chinese patients expect that the nurses respect the family's desires and regard the family as a care unit rather than the individual (Liu et al., 2005). Thus, nursing interventions should be jointly delivered to patients and their family caregivers with more communication.

Moreover, Chinese cultural beliefs affect the actions of self-care and receiving family caregiving among patients with a permanent colostomy. In Confucian ethical system of role relationships, family members universally believe that they have the moral obligation to care for their sick relatives rather than that the sick should be encouraged self-care (Wong & Pang, 2000). Hence, both inadequate self-care and excessive family care possibly coexist in family with colostomy patients. On the one hand, the excessive family care may hinder the patients' practice of self-care and delay their independence and adaptation. On the other hand, the excessive family care may become unnecessary family burden. In some cases, whatever the elderly patients with a colostomy can care by themselves or not, their adult children often take the responsibility of caring their elderly parents due to Chinese belief in filial piety. With changes in Chinese family structure attributing to one-child policy, the adult children will be overwhelmed by caring their elderly parents with a colostomy and other roles, e.g. working, parenting and caring other relatives. Therefore, both the patients and their family caregivers should be empowered to assume necessary responsibilities and tasks in colostomy care for reciprocal benefits.

Considering the above issues, a model appropriate for Chinese context should be family-based, i.e. take patients and their family caregivers as a unit of care. Meanwhile, this model should advocate active empowerment to inspire the patients' initiatives in colostomy self-care and enlighten the family caregivers' awareness about the properness of caregiving, and finally improve the patients' successful living with their colostomies and maintain the harmony of family. In this model, nurses would ally with their clients (both patients and family caregivers). Based on the active communication and dialogue, the nurse-client understanding would be improved. Nursing interventions would be able to better match the needs/expectations of patients and family caregivers. Moreover, the patients are empowered to assume reasonable responsibilities in caring by themselves, while the caregivers are empowered to provide the patients proper care and encourage their self-care. Thus, mutual support between the patients and their caregivers would be enhanced and further contribute to the patients' successful living with their colostomies.

Little was known about how a family-based care model would improve patients' successful living with a permanent colostomy. Action research is the most appropriate methodology to develop and validate the family-based care model through a cyclic, participatory and collective process of utilizing research evidence and self-reflection to make changes and improvement in practice (Glasson, Chang, & Bidewell, 2008; Kemmis & McTaggart, 1988). Different from the predetermined protocol in quasi-experimental and experimental studies, action research can flexibly employ a dynamic spiral to develop the most suitable care model in a real situation by constantly revising and refining the model and applying various strategies. During the process of developing this family-based care model, the intervention strategies would be chosen by the participants according to the changing needs of patients and their family caregivers at pre-operation, post-operation and after discharge. Also, the key components of this care model would be discovered and determined by the participants and the researcher together. Expectably, this developed family-based care model would be client-directed, applicable and sustainable.

## Purpose of the Study

The purpose of the study was to develop a family-based care model to enhance successful living with a permanent colostomy among Chinese patients.

## Research Questions

1. How do the patients take care of themselves to become successful in living with a permanent colostomy?
2. How do the family caregivers take care of the patients for successful living with a permanent colostomy?
3. What strategies can the nurses use to help the patients and their family caregivers for successful living with a permanent colostomy?

4. What are the components of the family-based care model to enhance the patients' successful living with a permanent colostomy?

5. How can the family-based care model work to enhance the patients' successful living with a permanent colostomy?

## Theoretical Framework of the Study

The theoretical framework of this study was constructed based on the following components: (1) successful living with a permanent colostomy, (2) family-based care, (3) empowerment, and (4) action research based on the philosophy of critical social theory. The first three components contribute to the conceptual framework and the last one provides the methodological framework (Figure 1).

Successful living with a permanent colostomy represents positive outcomes wanted and hoped by colostomy patients. In previous qualitative studies about lived experiences of ostomy patients, the meanings of successful living were mainly in relation to two themes: adaptation and life satisfaction. Adaptation refers to the sense of adapting to changes due to having an ostomy, in relation to alternations in both self and life (Andersson et al., 2010; Honkala & Berterö, 2009; Manderson, 2005). Life satisfaction can be defined as the sense of being satisfied with current life, which is expressed by using various words, e.g. satisfaction, comfort, goodness, appreciation and growth (Andersson et al., 2010; Manderson, 2005; Nicholas, Swan, Gerstle, Allan, & Griffiths, 2008). Moreover, most existing instruments focused on measuring adaptation and QOL of ostomy patients. High scores in positive factors and low scores in negative factors are explained as good patient outcomes. The subscales of these instruments involve physical, psychological, social and sexual domains, for example, acceptance, anxious preoccupation, social engagement and anger (Simmons, Smith, & Maekawa, 2009); work/social function, sexuality/body image, stoma function, financial impact, skin irritation and overall satisfaction (Baxter et al., 2006); sleep, sexual activity, relations to family and close friends, social relations to other than family and close friends (Prieto, Thorsen, & Juul, 2005).

In order to help the patients to achieve successful living with their colostomies, family involvement is necessary, especially after discharge at home, which can be associated with Confucian belief in caring for the sick relatives as a moral obligation of other family members (Wong & Pang, 2000). According to Schumacher (1996), family-based care can be defined as a dynamic and dyadic endeavor involving both patients and their family caregivers to manage illness itself and the impacts of illness on family life through the cognitive, behavioral and interactional processes. The dimensions of family-based care include 12 generic aspects of cancer care (Schumacher, 1996) and three aspects of ostomy care, including: managing symptoms and side effects, providing optimal nutrition, promoting emotional well-being, maintaining the sense of self, maintaining social activities, communicating with extended family members, communicating with health professionals, carrying out medical regimen, negotiating health care system, seeking out holistic or supplementary therapies, reallocating household responsibilities, preparing for an uncertain future, applying ostomy appliances and accessories, preventing/treating ostomy-related complications, and building the regular pattern of defecation. Furthermore, based on differences in the extent of family involvement, the family-based care can be classified into three behavioral patterns: (1) self-care pattern, in which illness management was mainly through self-care actions; (2) caregiving pattern, in which illness management was mainly through caregiving actions; (3) collaborative pattern, in which illness management was mainly through joint actions (Schumacher, 1996). In this study, self-care and collaborative care patterns would be encouraged and expected in interactions between patients and their family caregivers, because the two patterns are more beneficial to improve patients' independence, lighten family caregivers' burden, and thereby improve the harmony of family.

The lifelong feature of a permanent colostomy requires the patients or their family caregivers to develop the ability of performing colostomy care independently in order to deal with the long-term situation of living with a colostomy. Instead of directly doing for the patients, nurses should facilitate the empowerment of patients by enhancing their ability (power) of self-care. Meanwhile, their family caregivers should be empowered to provide necessary assistance to these patients. Gibson (1991) defined empowerment as "a social process of recognizing, promoting and enhancing persons' abilities to meet their own needs, solve their own problems and mobilize the necessary resources in order to feel in control of their own lives" (p. 339). Also, the empowerment is the process of client-nurse interaction including the following components: trust, empathy, participatory decision-making, mutual goal-setting, cooperation, collaboration, negotiation, overcoming organizational barriers, organizing, lobbying and legitimacy (clients as partners). In the process of empowerment, nurses play roles of helper, supporter, counselor, educator, resource consultant, resource mobilizer, facilitator, enabler and advocator (Gibson, 1991).

Action research shares the goals of empowerment, emancipation and change with critical social theory (Berman, Ford-Gilboe, & Campbell, 1998). Critical social theorists maintain that the production of knowledge is based on historical, social, political, gender, and economic conditions (Berman et al., 1998). Habermas advocated that people need emancipatory knowledge to liberate themselves from situational constraints for gaining freedom and autonomy (as cited in Holloway & Wheeler, 2010). Through critical self-reflection, people can empower themselves to change their world (Berman et al., 1998). If the patients are aware of their situations of living with a colostomy by critical self-reflection, and acquire the ability of colostomy care by active participation and constant exercise, they would be free from life restrictions and return to a normal life.

During the process of action research, all participants, including the clients (patients and family caregivers) and the nurses, can actively engage in the research and equally collaborate with the researcher as the autonomous and responsible individuals, in order to improve the changes of life conditions (Kemmis & McTaggart, 1988; Lauri & Sainio, 1998). Adopting a systematic and cyclical method composed with planning, taking acting, observing, critically reflecting and re-planning, action research can generate solutions of problems and changes in practice (Glasson et al., 2008; Holter & Schwartz-Barcott, 1993; Kemmis & McTaggart, 1988). Thus, action research is a good way to improve the interactions among nurses, patients with a permanent colostomy and their family caregivers in order to help the patients to achieve successful living with their colostomies.

To summarize, in this study, three concepts were used as the conceptual framework, i.e. successful living with a permanent colostomy, family-based care and empowerment; the approach of action research served as the methodological framework (Figure 1). These components are compatible with each other for the purpose of gaining personal control over living with a permanent colostomy. Following the tendency of critical social theory to pursue emancipatory knowledge, the methodology of action research was used by the researcher to develop the family-based care model to enhance successful living with a permanent colostomy among Chinese patients.

## Definition of Terms

A family-based care model refers to a pattern of care with the active interactions among the nurses, the dyads of patients with a permanent colostomy and their family caregivers, in order to achieve the mutual goal of patients' successful living with their colostomy. The nurses empower both the patients and their caregivers to make mutual care plan, develop knowledge and skills about colostomy care and management, and foster independent self-care and proper family caregiving. The patients make efforts to manage their colostomies and colostomy-related impacts through developing necessary ability of self-care. The family caregivers provide necessary assistance and support to improve development of the patients' self-care ability through preparing themselves well about colostomy care and management.

Successful living with a permanent colostomy is defined as patients' feeling of living well with their colostomies involving physical, psychological, social and spiritual aspects. It represents those positive outcomes expected/achieved by these patients and can be evaluated through understanding the patients' perceptions on meanings of successful living with a permanent colostomy and their actual feelings about this. The patients' self-care ability was appraised mainly using the Evaluation Form on the Skill of Using Ostomy Appliances (Appendix A6). Simultaneously, using this same form, the family caregivers' skill of using ostomy appliances was assessed, which can partially reflect their ability of caregiving.

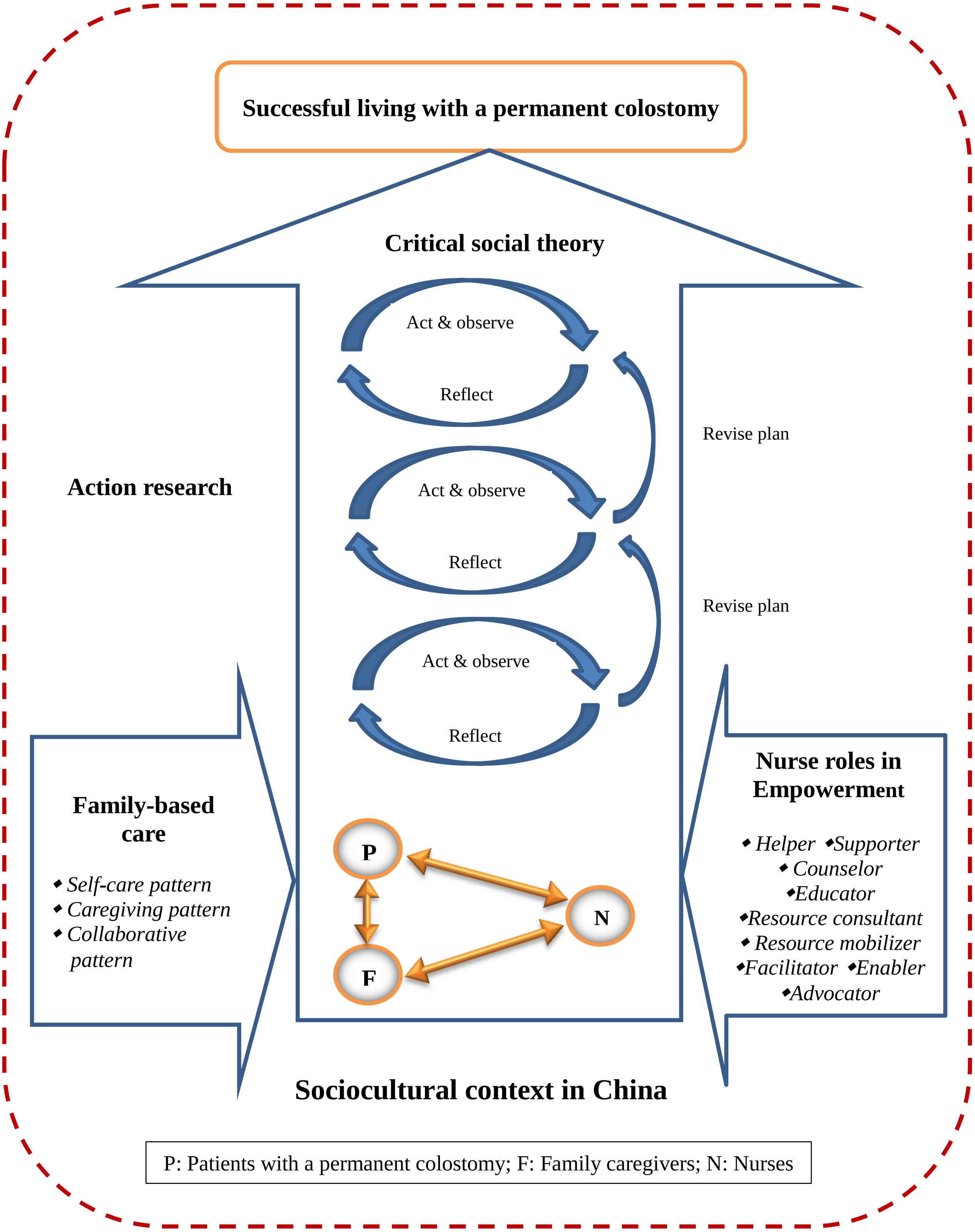


*Figure 1.* Theoretical Framework of This Study

## Significance of the Study

This study generated a family-based care model to enhance Chinese patients' successful living with a permanent colostomy in a university hospital of southwestern China. It can be useful for nurses to understand the meanings of successful living with a permanent colostomy in a Chinese sociocultural context; develop the partnering relationships with the dyads of patients and their family caregivers; empower both the patients and their family caregivers to perform independent colostomy care and management with a holistic vision. Besides, this study created a self-care manual for colostomy patients, and several instructional and operational materials for nurses, e.g. an instructional manual about this family-based care model, a record form of telephone follow-up for colostomy patients, and a manual of questions and answers about colostomy nursing care.

## Summary

The patients with a permanent colostomy for treating rectal cancer are the majority among people with an ostomy in China. These patients encounter a great quantity of problems in physical and psychosocial aspects, difficult adaptation to their lives and low QOL. Nursing support, family support and self-care are three important factors contributing to successful living with a permanent colostomy. However, there is paucity of continued nursing support, particularly in the early stage after discharge. Also, the mutual understanding and communication among nurses, patients and their family caregivers are insufficient. Action research approach can flexibly apply various intervention strategies to develop the family-based care model appropriate for Chinese sociocultural context. This model facilitated collective participation and collaboration in helping the patients to achieve successful living with their colostomies. During the process of conducting this study, the paradigm shift has happened from the traditional professional-directed (patient-compliance) approach to the client-directed approach with the equal partnering relationship.

# Chapter 2

# Literature Review

In order to providing a broad understanding on the phenomenon of living with a permanent colostomy, relevant literature was reviewed and presented as follows. Meanwhile, the methodological issues related to action research were also reviewed and summarized by the researcher. This chapter includes:

1. Experience of the patients in living with a permanent colostomy
    1.1 Impacts of a permanent colostomy on the patients
    1.2 Personal perceptions on having a permanent colostomy
    1.3 Coping with a permanent colostomy
    1.4 Coping outcomes
2. Successful living with a permanent colostomy
    2.1 Meanings of successful living
    2.2 Factors influencing successful living
    2.3 Nursing interventions to enhance successful living
3. Experience of the family caregivers to care for the colostomy patients
4. Foundational concepts used to develop the family-based care model
    4.1 Family-based care
    4.2 Self-care
    4.3 Empowerment
5. Action research

## Experience of the Patients in Living With a Permanent Colostomy

An ostomy refers to the surgical procedure to construct an artificial opening on the abdominal wall as an alternative passage of body waste elimination, which commonly attributes to bowel/bladder cancer, inflammatory bowel diseases, congenital diseases and trauma. The basic types of abdominal ostomies include colostomy, ileostomy and urostomy (ileal conduit) (Registered Nurses' Association of Ontario (RNAO), 2009; Wondergem, 2007). The constructed opening is generally called as stoma which is used interchangeably with ostomy.

A colostomy is most common among the three types of abdominal ostomies. The colostomy is generally created through the surgery of abdomino-perineal resection of the rectum, which is usually permanent. This surgery with a permanent colostomy is mostly to treat the advanced low rectal cancers which inferior margin is less than 5 cm from the anal verge (Fucini et al., 2008). Besides, surgery, postoperative chemotherapy and preoperative radiotherapy are major treatment methods for the patients with very low rectal cancer.

Different from a temporary ostomy, a permanent colostomy cannot be reversed, and thus the patients’ experience of living with it is long-lasting.

### Impacts of a permanent colostomy on the patients

Although the colostomy-related surgery saved the patients’ lives, it has brought many negative impacts on their living, involving physical, psychological, social and sexual aspects. Besides, ostomy-related complications have extra impacts on the patients’ living.

Firstly, the surgery induces the changes of bodily appearance and elimination pattern. A red lip-like ostomy suddenly appeared on the smooth abdominal wall. Some patients feel scared at the first time to look at their colostomies. Meanwhile, the function of defecation is uncontrolled and the opening is diverted from anus to abdomen. With frequent occurrence of ostomy-related complications and other symptoms, the patients undergo physical pain and discomfort.

Secondly, both the changes of bodily appearance and incontinence cause a series of psychological issues. Emotional disorders in terms of anxiety and depression were frequently reported (Boyles, 2010). Other psychosocial responses involved loss of personal control and autonomy (McVey et al., 2001); sense of less self-esteem, low value and self-inferiority (Honkala & Berterö, 2009; Li & Zou, 2008); feeling of distance from body (Thorpe et al., 2009); fear of leakage, odor, noise and come-off related to stoma appliance (Popek et al., 2010); disgust, embarrassment and unacceptance toward stoma (Smith, Loewenstein, Rozin, Sherriff, & Ubel, 2007); insecurity about life (Andersson et al., 2010); and social stigma and isolation (Williams, 2008).

Thirdly, some patients with a colostomy would rather stay at home than go outside to attend social activities owing to lack of self-confidence about body image, fear about leakage and odor, and inconvenience of changing or emptying pouch. Richbourg and colleagues (2007) reported that 47% participants were prevented from leaving their houses because of worry about leakage, and 54% had reduced their activities that they had previously enjoyed due to the existence of ostomy. Also, McKenzie and associates (2006) discovered that the patients eluded social and leisure activities when they considered the need of changing their pouches.

Moreover, the colostomy-related surgery influences personal sexual life. While physical problems (e.g. impotence or dyspareunia) hinder the fulfillment of normal sexual function, other subjective problems (e.g. damaged self-perception and lack of body confidence) disorder personal sexual life (Boyles, 2010). One study reported that 43% of patients with a colostomy had sexual function problems (Nugent et al., 1999).

In addition, the high incidence of ostomy-related complications leads to unbeneficial impacts on personal health. Studies showed that up to 43% of patients with a colostomy experienced complications (Persson, Gustavsson, Hellstrom, Lappas, & Hulten, 2005). Specifically, between 18% and 55% of patients with an ostomy experienced peristomal skin irritation, 1% to 37% experienced peristomal hernia, 2% to 25% experienced stomal prolapse, 2% to 10% experienced stenosis, and 1% to 11% experienced retraction of the ostomy (Colwell, Goldberg, & Carmel, 2001). These complications commonly cause physical pain and difficulties of ostomy care, which further arouse negative emotions and less of social activities. Hence, some patients with serious complications might feel hard to accept the presence of ostomy due to so much suffering.

### Personal perceptions on having a permanent colostomy

In order to understand the patients' perceptions on having a permanent colostomy, the researcher conducted a meta-synthesis by reviewing previous qualitative research related to the lived experiences of patients with an ostomy. Relevant literature was obtained through CINAHL and PubMed databases for English language papers, and CNKI database for Chinese language papers published from 1990 to March 2012. Sixteen articles were selected, which were conducted in various sites, including 4 studies in the United Kingdom, 3 in the United States, 2 in Australia, Brazil and Sweden, and 1 study in each of the following countries, Canada, China and Iran.

Despite the participants lived in different cultural contexts, a great number of similarities in their perceptions on having an ostomy were clustered into two themes: (1) altered self and (2) restricted life. Altered self was the whole picture of self-concept determined by the acting individuals after having an ostomy. Restricted life was the summary presented by the individuals about their life world.

#### ***1. Altered self***

The altered self was individual awareness about the self after ostomy formation, encompassing two subthemes: (1) being with bodily changes, (2) being different from others.

##### *1.1 Being with bodily changes*

An ostomy is commonly formed to divert the end of bowel onto the abdominal wall. The excrement is emptied into an outside pouch around the ostomy. Having an ostomy inevitably associated with the subjective awareness of bodily changes. According to Thorpe et al. (2009), the changes involved bodily appearance, function and sensation.

The changes of bodily appearance were with respect to outward looking of ostomy, profile of ostomy appliance and clothed bodily semblance. Universally, the patients regarded ostomy appearance as a terrible looking, especially at the first seeing an ostomy (Dazio, Sonobe, & Zago, 2009; Manderson, 2005; Nicholas et al., 2008). Moreover, the appliances including skin barrier and pouch hanged around an ostomy were apparently disrupting bodily appearance (Kelly, 1992; Manderson, 2005; Popek et al., 2010). Additionally, the patients had to change their usual dressing style and wear in loose and baggy clothes so as to conceal their ostomy bags for remaining common clothed appearance (Honkala & Berterö, 2009; Salter, 1992). Briefly, in the awareness of patients, their real bodily appearances with an ostomy were far away from a pleasant and nice impression in public eyes (Salter, 1992).

The changes of bodily function among ostomy patients are commonly relevant to defecation and sexual ability. Generally, a normal anus can control the excretion of feces and flatus, while an ostomy means loss of control about the elimination of bowel waste. The loss was related to the unprompted and unexpected feces or flatus output from an ostomy and the experience of appliance leakage (Dazio et al., 2009; Honkala & Berterö, 2009; Manderson, 2005; McMullen et al., 2008). Additionally, an ostomy also means altered sexual function. Whether men or women patients, pelvic surgery, especially abdomino-perineal resection of the rectum, often damaged the relevant nerves and tissues and then caused impotence in male and dyspareunia in female (Andersson et al., 2010; Deeny & McCrea, 1991; Kelly, 1992; Manderson, 2005).

For bodily sensation, the main changes are associated with the sound of bowel gas emission and the fecal odor. The sense was demonstrated by the uncontrolled sound of flatus passing through the ostomy; the smell of bowel contents when the appliance was changed, emptied or leaking (Andersson et al., 2010; Annells, 2006; Dabirian, Yaghmaei, Rassouli, & Tafreshi, 2010; Dazio et al., 2009; Deeny & McCrea, 1991; Grant et al., 2011; Honkala & Berterö, 2009; Manderson, 2005; McMullen et al., 2008; McVey et al., 2001; Popek et al., 2010; Salter, 1992).

As a result, the patients kept the strong self-consciousness about their bodies with an ostomy in mind (Kelly, 1992; Manderson, 2005), involving particular appearance with ostomy, appliance and wide clothes, incontinence of defecation and flatus, sensation of noise/odor and leakage.

### *1.2 Being different from others*

The inextricable self-consciousness on the bodily changes evoked strong self-determination, that is, individuals with an ostomy was completely different from the common others including the previous self. There were some reasons responsible for this: (1) incontinence and appliances became the permanent trait of individuals with an ostomy (Kelly, 1992); (2) appliance-related problems usually surrounded the individuals, e.g. burst, leakage, inflated pouch with gas and bag's come-off (Dabirian et al., 2010; Kelly, 1992; McMullen et al., 2008; Popek et al., 2010); (3) ostomy-related complications produced distinct experiences from others, e.g. hernia, infection, painful cramping and peristomal skin problems (Dabirian et al., 2010; McMullen et al., 2008); (4) individual toilet action was changed (Honkala & Berterö, 2009; Kelly, 1992; Popek et al., 2010); (5) the body with an ostomy was not a healthy and pleasant looks in the public vision (Salter, 1992).

Moreover, differences from others hinted that individuals with an ostomy were abnormal. Individuals imagined themselves allocated by others as a sick and non-normal person, or an illegitimate sex partner (Annells, 2006; Kelly, 1992). Some patients regarded an ostomy as a small handicap (Andersson et al., 2010). Some women felt themselves not like a normal woman but "half-man half-woman" (Deeny & McCrea, 1991). This was because: (1) they stood up in the toilet and emptied the ostomy bag; (2) they were unable to dress and attend the activities like a normal woman (Honkala & Berterö, 2009).

The individuals' cognitions about abnormality further leaded to the sense of low self-esteem and self-value. Some patients delineated their feelings of being undignified, stigmatized or marginalized by others (Annells, 2006; McMullen et al., 2008). Due to the presence of ostomy, women felt themselves unclean and unattractive, while men felt themselves loss of masculinity (Dazio et al., 2009; Honkala & Berterö, 2009; Manderson, 2005). Importantly, such the experiences of bag's leakage and come-off seemed to be childhood-like opposite to adulthood-like. The childhood symbolized dependence while the adulthood represented independence. Also, the incontinence and dependence on others' assistances constantly challenged the autonomous adulthood of the self with an ostomy and breached his/her self-esteem as an adult (Manderson, 2005).

Although the ideas of difference from others, abnormality and low self-esteem were full of the mind of individuals with an ostomy, they still were expecting to present an ordinary and normal self to the world (Kelly, 1992; McVey et al., 2001; Salter, 1992). The conflict between real private self and expected public self further reinforced the feeling of being limited in living with an ostomy.

### 2. *Restricted life*

The world in which the self was living could be determined as a life world full of restrictions due to the existence of ostomy. Individual daily life, social life and sexual life were disturbed. Even, some ostomy patients lost their senses of control in life (Popek et al., 2010).

Having an ostomy affected many aspects of individual daily life involving dressing, activity and rest, especially dietary routine. Previous clothing styles had to be modified to avoid pressing ostomy and pouch visualization (Grant et al., 2011; Honkala & Berterö, 2009). Because the dietary choice were widely relevant to many issues, such as excess bowel gas, disgusted odor, diarrhea, constipation and intestinal blockage, the individuals had to concern the avoidance of food that resulted in gas and rapid gastrointestinal movement (Dabirian et al., 2010; Grant et al., 2011; McMullen et al., 2008). A number of patients quit from previous physical exercises and chose other appropriate activities (Grant et al., 2011; Honkala & Berterö, 2009). In addition, ostomy patients were prohibited to lift heavy objects over 5 kilograms for preventing hernia (Dabirian et al., 2010). Some female patients mentioned sleep difficulties relevant to pouch leakage and uncomfortable position of sleeping (Grant et al., 2011).

The limitations of everyday life related to have an ostomy could become an obstacle of individual social life. Commonly, owing to leakage, come-off and fecal smell related to ostomy appliance, individuals with an ostomy were exposed under the watchful eyes. Being afraid of the exposure as a peculiar person, they avoided participating in social activities. The life limitations were presented in a lot of specific aspects, such as working, travelling, community gathering, visiting a cinema and having a shopping (Andersson et al., 2010; Dabirian et al., 2010; Dazio et al., 2009; Grant et al., 2011; Honkala & Berterö, 2009; Kelly, 1992; McMullen et al., 2008; Popek et al., 2010; Salter, 1992). Seriously, some ostomy patients lost their previous jobs, which caused decreased income. As a result, financial issues commonly challenged the individuals along with disease-related costs (Dabirian et al., 2010; Grant et al., 2011).

Particularly, individuals with an ostomy felt restricted even difficult in sexual life (Andersson et al., 2010; Dazio et al., 2009; Deeny & McCrea, 1991; Grant et al., 2011; Kelly, 1992; Popek et al., 2010), which attributed to both physical and psychological issues. Possible reasons were explained by several scholars as follows: (1) actual physical discomforts, such as anal scars, constant pain, nausea and tiredness (Andersson et al., 2010; Manderson, 2005; McMullen et al., 2008); (2) male erectile dysfunction (Deeny & McCrea, 1991; Manderson, 2005; Popek et al., 2010); (3) female intercourse pain due to narrow vagina (Andersson et al., 2010); (4) fear of the appliance's accidents (Manderson, 2005; McMullen et al., 2008); (5) no desire in sexual activity owing to side effect of antidepressants, embarrassment about body image, long-term sexual inactivity during the treatments, or no longer sexually active as elderly people (Deeny & McCrea, 1991; Manderson, 2005; McMullen et al., 2008); (6) no confidence for sex pleasure due to strong self-consciousness about ostomy and appliance (Manderson, 2005); (7) spouse's rejection or difficult acceptance (Manderson, 2005; Popek et al., 2010). In brief, the bodily changes become psychological barriers in sexual relationships, in turn the psychological barriers deteriorate bodily dysfunction.

### Coping with a permanent colostomy

According to the above meta-synthesis, the patients' coping with a permanent colostomy was further reviewed. A core category was obtained, namely, overcoming restrictions. The changes of body and self-concept aroused the sense of restricted life and actual restrictions, which stimulated the self with an ostomy to seek solutions so as to overcome the limitations. The adopted strategies were composed of accepting the reality, balancing revelation and concealment, utilizing internal resources and seeking/receiving external supports.

### 1. *Acceptance and rejection*

After encountering initial negative emotions, individuals would be trying to accept the reality of living with an ostomy. Studies discovered some facilitators and barriers contributing to the individual acceptance. The facilitators involved: (1) positive attitude, e.g. perceiving current life as better than before having an ostomy (Honkala & Berterö, 2009), having to face and get on with the life situation (Dazio et al., 2009; Kelly, 1992); (2) beginning to manage the ostomy by oneself (Deeny & McCrea, 1991); (3) being supported and accepted by significant others (Li & Zou, 2008; McMullen et al., 2008; Nicholas et al., 2008; Popek et al., 2010; Salter, 1992); (4) realizing disease severity and no more choice (Barnabe & Dell'acqua, 2008). Moreover, the barriers associated with: (1) difficult adaptation to the changed body appearance (Manderson, 2005); (2) non-supportive friends or family (Manderson, 2005; Popek et al., 2010); (3) being refused and alienated by relatives, colleagues and neighbors (Li & Zou, 2008); (4) fear of rejection and actual rejection in sexual relationships (Kelly, 1992). Besides, individual self-acceptance affected family members to accept him/her in turn (Dabirian et al., 2010; Deeny & McCrea, 1991). The interpersonal acceptance and rejection between individuals and their significant others apparently reflected the interactive feature of human actions.

### 2. *Revelation and concealment*

If individuals had accepted their ostomies and lives with an ostomy, they would have less worry that the truth of having an ostomy was known by others, and even initiatively inform their ostomies to significant others. The action of choosing self-revelation mostly attributed to: (1) expectation about the receiver's supportive response (Nicholas et al., 2008); (2) being accepted by others after disclosure (Andersson et al., 2010; Li & Zou, 2008; Nicholas et al., 2008; Salter, 1992); (3) feeling of self-relief after informing others (Nicholas et al., 2008).

Differently, some patients tended to keep their ostomies as a secret. They complied with limited choices of clothing, wore a pouch cover in order to disguise their ostomies and bags, or carefully prevented leakage (Annells, 2006; Grant et al., 2011; Honkala & Berterö, 2009; Manderson, 2005; McMullen et al., 2008; Salter, 1992). The actions of concealment usually were due to: (1) opinion that body waste should be hided and unobservable to others (Honkala & Berterö, 2009; Kelly, 1992); (2) thought that the body with an ostomy was unpleasant (Manderson, 2005; Salter, 1992); (3) expectation of keeping an ordinary body image in public eyes (Kelly, 1992); (4) experiences of embarrassment and shame about an ostomy (Nicholas et al., 2008); (5) fear of stigma and non-acceptance from others (Nicholas et al., 2008); (6) being rejected by others (Kelly, 1992; Li & Zou, 2008).

Reflectively, the revelation and concealment were often related to the acceptance and rejection, which was another obvious example about the interactive feature of human actions in the complex phenomenon of living with an ostomy. Self-acceptance supported individuals to reveal the reality of having an ostomy to significant others without much worry. Once individuals obtained others' acceptances, they would have more confidence about the action of revelation. Conversely, if individuals were rejected by others, they would keep caution for next revelation or maintain concealment.

### 3. Utilizing internal resources

The internal resources utilized by individuals to cope with the limitations in life with an ostomy emerged in two main aspects: (1) exploiting internal strength; (2) engaging in self-care.

#### *3.1 Exploiting internal strength*

Individual internal strength plays a significant role to overcome life restrictions, which is the source of reappraising self and facing life with positive attitude. First of all, individuals tried to actively reappraise ostomy, self and life and look forward to the future. An ostomy was appraised as not only the cost of saving life or curing illness but also something that the individual has to live with and can manage (Andersson et al., 2010; Kelly, 1992; McMullen et al., 2008). The self was perceived as a "fighter or survivor" (McVey et al., 2001, p. 348), so that the individual felt happy and thankful to the current life of having survived from illness (Andersson et al., 2010; McMullen et al., 2008). The experience of illness and ostomy was helpful for the individual to raise awareness through the assimilation of stressful events (McVey et al., 2001; Nicholas et al., 2008). Moreover, the positive reappraisals urged the shift of individual life attitude. Individuals became positive to accept difficulties of living with ostomy, reconsider their life priorities, enjoy each day, and look ahead the future of life with an ostomy (Andersson et al., 2010; Barnabe & Dell'acqua, 2008; McMullen et al., 2008; McVey et al., 2001; Nicholas et al., 2008). Additionally, Popek et al. (2010) found that the variance of coping strategies between ostomy patients with different level of quality of life (QOL). The patients with high QOL possessed humor, optimism, gratitude and positive attitude, while those with low QOL more expressed loss of control and humiliation. Grant et al. (2011) proposed that resilience is important for individuals with an ostomy.

### *3.2 Engaging in self-care*

Good self-care is very imperative for ostomy patients to maintain physical comfort and an ordinary body image in public sights. Hence, a number of patients take efforts to learn the knowledge and skills about ostomy care and proactively apply into the practice of management.

Individuals were learning ostomy care by various ways, such as consulting health care professionals, discussing with other ostomy patients, reading books and seeking Internet resources (Andersson et al., 2010; Deeny & McCrea, 1991; Li & Zou, 2008; Nicholas et al., 2008). During the practice of self-care, individuals also accumulated a great number of skills and tips, for instance, preparing extra appliances and clothes in case of leakage, concerning the location of bathroom, having a habit of stroking the stomach to check the content volume in pouch, and using colostomy irrigation technique to regulate defecation (Andersson et al., 2010; Honkala & Berterö, 2009; Kelly, 1992; McMullen et al., 2008).

Through effective self-care, individuals could fit the public expectation about satisfactory impression management (Salter, 1992) and develop own independences, confidences and capabilities (Barnabe & Dell'acqua, 2008; Deeny & McCrea, 1991; McVey et al., 2001; Nicholas et al., 2008). However, there were still some ostomy patients who had difficulties with self-care owing to physical deficit, faulty ostomy site selection, or inappropriate appliance (Deeny & McCrea, 1991). Popek et al. (2010) commented that patients in high QOL group actively engaged in self-care, while patients in low QOL group requested more caregiving.

### *4. Seeking and receiving external supports*

Individuals seek and receive external supports to deal with the limitations in life with an ostomy in order to release negative emotions, feel being accepted, and acquire useful information and actual ostomy care.

The types of supports involved practical, informational and emotional supports (Andersson et al., 2010; Deeny & McCrea, 1991; Li & Zou, 2008; McVey et al., 2001; Nicholas et al., 2008). Practical supports referred to actual ostomy care provided by others, e.g. changing ostomy appliance. Informational supports were related to the individual needs of information about disease, treatments, operation, ostomy care, diet, activities, clothes and sexual activities (Andersson et al., 2010; Deeny & McCrea, 1991). Emotional supports were with regard to the individual needs of expressing emotions and attaining consolations or encouragement (Deeny & McCrea, 1991; McVey et al., 2001).

Additionally, the sources of supports included: (1) health care professionals who provided practical and informational supports and consisted of doctors, nurses, especially enterostomal therapist (ET) nurses (Andersson et al., 2010; Deeny & McCrea, 1991; Li & Zou, 2008; McMullen et al., 2008; McVey et al., 2001); (2) family members who contributed actual care and emotional supports mostly from partners/spouses (Andersson et al., 2010; Li & Zou, 2008; Manderson, 2005; McMullen et al., 2008; McVey et al., 2001; Popek et al., 2010); (3) ostomy self-help/support group which consists of ostomy patients and performed mutual informational and emotional supports (Andersson et al., 2010; Dabirian et al., 2010; Li & Zou, 2008; McMullen et al., 2008; McVey et al., 2001); (4) others who were composed of friends, colleagues or peers (Andersson et al., 2010; Li & Zou, 2008; Manderson, 2005; Nicholas et al., 2008).

### Coping outcomes

Reviewing existing research, the outcomes of coping with a permanent colostomy were presented by more/less positive aspect, high/low adaptation level, and high/low QOL.

McVey et al. (2001) conducted a longitudinal study to explore the experience of patients with an ostomy for treating cancer using grounded theory approach.

During three months after surgery, the consequences of coping actions were divided into two aspects: more positive and less positive. The more positive aspect included: controlling and limiting fear, limiting traumatic information processing, looking towards life with ostomy honeymoon period, accepting ostomy, assimilating the trauma, facing reality and returning to usual activities. Differently, the less positive aspect involved: deterioration, withdrawal, alienation, anxiety about continuing symptoms and further procedures.

Simmons et al. (2009) developed the Ostomy Adjustment Inventory-23 (OAI-23) and defined adaptation as "acceptance of the ostomy and behaviors associated with coping with the ostomy" (p. 6). The instrument consists of 23 items measured on a 5-point Likert scale (0 - 4). The scope of scores is 0 - 92 and higher scores imply better adaption to an ostomy. The OAI-23 was tested (*n* = 570) and displayed satisfied reliability and validity. The factor analysis identified four subscales: acceptance, anxious preoccupation, social engagement and anger. Furthermore, Xu and colleagues (2010) modified the OAI-23 and examined in Chinese ostomy patients (*n* = 118). Three items were deleted based on the cultural difference. The factor analysis obtained three subscales: positive feeling, negative feeling and social adjustment.

Several ostomy-specific QOL instruments were found: (1) the Stoma Quality of Life Scale (SQOLS) with six subscales, i.e. work/social function, sexuality/body image, stoma function, financial impact, skin irritation and overall satisfaction (Baxter et al., 2006); (2) the Stoma Quality of Life Index (SQLI) including three subscales, i.e. QOL, satisfaction with medical care and self-efficacy (Marquis et al., 2003); (3) the Stoma Quality of Life Instrument (Stoma-QOL) composed of four factors, i.e. sleep, sexual activity, relations to family and close friends, social relations to other than family and close friends (Prieto et al., 2005); (4) the Chinese Version of Stoma-QOL adapted from Stoma-QOL (Prieto et al., 2005), which consists of five factors, i.e. social interaction, impact of ostomy pouch on patients, relationships with family and friends, physical and psychological conditions, need to know the location of bathroom (Wu, Jin, Shang, Liang, & Yang, 2011). Using these instruments, QOL of the patients with an ostomy can be evaluated, and higher scores refer to better QOL.

To conclude, the outcomes of coping with a permanent colostomy can be presented in various ways and commonly involve positive and negative aspects. According to *Cambridge Dictionaries Online*, success can be defined as the achieving of the results wanted or hoped for; or something that achieves positive results. Thus, in this study, successful living was employed to express the positive outcomes which is wanted and hoped by the patients in living with a permanent colostomy.

## Successful Living With a Permanent Colostomy

Successful living with a permanent colostomy may associate with many concepts, e.g. adaptation, life satisfaction, self-care and empowerment. According to Andrews and Roy (1991), successful adaptation results in optimal health, well-being and QOL. Masters (2014) pointed that “the goal of nursing is to foster successful adaptation” (p. 60). In professional ostomy care, continued support after discharge from hospital is vital for ostomy patients to facilitate positive adaptation and successful rehabilitation (Borwell, 2009; O'Connor, 2005). Only when the patients obtained ability and confidence in practical ostomy care could they accomplish successful adaptation to an ostomy (Mead, 1994). In other words, the patients are empowered to manage colostomy-related impacts by themselves and thereby they can successfully adapt to changes due to having a colostomy and obtain satisfying life. In this part, the meanings of successful living with a permanent colostomy, influencing factors, and relevant nursing interventions were reviewed as follows. The concepts of self-care and empowerment were discussed later.

### Meanings of successful living

As mentioned early, successful living with a permanent colostomy is defined as the sense of living well with a permanent colostomy, which is used to present the positive results of coping with the colostomy formation.

Through examining previous qualitative studies, the descriptions of positive outcomes in the lived experience of patients with an ostomy were identified to interpret the meanings of successful living with a permanent colostomy. The meanings were mainly perceived as (1) adaptation and (2) life satisfaction.

### 1. *Adaptation*

The term of adaptation was frequently used in existing studies related to ostomy care, which was interchangeably applied with adjustment. Honkala and Berterö (2009) contributed three expressions: bodily adaptation, psychological adaptation and adaptation to daily life. The bodily adaptation refers to practical dealing with ostomy, e.g. emptying, cleaning and changing ostomy pouch. The psychological adaptation is associated with coping with the initial grief response to bodily changes. Adaptation to daily life displays how the patients with an ostomy employ various strategies to manage their daily life. Furthermore, Andersson et al. (2010) discussed adaptation to life with an ostomy by highlighting the importance of reconfirming self-esteem and belief in own ability of self-care. Besides, adapting to bodily changes was emphasized by Manderson (2005), which was related to loss of bodily control over body waste and ugly bodily appearance. Also, the achievement of social adaption was described in conjunction with the utilization of social support system, and overcoming sense of self-inferiority and helplessness (Li & Zou, 2008). In brief, adaptation is associated with both self and life changes involving physical, psychological, social and daily life adaptation. Adaptation can be interpreted as the individuals' sense of adapting successfully to changes due to having a colostomy.

### 2. *Life satisfaction*

Life satisfaction can be defined as the individuals' sense of being satisfied with current life with a colostomy. The sense of satisfaction was expressed by previous qualitative studies using diverse terms. Nicholas et al. (2008) reported that the participants acquired personal satisfaction and growth in life through struggling with their experience of having an ostomy, accumulating skills and insight, reflecting and assimilating the experience of illness in daily life. Besides, using the term of comfort, the participants expressed that they felt comfortable about having an ostomy and being in the bathroom to change a bag (Manderson, 2005). Specifically, the patients with a colostomy for treating rectal cancer presented that they were happy to survive the cancer, which facilitated them to accept reality and have a good life with a colostomy (Andersson et al., 2010). In a word, the sense of life satisfaction is widely linked to not only satisfaction (contentment) but also growth, comfort, happiness and goodness.

### Factors influencing successful living

A variety of factors influence the patients' successful living with a permanent colostomy. Reviewing relevant studies, the main influencing factors involved three types: socio-demographic, psychological and situational factors (Cheng & Xu, 2009; Hu et al., 2010; Marquis et al., 2003; Piwonka & Merino, 1999; Simmons, Smith, Bobb, & Liles, 2007; Sinha, Goyal, Singh, & Rana, 2009). Besides, the impacts of Chinese culture were also discussed as cultural factors in this part.

#### ***1. Socio-demographic factors***

The socio-demographic factors included age, gender, educational level, income level, occupational status and availability of social security.

##### *1.1 Age*

The elderly people easily face the difficulty in ostomy self-care due to a decline in vision or hand flexibility, while younger people usually encounter the issues in sexual life. Piwonka and Merino (1999) reported self-care was more significant for predicting adaptation to a colostomy in older group than younger group. Manderson (2005) found that older patients were not sexually active, so that they could easily adapt to the change of sexual function due to ostomy-related surgery. Conversely, the sexual life in younger patients was obviously affected.

##### *1.2 Gender*

Previous studies showed that gender difference affected the patients' successful living with a colostomy. In a long-term study of rectal cancer survivors living with an ostomy for at least 5 years (Krouse et al., 2009), women were found to be more likely to employ coping strategies and engage in social support than men. However, women also felt more depression and lower score for and psychosocial well-being. Xu and colleagues (2010) found that male colostomy patients had higher adaptation level than female ones, possibly because there are more expectancy for male about bravery and forcefulness in Chinese traditional views, which becomes the motivation of positive adaptation. Moreover, there are differences on sexual problems between male and female with an ostomy, which is associated with their adaptation in sexual life. Impotence (erectile dysfunction) is significant for male, while dyspareunia is common for female due to vaginal dryness/damage and pain on vaginal penetration (Strode, 2009). Besides, Piwonka and Merino (1999) found that ostomy self-care, body image, social support and socio-economic status emerged as significant predictors of adaptation among male patients, while ostomy self-care, time since surgery and social support were significant among women.

*1.3 Educational level*

The ostomy patients with higher educational level commonly possess higher income and more opportunities of accessing quality health care services Thus, higher educational level was correlated to better adaptation and QOL in ostomy patients (Piwonka & Merino, 1999; Sinha et al., 2009).

*1.4 Income level*

Income level was positively correlated with the adaptation of ostomy patients. Bekkers and associates (1997) reported that higher income was related to a better adaptation score. Besides, Lundy et al. (2009) demonstrated a positive significant relationship between household income and psychological well-being in colorectal cancer survivors (with or without ostomy), that is, higher income level referred to better psychological well-being.

*1.5 Occupational status*

Having an ostomy has the effect of different degree on the patients’ occupational status. One study displayed that 20% of colostomy patients had to change their work after surgery (Nugent et al., 1999). Moreover, Pittman et al. (2008) stated that the employed participants were more likely to have severe difficulty in adapting to an ostomy.

*1.6 Availability of social security*

Both availability of social security and income are associated with the costs of ostomy appliances and health care services. Colostomy patients with lack of social security and low income are confronted with more financial hardships (Piwonka & Merino, 1999). Additionally, the out-of-pocket financial costs for ostomy management were negatively correlated with QOL (Youngberg, 2010). In China, although it was reported that Chinese public medical insurance coverage has been more than 95% in 2011 (F. J. Li, 2009, February 9), the actual reimbursement rate was low because many items have to be paid by out-of-pocket. The cost of ostomy appliances and accessories is not still covered by the public medical insurance (F. He, personal communication, May 22, 2011), which induces the financial difficulties to some low-income family with ostomy patients, especially in rural areas.

### 2. *Psychological factors*

The psychological factors are the imperative predictors for successful living with a permanent colostomy, which consist of self-efficacy, ability of ostomy self-care and ostomy acceptance.

#### *2.1 Self-efficacy*

As a positive factor, self-efficacy can contribute to both good adaptation and QOL among ostomy patients. Bandura (1982) identified self-efficacy as “judgments of how well one can execute courses of action required to deal with prospective situations” (p. 122). Simmons et al. (2007) demonstrated that stoma care self-efficacy referred to “the conviction by patients that they can successfully manage their stoma to minimize adverse outcomes” (p. 630). Bekkers and colleagues (1996) defined self-efficacy as “one's expectations regarding the ability to perform some specific task in the adaptation process of stoma patients” (p. 183), and developed the Stoma Self-Efficacy Scale which comprised 2 factors with 22 items. The two factors were: (1) stoma care self-efficacy referred to expected self-efficacy regarding the patients’ capability to care for their ostomies; (2) social self-efficacy determined as expected self-efficacy related to the patients’ social functioning.

#### *2.2 Ability of ostomy self-care*

The ability of ostomy self-care is a positive factor contributing to the successful living with a permanent colostomy. Orem (2001) used this term of self-care agency to refer to a kind of complex ability obtained by individuals in order to maintain or improve well-being and human development. Applying the Ostomy Self-Care Scale, Piwonka and Merino (1999) verified that ostomy self-care was positively correlated with adaptation to a colostomy. Also, studies among Chinese people with a permanent colostomy reported that higher ability of self-care was in relation to better adaptation (Hu et al., 2010; Xu, Cheng, Dai, et al., 2010).

### *2.3 Ostomy acceptance*

Ostomy acceptance plays a key role in predicting successful living with a permanent colostomy. Simmons et al. (2007) found that ostomy acceptance was significantly associated with adaptation to a colostomy. The patients who readily accept their colostomies could confidently perform self-care, encounter little stress in interpersonal relationships, and thereby better adapt to life changes due to a colostomy. Ostomy acceptance was defined as “the extent to which patients with colostomies accept the limitations of their surgery without experiencing negative feelings” (Simmons et al., 2007, p. 630). Moreover, acceptance meant that not only the individuals could accept their own ostomies but also they could be accepted by significant others (Nicholas et al., 2008). Ideally, the patients with an ostomy wished that others could treat them as a normal person (Salter, 1992).

## ***3. Situational factors***

The situational factors emphasize on the current situations of patients with a permanent colostomy, which comprise disease-related and environmental factors involving: time since ostomy surgery, ostomy-related complications, side effects of chemotherapy, family support, social support and professional support.

### *3.1 Time since ostomy surgery*

Studies indicated that both adaptation and QOL among ostomy patients could be gradually improved over time. Piwonka and Merino (1999) discovered that the patients’ adaptation to colostomy changed with the time lapse since surgery, and the first postoperative year should be a cut-off point for individual adaptation. Pittman, Kozell, and Gray (2009) stated that the impact of intestinal ostomy formation mostly emerged in the early postoperative stage, which was improved dramatically by 3 months after surgery and then promoted gradually over the rest of the first year.

### *3.2 Ostomy-related complications*

Ostomy-related complication was a common negative factor influencing successful living with a permanent colostomy. Youngberg (2010) reported that the patients who were with irritant contact dermatitis got lower QOL total scores than those without irritant contact dermatitis, and the number of complications was negatively correlated with QOL. Boyles (2010) claimed that the incidence of stomal complications directly effects on patients’ objective functioning. The severity of the complications was significantly correlated with the severity of the impact, leading to difficulties with adaptation after the surgery, thereby brings a negative influence on QOL (Pittman et al., 2009).

### *3.3 Side effects of chemotherapy*

Most of patients with a permanent colostomy are recommended to perform the postoperative chemotherapy which is likely to occur during several months. The side effects of chemotherapy raise many uncomfortable symptoms and impede ostomy self-care, and thus become a barrier of successful living with a permanent colostomy. It is global for the rectal cancer patients with a newly formed ostomy to cyclically encounter side effects of chemotherapy, such as fatigue, nausea and diarrhea. Moreover, peripheral neuropathy and palmar-plantar erythrodyaesthesia (hand-foot syndrome) associated with new chemotherapy agents are generally dose-accumulated and have impacts on the patients’ energy recovery and self-care. Wallace and Taylor (2011) reported an example that a patient developed peripheral neuropathy and palmar-plantar erythrodyaesthesia following adjuvant chemotherapy, which made difficult in ostomy self-care.

### *3.4 Family support*

Previous studies often incorporated family support into social support for discussing the impacts of non-professional support on adaptation to an ostomy. However, family support is more fundamental than other social support (e.g. support from friends, colleagues, fellow patients) (Piwonka & Merino, 1999), which is a key to successful living with an ostomy (McMullen et al., 2008). The family caregivers take a variety of care responsibilities at home, such as changing ostomy appliance, dealing with ostomy accident, preventing complications, symptom control, and assisting activities of daily living, general encouragement, accepting ostomy and humor (Cameron et al., 2004; McMullen et al., 2008; Persson et al., 2004). Studies found that the patients’ spouses took most responsibilities among the family caregivers who contributed to actual ostomy care and emotional support (Andersson et al., 2010; Li & Zou, 2008; Manderson, 2005; McMullen et al., 2008; McVey et al., 2001; Popek et al., 2010).

### *3.5 Social support*

Social support is a positive factor contributing to successful living with a permanent colostomy. Hu et al. (2010) discovered that the adaptation scores of colostomy patients were positively correlated with the scores of perceived social support, namely, higher level of perceived social support mobilized better adaptation. Here, social support was broadly defined as an individual's emotional experience and satisfaction level to be respected, supported and understood by family, friends, neighbors, colleagues or others. Similarly, Piwonka and Merino (1999) reported that the patients who perceived little social support felt more difficult in adapting to a colostomy than those who perceived greater social support. After starting work again, it was also vital for ostomy patients to feel accepted by their colleagues and managers (Kelly, 1992). Moreover, ostomy self-help/support group is beneficial for the patients to live successfully with an ostomy. As McMullen et al. (2008) found, the participants highlighted the value of ostomy visitors who have recovered from ostomy surgery and spend time with patients who will undergo ostomy surgery; they obtained many lessons learned and inspiration from ostomy visitors and self-help/support group, e.g. tips concerning odor control and hygiene maintenance, and confidence in resuming a normal life.

### *3.6 Professional support*

Professional support derives from multidisciplinary health care team. In particular, ET nurses have crucial roles in facilitating the patients' successful living with their colostomies. Marquis et al. (2003) stressed that the access to ET nurses was very important in the early stage of post-operation, which was positively associated with QOL of ostomy patients. Ito and Kazuma (2005) found that the periodical contact with ET nurses could contribute to the absence of worry about peristomal skin problems and ensure the patients to get the opportunity of consultation when they needed. Moreover, other nurses associated with ostomy care are also responsible for the patients' successful living after surgery. Nurses can provide opportunities about open and general communication to enhance positive feeling of the patients with an ostomy (Brown & Randle, 2005). According to Orem (2001), nurses can contribute to personal self-care through doing for, teaching, guiding, supporting another, and providing good environment.

### *4. Cultural factors*

Chinese cultural beliefs affect the patients' successful living with a permanent colostomy mainly in the three ways: (1) dependence on family caregiving, (2) not seeking emotional support from nurses, (3) utilizing the therapies of traditional Chinese medicine (TCM). Additionally, the transformation of Chinese family was reviewed here.

Firstly, in a traditional Chinese community, family members accept a moral obligation to look after their sick relatives, rooted in the Confucian ethical system of role relationships (Wong & Pang, 2000). Thus, valuing care dependence rather than self-care is common among elderly patients with a colostomy. Many elderly patients with a colostomy are cared by their adult children rather than their spouses. Based on Chinese beliefs in filial piety, it seems taken-for-granded. However, with the change of Chinese family structure owing to the one-child policy, elderly people are advocated to take more responsibility in their own care. The maximized self-care is beneficial for both individual and family health.

Secondly, different from open communication in Western culture, few Chinese patients with a colostomy seek emotional support from nurses. Liu et al. (2005) summarized the following reasons based on patients' perceptions: (1) nurses were always busy with task-orientated work and had no time for patients' psychological problems; (2) nurses' responsibilities are mainly for patients' physical rather than psychological condition; (3) nurses are not psychologists; (4) psychological concerns are private; (5) family members are the source of emotional support. Although the patients needed to express their worries to others, they would not like to burden their listeners. Hence, many patients chose to keep their psychological issues in themselves.

Thirdly, based on beliefs in TCM, Chinese patients with a permanent colostomy for treating rectal cancer are likely to seek and adopt TCM therapies at the same time of undergoing the treatment and care originated from the conventional Western medicine (CWM). TCM stresses that the goal of treatment and care is to achieve the harmony of human and universe, the balance of Yin and Yang, and the harmony of body and mind. Common utilized therapies encompass dietary therapy, herbal therapy, acupuncture and moxibustion, massage (Tui Na), breathing exercises

(Qi Gong) and Tai Chi and so on. For example, the patients use dietary therapy (herbal dinner) to supplement Qi and blood after colostomy-related surgery; deal with appetite loss, nausea and vomiting owing to chemotherapy; enhance immunity for preventing cancer recurrence.

Additionally, recent studies (Y. H. Li, 2011; Tang & Chen, 2012; Yan, 1997) revealed the following characteristics about the transformation of Chinese family: (1) nuclear family becomes the major type of Chinese family structure; (2) conjugal relationship has replaced parent-child relationship to become the central axis of Chinese family relations; (3) the equality of conjugal relationship has been similar to that in Western family; (4) feeding and nurturing relationship between parents and children is still present, which is different from Western individualism and family relationships; (5) developing kinship is still valued, which is influenced by blood relationship and space distance. However, due to one-child policy, ageing trend, economic development, more women now in workplace, and the declining number of extended family, more sick/elderly people will be cared for by professional institutions rather than their family members. Further, the weakening of family caregiving and the strengthening of self-care will occur simultaneously.

### Nursing interventions to enhance successful living

Through reviewing previous studies, some features were identified in nursing interventions related to enhance successful living with a permanent colostomy.

Firstly, patient education was a major intervention method. There were several characteristics presented: (1) preoperative education was paid more attention than before, e.g. preoperative community-based ostomy education (Chaudhri, Brown, Hassan, & Horgan, 2005), enhanced recovery program for ostomy patients (Bryan & Dukes, 2010); (2) teaching methods utilized modern multimedia technology, e.g. multimedia education program for ostomy patients (Lo et al., 2011); (3) training expert patients as educators, e.g. expert patient program for colostomy patients (Cheng, Xu, Dai, & Yang, 2012). However, the choices of educational timing and contents are still in discussion. For instance, the preoperative education about emptying and changing the ostomy pouch was accepted by patients in UK (Bryan &

Dukes, 2010), while some Chinese patients refused to be taught about the application of ostomy appliances before surgery (Zhang & Zheng, 2010).

Secondly, some intervention studies have involved counseling service. But, the counseling mainly focused on practical problems of ostomy care more than psychological or sexual issues. For example, an ostomy education program with some elements of counseling revealed the significant improvement in study group involving time to ostomy proficiency, postoperative hospital stay and number of postoperative unplanned interventions, but there was no significant difference between groups about the relief of anxiety and depression (Chaudhri et al., 2005).

Thirdly, modern communication techniques (e.g. telephone, telenursing) were applied into follow-up for ostomy patients. Considering various factors composed of human resource, financial support, equipment, time and patients' changing needs, the most effective follow-up methods and procedures still need further exploration (de la Quintana Jimenez et al., 2010). Also, the traditional method of home visit is still in need.

In addition, some complementary therapy techniques were utilized in caring the patients with an ostomy. For instance, using muscle relaxation training was to decrease anxiety and improve QOL among ostomy patients (Cheung, Molassiotis, & Chang, 2003). Aside from relaxation therapy, there are many relevant therapeutic techniques that might be used in ostomy care, such as music therapy, massage, acupuncture therapy, aromatherapy, biofeedback, breathing exercises, hypnosis, imagery and meditation etc. Of course, the research evidences about their effects are necessary. Also, it must be considered what techniques are appropriate for ostomy patients, and when, where, how to perform.

Furthermore, among previous intervention studies on ostomy care, the main evaluation indicators encompassed: (1) clinical outcomes, e.g. costs, hospital stay, time to ostomy proficiency, number of unplanned ostomy-related interventions (Bohnenkamp, McDonald, Lopez, Krupinski, & Blackett, 2004; Bryan & Dukes, 2010; Chaudhri et al., 2005), and anxiety (Cheung et al., 2003); (2) indicators relevant to self-care, e.g. self-management (including ability and performance) (Cheng et al., 2012), self-care (involving knowledge, attitude and behavior) (Lo et al., 2011), and self-efficacy (Cheng et al., 2012); (3) patient outcomes, e.g. adaptation (Cheng et al., 2012), quality of life (Cheung et al., 2003; de la Quintana Jimenez et al., 2010), patient satisfaction (Bohnenkamp et al., 2004).

In the guideline of *Ostomy Care and Management* by RNAO (2009), 11 of total 26 recommendations advocate family involvement in conjunction with therapeutic relationship, comprehensive assessment, individualized ostomy care plan, teaching skills, home care support, follow-up by an ET nurse etc. However, in fact, little family-based care intervention or program (Guan, Wang, Yuan, Wang, & Song, 2008; Lo et al., 2011) have been developed for both ostomy patients and their family caregivers. Additionally, this guideline cannot be directly applied into clinical nursing practice due to its format of recommendations plus evidence. The RNAO (2009) suggested that the guideline can be utilized as a resource tool to develop further procedures, protocols and documentation tools.

In this study, this guideline and other useful literature were introduced to the participants. According to local actual conditions and participants' preference, these resources were used to generate several instructional and operational materials for nurses, and a manual of self-care for patients and their family caregivers during the process of the action research.

### Experience of the Family Caregivers to Care for the Colostomy Patients

The family caregivers are the important contributors for the patients to achieve successful living with a permanent colostomy. However, health professionals often focus on only the patients and ignore the needs of family caregivers. They obtained limited preparation, information and support to care for their sick relatives (Given, Given, & Kozachik, 2001; Persson et al., 2004). Also, caring for the patients affected the family caregivers' health which was related to the possible quality of caregiving (Northouse et al., 2010). Therefore, it is necessary to understand the experience and needs of family caregivers, and provide nursing interventions involving both the patients and their family caregivers.

The researcher searched relevant literature through CINAHL and PubMed databases for papers published in English, and CNKI database for papers published in Chinese since 2000. A few papers were obtained focusing on the family caregivers of ostomy patients. These studies revealed that the family caregivers experienced emotional distress, caregiving burden, low QOL, difficult involvement in caring ostomy patients and few support from health care professionals.

Firstly, emotional distress is common among the family caregivers of ostomy patients. Cotrim and Pereira (2008) found that the caregivers of ostomy patients had more anxiety and depression than those of non-ostomy patients. Also, the anxiety of caregivers was significantly correlated with the anxiety of ostomy patients. Similarly, the emotional reactions of anxiety and depression were reported in both cancer patients and their caregivers (Given et al., 2001; Northouse et al., 2010).

Secondly, the family caregivers encounter certain burden in caring ostomy patients. One study reported that the caregivers of ostomy patients experienced the bearable burden despite obvious psychological overload and loss of opportunities (Palma, Simonetti, Franchelli, Pavone, & Cicolini, 2012). Another study showed that 90% caregivers of colostomy patients had medium level caring burden (Ji, Zhu, & Hu, 2012). The caregivers take responsibilities of home care in diet and nutrition, physical exercises, mood adjustment, changing ostomy pouch, prevention/treatment of complications and periodical medical check-up. They felt heavy burden due to caring tasks, medical costs, worry about prognosis, raising a family and maintaining a job (Ji et al., 2012; Palma et al., 2012).

Thirdly, the QOL of family caregivers of ostomy patients are low. Palma et al. (2012) reported that the QOL among the caregivers of ostomy patients was averagely 97.11 far away from a potential score of 140. The instrument examines four domains related to caregivers’ QOL including burden, disruptiveness, positive adaptation, and financial concerns. Also, another instrument showed the poor QOL mean score which was 176.7 (possible range: 0-350) (Ji et al., 2012). The tool involves four aspects: physical, psychological, social and spiritual health. Besides, Cakmak, Aylaz, and Kuzu (2010) reported that the spouses as caregivers were affected in social and sexual life, e.g. increased time at home and sexual inactiveness.

Fourthly, the involvement difficulty is an issue faced by the family caregivers during caring the patients with an ostomy. Persson et al. (2004) explored the spouses’ perceptions of living with their partners who have an ostomy. The participants usually expressed that they had few opportunities to attend the education sessions for patients provided by heath care professionals, and thus they felt lonely when everyone focused on only the patients. In fact, they wanted to become supportive for their partners pre and post operation. Moreover, studies on cancer population revealed that the patients and caregivers often conceal worry to each other and escape discussing about sensitive issues which are in relation to cancer diagnosis, treatment and prognosis (Kuijer, Buunk, Ybema, & Wobbes, 2002). The mutual support between the patients and caregivers can be impeded by the difficulties in communicating and negotiating the family roles, and thus the marital and family relationships can be influenced negatively (Porter, Keefe, Hurwitz, & Faber, 2005).

Moreover, a limited number of intervention programs have been provided to the family caregivers of ostomy patients. Although numerous intervention studies have been accomplished among ostomy patients, little studies (Guan et al., 2008; Lo et al., 2011) involved their family caregivers. On the other hand, several intervention studies focusing on the caregivers of ostomy patients have showed the positive outcomes of caregivers or patients (Tian, 2010; Zeng, 2008). However, most of these interventions were delivered at hospitalization. There was lack of continued nursing support for both patients and caregivers after discharge.

Evidence from a meta-analysis revealed that the interventions among family caregivers of cancer patients had positive effects and embraced the following characteristics of: (1) the majority of interventions were jointly provided to patients and caregivers; (2) the average duration of intervention was 7.8 weeks; (3) the initial outcomes were assessed during the first 3 months after the intervention; (4) the face-to-face visit was the main method of intervention delivery, in addition to telephone delivery and group meetings; (5) the major type of intervention was psychoeducational apart from skills training and therapeutic counseling; (6) the content of interventions broadly involved patient caregiving, marital/family care and caregiver self-care; (7) the caregiver outcomes involved caregiving burden/benefit, information needs, coping strategies, caregiver self-efficacy, physical functioning, distress and anxiety, depression, marital-family relationship and social functioning (Northouse et al., 2010).

At present, health care professionals have realized that it is important to treat patients and their family caregivers simultaneously in order to achieve the well-being of each person and the best care for patients, because much care for patients relies on their family caregivers, especially after discharge. If the caregivers' needs have not been addressed, they would stay at a weak health state which could hinder the quality care for patients (Hagedoorn et al., 2008; Northouse et al., 2010). Therefore, the care plan must serve for both patient and caregiver as a unit, covering hospitalization and home discharge. Also, the health care professionals should make partnering relationships with both patients and caregivers for the optimal care outcomes.

## Foundational Concepts Used to Develop the Family-Based Care Model

Three foundational concepts were used to develop the family-based care model to enhance successful living with a colostomy. These concepts were: family-based care, self-care and empowerment.

### Family-based care

The importance of family involvement has been paid more attention in health care research. Using the keywords of family-based and care (intervention or program) through CINAHL and PubMed database, many studies were obtained in relation to various areas. However, no study focusing on family-based care (intervention or program) was found in the area of ostomy care although family support is imperative for the patients' successful living with an ostomy. Considering most of patients with a permanent colostomy for treating cancer, the further search was limited in cancer area. Only a few articles were published from 1994 to 2012, in which the findings on the concept of family-based care proposed by Schumacher (1996) was selected into the conceptual framework of this study.

Schumacher (1996) developed the concept of family-based care in the context of patients with cancer during chemotherapy and their family caregivers, in which the interactions between patients and their family caregivers were explored. Similarly, in the context of ostomy care, most of patients undergone the surgery with a permanent colostomy are for treating cancer, and their interactions with own family caregivers influence their living after surgery. Hence, in this study, the concept of family-based care was modified and used in the development of the family-based care model for enhancing successful living with a permanent colostomy among Chinese patients. The concept’s definition, dimensions, patterns and property were discussed as follows.

Firstly, family-based care is defined as a dynamic and dyadic endeavor involving both patients and their family caregivers, which aims at the care of illness itself and the care of managing the impacts of illness on family life. Self-care by the patients and caregiving by their family caregivers are paired and interconnected. With the evolution of the patients’ actions of self-care, their family caregivers’ actions of caregiving are shifting over time.

Secondly, the dimensions of family-based care with regard to self-care and caregiving were identified from participants’ narrative, including: managing symptoms and side effects, providing optimal nutrition, promoting emotional well-being, maintaining the sense of self, maintaining social activities, communicating with extended family members, communicating with health professionals, carrying out medical regimen, negotiating health care system, seeking out holistic or supplementary therapies, reallocating household responsibilities, and preparing for an uncertain future. Apart from the twelve dimensions, other aspects related to colostomy care are considered in this study, e.g. applying ostomy appliance and accessories, preventing/treating ostomy-related complications, and building the regular pattern of defecation.

Thirdly, both patients and their family caregivers as dyads engage into the family-based care. According to the variation on the extent of their involvement, three behavioral patterns were determined: (1) self-care pattern, in which illness management was mainly through self-care actions; (2) caregiving pattern, in which illness management was mainly through caregiving actions; (3) collaborative pattern, in which illness management was mainly through joint actions. Which pattern was performed depended on the needs, abilities, availabilities and preferences of each dyad.

Moreover, collaborative pattern can be divided into two modes: task specialization and task sharing. First, task specialization mode means that one member of the dyad implements some care tasks while other care tasks are implemented by another member of the dyad. Namely, care tasks in different dimensions are separated between patients and their caregivers. For example, a patient is responsible for managing symptoms and side effects with rare caregiver involvement, while his/her caregiver is in charge of providing optimal nutrition. This kind of care mode is a good way to guarantee the involvement of caregivers without disturbing the independence of patients. Second, task sharing mode emphasizes that a patient and his/her caregiver implement care tasks together based on the belief in "two heads are better than one" (Schumacher, 1996, P. 266). The shared involvement may generate the whole synergistic effect which is greater than what an individual can do alone. For instance, a patient and his/her caregiver discuss and make decision on taking medication.

Importantly, the property of family-based care was termed as shifting patterns of self-care and caregiving, because the patterns of self-care and caregiving were dynamically responding to changes of illness care situations. For example, the caregiving pattern is predominant when patients with a colostomy are fragile at immediate post-operation. When the patients' conditions have gradual improvement after discharge, the self-care/collaborative pattern is taken on with reduced involvement of their caregivers. Conversely, the caregiving pattern may return if the patients encounter serious ostomy-related complications or side effects of chemotherapy. However, both self-care and collaborative care pattern tend to be preferred because they may maintain individuals' independence and autonomy to the greatest degree.

In this study, the family-based care involves not only the interactions between patients with a permanent colostomy and their family caregivers but also the interactions of patient-nurse and caregiver-nurse. The nurses empower both the patients and their family caregivers for the thematic concern of successful living with a permanent colostomy through maximizing the patients' self-care. Here, the interactions are emphasized on not the simple involvement but the partnering relationships among the nurses, the patients and their family caregivers.

### Self-care

Self-care is the core of family-based care and also plays a crucial role in the patients' adaptation to changes due to having a permanent colostomy. The patients who have better ability of self-care would embrace higher level of adaption (Hu et al., 2010; Piwonka & Merino, 1999; Xu, Cheng, Dai, et al., 2010).

Among previous studies related to ostomy care, self-care was usually applied with self-management interchangeably, which was demonstrated in similar ways, such as learning hand-skills of using ostomy appliances and becoming highly skilled in impression management (Kelly, 1992); acquiring confidence in self-care (Dazio et al., 2009); becoming skilled at ostomy self-care and regaining autonomy (McVey et al., 2001); looking after ostomy independently (Deeny & McCrea, 1991); managing ostomy confidently and independently (Nicholas, Swan, Gerstle, Allan, & Griffiths, 2008); managing satisfactorily the figure with ostomy (Salter, 1992).

Related to the empowerment of the patients with a permanent colostomy, self-care can be perceived as not only personal ability (power) to manage the colostomy-related impacts but also the process of gaining and adopting the ability. As defined by Thorne and colleagues (2003), self-care is both the ability and the process that the individuals consciously use to obtain control over their chronic conditions. Also, self-care involves managing symptoms, treatment, lifestyle changes and other psychosocial, cultural and spiritual aspects, which is in conjunction with family, community and health care professionals (Wilkinson & Whitehead, 2009).

The attributes of self-care were integrated as: (1) ability, (2) performance, (3) active participation, (4) awareness, (5) decision making (Richard & Shea, 2011; Udlis, 2011). The patients with a permanent colostomy need to learn and master necessary knowledge and skills for fostering the ability of self-care, such as the usage of ostomy appliances, ostomy-related complication prevention and treatment, diet and training defecation habit. The acquisition of ability guarantees the performance of self-care and makes possible that the patients actively take responsibility of their own care and participate in relevant activities. Moreover, the patients can be aware of problems in care and make decision by themselves to take appropriative actions.

According to Udlis (2011), the antecedents of self-care are considered: (1) information, (2) self-efficacy, (3) support, (4) intention, and (5) mutual investment. In the case of colostomy self-care, the information is with respect to the reasons and types of colostomy formation, the anatomy and physiology of colostomy, practical colostomy care, lifestyle changes and psychosocial adaptation. The self-efficacy refers to the perception/belief/confidence in the patient’s ability to perform the colostomy care. The support can be obtained from family, society and health care professionals. The intention emphasize on the motivation of interaction between professionals and patients. The mutual investment means sharing goal-setting and responsibilities.

Following the guidance by Udlis (2011), the outcomes of self-care can be portrayed in (1) improved clinical outcomes, e.g. reduction of ostomy-related complications and regular defecation; (2) reduced health care expenditures, e.g. effective complication prevention and appropriative use of ostomy appliance, and (3) improved quality of life involving physical and psychosocial well-being, e.g. absence of physical discomfort and psychological distress.

Importantly, the traditional paradigm of patient compliance/adherence is being shifted to the more mutual and partnering relationship between patients and health care professionals (Holman & Lorig, 2004; Newman, Steed, & Mulligan, 2004). The method of self-care is widely applied to improve chronic illness outcomes. Specifically, the integrated approach with active involvement of the patients, families and health care professionals is recommended for successful management of chronic condition (Udlis, 2011). Thus, this study employed the family-based approach with the participation and collaboration among the patients with a colostomy, their family caregivers and the nurses, in order to facilitate the patients’ successful living with a colostomy.

In this study, the concept of self-care refers to the individuals’ efforts to manage their own colostomies and colostomy-related impacts. The attributes of self-care include ability, performance, active participation, awareness and decision making.

### Empowerment

Empowerment is a popular term in nursing. Existing literature involved a number of specific areas, such as, cancer (Stang & Mittelmark, 2010), disability (Watson & Larson, 2006), HIV/AIDS (Mutchler et al., 2011), social discrimination (Lundberg, Hansson, Wentz, & Björkman, 2008), community health (Suarez-Balcazar, 2005), workplace empowerment of nurses (Harwood, Ridley, Wilson, & Laschinger, 2010).

Although several articles discussed ostomy self-care linking the concept of empowerment, there was still lack of a well-developed empowerment model in this area. For example, Kittinouvarat and associates (2011) developed a self-care empowerment model for patients with fecal diversion using Orem's self-care theory of nursing system through one-group and quasi-experimental design (*n* = 15). Results revealed only significant improvement on patients' knowledge except self-care behavior between pre and post intervention.

In the part, the concept of empowerment was reviewed in order to better apply into care for the patients with a permanent colostomy, including its definition, three theoretical approaches, process, antecedents and consequences.

### 1. *Definition of empowerment*

Empowerment and power are twin concepts, and thus both are discussed together. According to the Oxford Advanced Learner's Dictionary of Current English (Hornby, 2005), the verb empower is "to give somebody the power or authority to do something" or "to give somebody more control over their own life or the situation they are in" (p. 479). Empowerment belongs to its form of noun, which can be in relation to the action of empowering or the state of being empowered. Correspondently, the noun power can be defined as "the ability or opportunity to do something (in people)" or "the ability to control people or things" (p. 1136). Obviously, power, ability, authority, opportunity and control are common themes on empowerment.

Moreover, empowerment is a process of exercising power. The patients with a permanent colostomy can empower themselves under the assistance of nurses and others (e.g. family caregivers). Rodwell (1996) claimed that nurses should give up their professional power for more empowering patients. However, power is not something that one person's gain is inevitably another's loss. According to Foucault (1995) , power is "exercised rather than possessed" (p. 26). Power is exercised in unfixed relations and meanwhile implanted into people's everyday interactions (Leyshon, 2002; Wellard & Bethune, 1996). Therefore, people are both objects and subjects of empowerment in universal human interactions. The nurses can facilitate the clients' empowerment rather than empower them (Gibson, 1991). The family caregivers and other significant people can also be the facilitators in the process of empowerment for the patients with a permanent colostomy.

Furthermore, there are some consensuses about the attributes of empowerment in nursing despite the concept is broad and complex. Most opinions are regarded empowerment as a process involving interactions between an individual and environment, others and self, individual and internal self. First of all, the process of empowerment is associated with interactions between the individual and environment, which require understanding on the complicated social, political, economic and cultural powers that influence people's lives (Gibson, 1991). Secondly, the empowerment is relevant to interactions between the individual and significant others e.g. nurses and family caregivers. For example, the patients equitably collaborate with nurses to change conditions in their daily life in order to achieve optimal health (Laschinger, Gilbert, Smith, & Leslie, 2010; McWilliam et al., 1997; Virtanen, Leino-Kilpi, & Salantera, 2007). Thirdly, Kieffer (1984) conceptualized empowerment as a process of becoming with regard to interactions between the individual and internal self, which is composed of four eras, i.e. entry, advancement, incorporation and commitment. This process represents personal growth and development through the long-term evolvement of the individual's participatory skills and political awareness. In this study, empowerment is a process that the patients obtain the sense of control over their living with a permanent colostomy through interactions with environments surrounding them, others and internal self.

### 2. *Theoretical approaches of empowerment*

Kuokkanen and Leino-Kilpi (2000) categorized three theoretical approaches with respect to the usage of empowerment in nursing, including: (1) critical social theory, (2) organizational and management theories, and (3) social psychological theories.

Firstly, empowerment in the approach of critical social theory aims to improve the living conditions among oppressed groups. On the basis of self-reflection on constraints and conflicts in their situations, the oppressed groups take actions to change current conditions and obtain own emancipation. In nursing, both patients (a group short of health care knowledge) and nurses (a group of female-dominated employees) are underprivileged groups who are oppressed by privileged groups with patriarchal or authoritarian power. The two underprivileged groups need the exercises of power in interactive relationships for being empowered by themselves. Based on positive patient-nurse relationship, the patients can equally participate in their own empowerment and actively collaborate with the nurses in order to accomplish their optimal health. Meanwhile, nurses can enhance their professional competences by facilitating the patients' empowerment (Anderson, 1996; Gibson, 1991).

Secondly, empowerment in organization and management theories pursues the increase of organizational productivity and effectiveness by the way of reorganizing work and managing human resource. Different from the concept of oppressed groups in critical social theory, the approach is based on the organizational hierarchical structure from top to down. The workplace empowerment can produce the positive outcomes for both the individuals and the organizations, such as, job satisfaction, work commitment, staff well-being, organizational effective operation and achievement of organizational goals.

Thirdly, empowerment in the approach of social psychological theories is generally described as a process of personal growth and development from an individual's horizon, which is influenced by the individual's characteristics, such as beliefs, views, values, perceptions and relationships with environment. Bandura (1977) maintained that reflection is a prerequisite of increasing knowledge and improving personal development. Similarly, Kieffer (1984) suggested that the extensive reflection of the individual's environment is necessary for the enhancement of empowerment experience, which is in conjunction with two other dimensions, i.e. positive self-identity and ability of social interaction. In addition, psychological empowerment is viewed as the mechanism that the external facilitators improve self-empowerment for gaining control over their own lives (Laschinger, Finegan, Shamian, & Wilk, 2001; Laschinger et al., 2010; Rappaport, 1984).

Obviously, the three theoretical approaches signify the three levels of empowerment, namely collective, organizational and individual level. At the individual level, concerning maximized self-care, the empowerment of patients with a permanent colostomy would be the core focus in this study. At the organizational level, the empowerment would consider the reorganization of nurses' works through the shift from the past routine care to the family-based care model. At the collective level, the empowerment would be practiced though discussions among the nurses, the patients with a permanent colostomy and their family caregivers. Starting and maintaining the ostomy support group would be another possible approach for collective empowerment.

### 3. *Process of empowerment*

In this study, empowerment is regarded as an interactive process, thus the elements of client-nurse interaction integrated by Gibson (1991) was utilized to guide the empowerment process. Here, the clients include both the patients with a permanent colostomy and their family caregivers.

Gibson's empowerment model for nursing identified three domains, i.e. client, nurse and client-nurse interaction (Gibson, 1991) (Figure 2). The elements of client-nurse interaction include trust, empathy, participatory decision-making, mutual goal-setting, cooperation, collaboration, negotiation, overcoming organizational barriers, organizing, lobbying and legitimacy (people as equal partners). During the patient-nurse interaction, the nurses assume responsibilities as helper, supporter, counselor, educator, resource consultant, resource mobilizer, facilitator, enabler and advocator.

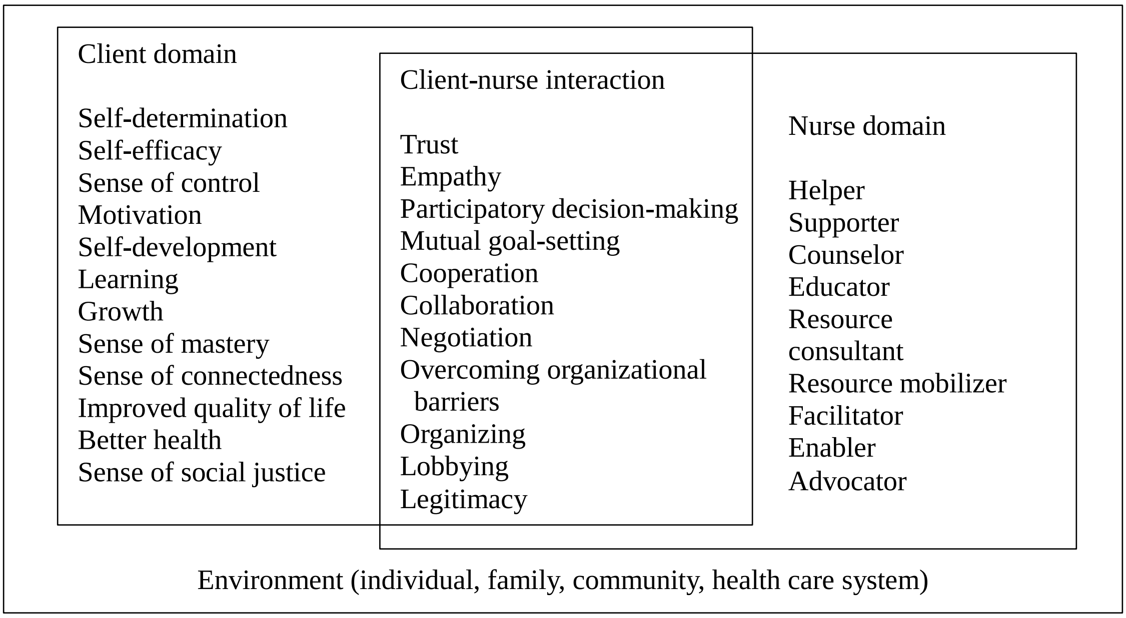


*Figure 2.* An Empowerment Model for Nursing (Gibson, 1991, p. 359)

### ***4. Antecedents of empowerment***

The antecedents of empowerment involve both clients and nurses because empowerment is an interactive process between the two groups. Gibson (1991) suggested the following aspects between/within nurses and clients: respectful and trust relationship; being aware of situations where people experience loss of power; willingness to participate, collaborate, assume responsibility, share power and accept change; beliefs in personal capacity for growth (e.g. decision-making and action); recognizing that nurses cannot empower clients while clients can empower themselves. Moreover, the individuals' desires for autonomy and self-determination, and communication skills are necessary for effective empowerment (McCarthy & Freeman, 2008; Ryles, 1999).

Importantly, nurses need knowledge of health care system and awareness of social, political, economic and cultural conditions in order to facilitate people's empowerment in self-care, self-help, health promotion and environmental improvement (Williams, 1989). In order to help others' empowerment, nurses must also foster own attributes, e.g. courage, commitment, intuitive understanding, accepting diversity, flexibility, tolerance, cooperativeness, empathy and willingness to compromise and so on (Gibson, 1991; Watts, 1990).

### ***5. Consequences of empowerment***

In the context of nursing, the consequences of empowerment value the optimal health in patient outcomes. Thus, the optimal sense of living well with a permanent colostomy was expected in this study.

At the individual level, the sense of being empowered psychologically is associated with both clients and nurses. Gibson (1991) summarized a series of consequences on clients' psychological empowerment including self-determination, self-efficacy, sense of control, motivation, self-development, learning, growth, sense of mastery, sense of connectedness, improved quality of life, better health and sense of social justice. Simultaneously, nurses can also obtain the enhancement of psychological empowerment (e.g. professional confidence and self-actualization) from positive patient outcomes. Laschinger et al. (2010) described psychological empowerment as a response to work in the environment where nurses can access to information, support, resources and opportunity. The response is composed of autonomy, self-efficacy, sense of job meaningfulness and the ability to impact on the organization.

At the organizational level, the overall organizational functioning can be improved by the empowered employees who feel more control over work conditions (Laschinger et al., 2010). With access to the power and opportunity in an organization, the employees become motivated and able to motivate others by the way of sharing the power sources (Kanter, 1979). Thus, the empowered employees can contribute to better work performance for organizational effectiveness and productivity, such as lower health service use thanks to patients’ stronger self-care abilities and better health.

At the collective level, group members can make better conditions in their daily life situations through mutual empowerment. In nursing, both nurses and clients are the group members. Here, the nature of empowerment can be viewed as a process of client-nurse interaction in which nurses collaborate with clients for optimize health (Laschinger et al., 2010; McWilliam, Ward-Griffin, Sweetland, Sutherland, & O'Halloran, 2001). The nurses and clients work together to identify possible problems, solutions, information, resources and support for the purpose of optimizing health. Moreover, Williams (1989) argued that nurses can pay attention to assess the social, political, cultural and economic conditions which affect human health, and then provide effective interventions in the macro-social vision. Strengthening the clients’ social network and support system can enhance their self-care efforts (Gibson, 1991). The support group composed of patients is a beneficial approach of strengthening patients’ support system. Nurses can organize and maintain the support group.

This study focused on the empowerment of patients with a permanent colostomy through their interactions with nurses and family caregivers in order to achieve their maximized self-care and optimal sense of living well. Meanwhile, the change from the past routine care to the family-based care model would be considered as the organizational level empowerment. The group discussions and the operation of ostomy support group would be related to the collective level empowerment.

## Action Research

Action research is paid attention by scholars thanks to its advantage in flexibly and sustainably translating theory into practice by the process of research. Holter and Schwartz-Barcott (1993) stated that “action research was designed specifically to bridge the gap between theory, research and practice and incorporates both humanistic and naturalistic scientific methods” (p. 298). Similarly, Kemmis and McTaggart (1988) valued the function of action research in connecting theory and practice into one whole as “idea-in-action” (p. 6). Moreover, Streubert and Carpenter (2003) indicated that action research transcends the traditional dichotomy of researcher and participant to understand human experience through democratizing the research process. Therefore, action research has a strong vitality in generating individual, organizational and social changes in specific situations. For the purpose of understanding and application, the knowledge on action research was reviewed involving its philosophic foundations, definition, characteristics, types and process.

### Philosophic foundations of action research

Delineating the philosophic foundations of action research is difficult because the methodology of action research has been applied in a large scope of problematic situations and possesses a complex genealogy. Modern action research has mainly shared ideas from critical social theory which is “critical of positivist and complementary to interpretive research” (Holloway & Wheeler, 2010, p. 236).

Grounded in Marxist philosophy, Habermas proposed that human actions are on the basis of cognitive interests and needs which motivate people to acquire three categories of knowledge: technical, practical and emancipatory (as cited in Holloway & Wheeler, 2010). The technical interest seeks the explanation of cause and effect for obtaining the power of control over nature and guaranteeing effective actions. Despite the technical knowledge is necessary, some things cannot be scientifically explained. People need to capture the meanings of life for understanding each other through inter-subjectively interpreting social situations, and thereby obtain practical knowledge. Further, human actions are influenced by board social, political, economic and cultural context. People also need emancipatory knowledge to liberate themselves from situational constraints for gaining freedom and autonomy. Although action researchers pursue emancipatory knowledge, they do not object to technical and practical knowledge because the three categories of knowledge are interconnected.

Tracing the origin of critical social theory, the Frankfurt school of Germany in the 1920s is its starting point, in which intellectuals reappraised Marxist theory and expanded the notion of domination exceeding economic and class struggle (Kim & Holter, 1995). Later, many critical theorists enrich and develop it, such as Max Horkheimer, Herbert Marcuse, Theodor Adorno and Jurgen Habermas (Kim & Holter, 1995). Berman et al. (1998) used the term of critical paradigm to represent the group of critical social theory and summarized several assumptions. Firstly, all knowledge is value laden. The production of knowledge is based on historical, social, political, gender, and economic conditions. The taken-for-granted assumptions and values often generate a social structure that constrains the available options of the oppressed groups. Secondly, research (theory) and action (practice) is linked together. The oppressive structure can be changed by critical self-reflection to reveal the potential power imbalance and by taking action. Thirdly, the oppressed groups can change their world. People are the experts in their own lives. They have capacity to resolve problems and obtain control over their life conditions by empowering themselves. Finally, the goal of critical researchers is to change the world. The goal is different from the causal explanation of positivist paradigm, and the understanding of interpretive paradigm.

Complying with the above assumptions and Habermas’s thinking, action research employs the strategy of critical self-reflection to motivate active actions with respect to self-empowerment and self-emancipation in the oppressed groups, in order to change the distribution of power in society. In this study, the pursuit of emancipatory knowledge of critical social theorists inspired the researcher and the participants to: be aware of the patients’ situations in living with a permanent colostomy, problems in the situations, and constraints to take problem-solving action; learn from each other about individual expectations and needs, and personal knowledge and experience; and actively participate in goal-setting, decision-making and action-taking. Through critical individual/collective reflection and active action, personal awareness and ability were improved, and meanwhile the ideological transformations could happen to make changes in action sustainable.

### Definition of action research

The classic definition of action research is “a form of collective self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out” (Kemmis & McTaggart, 1988, p. 5).

In addition, Holloway and Wheeler (2010) described action research as “a type of inquiry generally undertaken by practitioners who become researchers, or who work in partnership with university researchers, to examine issues and problems in their own settings; it is carried out through a cyclical process in which each cycle depends on the one before” (p. 233).

However, numerous debates on the terminology of action research makes difficult to use one unified definition (Streubert & Carpenter, 2003). Apart from the term of action research, other various names are used, such as cooperative inquiry (Heron & Reason, 2008), action inquiry (Reason, 1998), participative inquiry (Reason, 1998), participatory research (Tetley & Hanson, 2001), participatory action research (McIntyre, 2008), community-based participatory action research (Koch, Selim, & Kralik, 2002), critical action research (Holter & Kim, 1995), and critical participatory action research (Kemmis, 2008).

Therefore, Holter and Schwartz-Barcott (1993) suggested that it is more significant to discuss the central characteristics of action research in order to clearly understand this methodology.

### Characteristics of action research

Although the definitions and terms of action research remain diverse, there exist consensuses about its main characteristics. Examining the opinions from different scholars, the similarities on the characteristics of action research were identified and synthesized: (1) collaboration and participation; (2) cyclic and dynamic process; (3) focusing on practical problems; (4) change in practice and theory development; and (5) empowerment by self-critical and self-reflective process.

### ***1. Collaboration and participation***

Action research is collaborative and participatory (Holloway & Wheeler, 2010; Kemmis & McTaggart, 1988). Group members participate in the process of action research to different degree. They plan, act, observe and reflect together for the aim of changes in local situations. Holter and Schwartz-Barcott (1993) stressed the collaboration between researchers and practitioners. Standing the position of insiders, the practitioners are the experts in the settings under study. They do not only understand the history of their organizations but also possess professional knowledge and skills in specific fields. Differently, the researchers are the outsiders who work in out of the settings, and they have been trained with research methods and theoretical knowledge. This kind of collaboration can facilitate the utilization of theory and research findings in practice, and thereby bring changes in real situations. Moreover, the participation and collaboration of clients are encouraged in order to develop new or existing health care services appropriative for the needs and expectations of clients (Tetley & Hanson, 2001). In brief, action research emphasizes on both collaboration and participation from individuals who are responsible for or affected by the practice (Grundy, 1982).

### ***2. Cyclic and dynamic process***

Any type of action research commonly follows a cyclic and dynamic process with four components advocated by Kemmis and McTaggart (1988), i.e. plan, action, observation and reflection. The process is described more practically as “problem identification or situation analysis (including reflection), planning, action (implementation of change and monitoring) and evaluation, which may lead to identification of new problems, planning, action and evaluation, and so on” (Waterman, Tillen, Dickson, & de Koning, 2001, p. 12).

### 3. *Focusing on practical problems*

In action research, group members identify practical problems in a specific setting or situation. The participants are motivated to understand and improve the world in which they live by the way of changing it and learning from the effects of changes (Kemmis & McTaggart, 1988). For example, one study found that 75% people were living with chronic illness in their community, so that this study focused on understanding people's experiences of living with chronic illness and the ways of their interactions with community nurses in order to better support their self-care (Koch et al., 2002).

### 4. *Change in practice and theory development*

The actual changes in practice not only are in relation to the nature of problems, but also rely on the implementation of interventions which are proposed by the researchers ahead or in the collaboration of group members (Holter & Schwartz-Barcott, 1993). Different from the inference of cause and effect in experimental studies, action research "is about taking action in the real world and a close examination of the effects of the action taken, thus it always involves intervention" (Lathlean, 1994, p. 35). The consequence of intervention is in conjunction with changes in practice, which can happen at both an individual level and a collective level, such as enhanced self-care of chronic illness at an individual level, and more tentative strategies proposed/performed by collective members (Koch & Kralik, 2001). Finally, a new theory can be developed during the process of action research (Holter & Schwartz-Barcott, 1993). For instance, a model of care was developed in an emergency department by action research strategy, which comprised two components including a screening tool used by triage nurses for identifying at-risk psychiatric patients and the corresponding clinical pathways for each category (Heslop, Elsom, & Parker, 2000).

### 5. *Empowerment by self-critical and self-reflective process*

Both self-criticism and self-reflection can nurture self-empowerment which generates the power of action (Kemmis & McTaggart, 1988; Streubert & Carpenter, 2003). The self-critical and self-reflective process facilitates the participants not only to be aware of the relationships between circumstance, action and consequence in their experiences and situations, but also to make sense the organizational and personal constraints which bind their power to live better. Subsequently, the participants are empowered by themselves to take actions for both emancipating themselves from the constraints and reconstructing the power relationships.

### Types of action research

The methodology of action research is very flexible and diverse following different goals and situations. Thus, understanding the types of action research, the researchers can optimize their predispositions in applying the approach of action research.

Holter and Schwartz-Barcott (1993) summarized three types of action research and discussed their application in nursing including: technical collaborative, mutual collaborative and enhancement action research. These three types are respectively similar to technical, practical and emancipatory action research in education proposed by Grundy (1982). Firstly, the technical collaborative action research aims at testing a specific intervention designed by the researcher according to a predetermined theoretic framework. The collaboration and mutual understanding between the researcher and the practitioners stays at a low level. The practitioners are expected only to provide the assistance for the implementation of the particular intervention. The effects of intervention are immediate but generally unsustainable. Secondly, in the mutual collaborative action research, the researcher and the practitioners identify latent problems, analyze basic causes and decide potential interventions together. In virtue of the collaboration and mutual understanding with middle-level, the plan and action are initiated into a spiral of action research. The consensus with regard to problems, causes and interventions contributes to the generation of a new prescriptive theory. However, attributing to lack of understanding on the constraints at personal and organizational level, the changes in practice cannot usually be maintained for long time. Thirdly, through the critically-reflective process, the enhancement action research emphasizes on improving collective consciousness about the personal and organizational constraints which heavily affect practice. Based on the clear awareness about institutional and cultural norms, the corresponding action will create a thoughtful change that can be reached and sustained. Here, a new theory is constructed and refined under the high-level collaboration and mutual understanding between the researcher and the practitioners.

In this study, group members worked together to identify main problems and optimize the choices of solutions on the basis of improved mutual understanding among nurses, patients with a permanent colostomy and their family caregivers. The nurses can facilitate the empowerment of the patients and their family caregivers. The family caregivers can provide appropriate care and support to the patients. The patients can take responsibilities to manage their own lives and obtain the sense of successful living with a permanent colostomy. Moreover, during the process of action research, the researcher took efforts to encourage the participants' self-reflection and enlighten their awareness about the constraints which influence their actions. Therefore, the ideological changes would assure the sustainability of action changes. Also, some organizational changes may be achieved, such as reorganizing routine care for patients with a colostomy, starting and maintaining the operation of ostomy support group.

### Process of action research

Following Lewin's approach to action research with a spiral of steps, Kemmis and McTaggart (1988) described "a thematic concern and four moments" of action research (p. 9). A thematic concern refers to a problematic area perceived and identified by a group, which could be improved through group members working together. In this group, plan is discussed collectively, action and observation are implemented individually or collectively, and reflection is carried out collectively. Plan, action, observation and reflection are composed of the four moments of action research.

The plan is a prospective construction of future action, which can be flexibly adjusted to the emerging constraints and unpredicted effects. The prescribed action must be critically informed on the basis of considering the authentic material and political restrictions, the possible risks in consequent social change, and the maximization of actions' effectiveness. Also, the action may facilitate the actors to get through current constraints and to be empowered for acting more effectively in the actual situation.

Action is a careful and thoughtful practice guided by planning but not entirely manipulated by the plan. Action is dynamic, requesting immediate decision, virtual judgment, fighting for improvement, negotiation and necessary compromise. Each action can be a platform of developing next action in the spiral of action research.

Observation may provide a reasonable foundation of critical reflection. On the one hand, observation must be planned in advance to guarantee the documental basis of further reflection. On the other hand, observation must be flexible to capture the unexpected data. The contents of observation include the action process, the action effects, the circumstances in which action is implemented, the constraints on action, the way that action is influenced by relevant circumstances and constraints, and other arising issues. In brief, action, process, effects, circumstances and constraints are the cores of observation in action research.

Reflection aims to understand process, problems and constraints in the strategic action through recalling the records in observation. Reflection is interpretive (reconstructing the meaning of the situation and thereby providing basis for revising the plan), evaluative (appraising the effects of action and advising further strategies), and descriptive (obtaining a vivid understanding about life in the situation).

To summarize, action research is a fluid process by the spiral of four moments. During the cycle of planning, acting, observing and reflecting, the improvement in understanding the situation triggers a more appropriative rationale for practice. Further, the rationale can be continuously tested in practice until forming a situation-specific theory.

In this study, the thematic concern was to enhance Chinese patients’ successful living with a permanent colostomy. Following the spiral of action research, the nurses would ally with the patients and their family caregivers to facilitate the patients’ empowerment for maximizing self-care and successful living with a permanent colostomy.

## Summary

The chapter reviewed the literature related to this study in five aspects: experience of patients in living with a permanent colostomy, successful living with a permanent colostomy, experience of family caregivers to care for colostomy patients, foundational concepts used to develop the family-based care model, and action research. Living with a permanent colostomy is a very stressful experience which affects the patients' living in physical, psychological, social and sexual domains. The patients' perceptions on having a colostomy are associated with altered self and restricted life. They employ various coping strategies to overcome life restriction due to having a colostomy, such as accepting the reality, balancing revelation and concealment, utilizing internal resources and seeking external supports. Consequently, some people can achieve successful living with their colostomies, in other words, feel adaptation and life satisfaction. A number of factors can influence the patients' successful living with a colostomy encompassing socio-demographic, psychological, situational and cultural factors, such as, self-care, family support, professional support, and Chinese belief in the moral obligation of family caregiving. Nurses need to be aware of these factors, collaborate with family caregivers, and encourage the patients' self-care actions to achieve successful living with their colostomies. Action research is the most appropriate way to develop the family-based care model to enhance successful living with a colostomy through improving mutual understanding, collaboration and self-reflection among the nurses, the dyads of patients and their family caregivers.

# Chapter 3
# Methodology

This chapter was divided into the following aspects to present the research methodology: research design, research setting, participants, ethical consideration, instruments of data collection, research process and data collection, data analysis and trustworthiness.

## Research Design

The research design of this study was action research proposed by Kemmis and McTaggart (1988). A family-based care model to enhance Chinese patients' successful living with a permanent colostomy was developed and refined through active collaboration among patients, their primary family caregivers, nurses and the researcher in a Chinese cultural context. This study was carried out from January to November 2013.

## Research Setting

This study was conducted at an abdominal surgical unit of a university hospital (a tertiary hospital) in a southwestern province of People's Republic of China.

This hospital located at the provincial capital and possessed 1200 hospital beds, 22 clinical units, 11 assistant units and about 900 employees until December 2012. Patients come to this hospital from 16 regions of this province which possessed 394,000 square kilometers and 45,966,239 populations in 2010.

This surgical unit was selected because: (1) it is a provincial center of excellence in large bowel cancer treatment and research; (2) patients with a permanent colostomy are mainly hospitalized in this unit; and (3) an experienced enterostomal therapist (ET) nurse is working in this unit. According to this unit's record of patients who underwent ostomy-related surgery from July 2010 to May 2011, about seven patients with a permanent colostomy were hospitalized here each month.

Moreover, this surgical unit has been renamed as the Colorectal Cancer Department since it was moved to the new in-patient building in September 2012, in which there are two floors and 88 patient beds. 20 surgeons and 34 nurses were working in this unit in January 2013. The head of this unit was called as the director who was also a surgeon. A head nurse was led by this director and responsible for nursing affairs of this unit. Four nursing team leaders, who respectively led a team of ward nurses, were managed by this head nurse. An ET nurse was directly led by the head nurse and did not belong to any nursing team. Additionally, this head nurse moved to this unit since early January 2013. She was active to improve quality of nursing care in this unit, especially ostomy care.

## Participants

In this study, the participants were comprised of 21 patients with a permanent colostomy (seven experienced patients and 14 novice patients), 18 primary family caregivers (four caregivers of experienced patients and 14 caregivers of novice patients), and nine nurses of the core working group (one head nurse, one ET nurse, four nursing team leaders, and three senior nurses).

***Patients.*** The criteria of choosing patients were as follows. Inclusion criteria were: (1) Chinese adult; (2) having had a permanent colostomy less than one year (experienced patient), or being newly admitted for requiring the first colostomy-related surgery (novice patient); (3) being able to communicate with the researcher in mandarin or local languages; and (4) having at least a family caregiver. Exclusion criteria were: (1) unaware of their diagnoses of cancer; (2) having the history of psychiatric disease; (3) unable to be interviewed and participate in self-care due to significant physical or psychiatric disorders; and (4) having avoided a permanent colostomy after surgery.

***Family caregivers.*** The selection criteria were: (1) Chinese adult; (2) being able to communicate with the researcher in mandarin or local languages; (3) identified by the patient as a primary family caregiver; and (4) providing primary and unpaid care to patients during hospitalization and at home.

***Nurses.*** The inclusion criteria were: (1) registered nurse; (2) working in this selected unit; and (3) having nursing diploma, Bachelor degree or higher education level.

## Ethical Consideration

Permission for involvement of participants was obtained from the Institutional Review Board (IRB), Faculty of Nursing, Prince of Songkla University (Appendix B1) and the Medical Ethical Committee of the hospital where this study was conducted (Appendix B2).

The participants were invited to take part in this study on a voluntary basis, including the nurses, the patients with a permanent colostomy and their family caregivers. The researcher informed each participant the following information: the purpose of this study, what they could involve in this study, the guarantee of confidentiality and anonymity, the freedom of withdraw at any time without negative repercussions. The participants who consented to participate in this study were asked to sign a written consent form (Appendix B3).

## Instruments of Data Collection

### The researcher

The researcher was an important instrument in this action research. The roles of the researcher included: (1) the catalyst to help the participants discover and identify their thematic concerns, current problems, causes and possible solutions; (2) the facilitator to improve communication and mutual support between the patients and their family caregivers through dialogue with them together, verbally sharing information of colostomy care, and distributing written learning materials edited by the researcher; to share knowledge of colostomy care with the nurses through organizing group meetings, conducting workshops, recommending useful literature and books, designing operational record forms and corresponding learning materials; (3) the instrument of collecting and analyzing data by asking questions, conducting observation and reviewing documents; and (4) the surgical nurse to provide information on colostomy care and inspirational support to patients and family caregivers.

The relevant educational background and working experience supported this researcher to be competent to play the above roles. The researcher has been equipped to be a qualified surgical nurse through 5-year study in the program of Bachelor of Science in Nursing, 5-year working experience as a surgical nurse (in which 3-year vice head nurse of operation room) in a university hospital, and 5-year experience of teaching both surgical nursing and community nursing in a medical university. Also, the past study in the program of Master of Public Health, and the present study in the program of PhD in Nursing have prepared her as a trained researcher.

### Other instruments

Except for the last three instruments, the others were reviewed by five experts including one Thai ET nurse, one Thai nursing faculty member, one Chinese ET nurse, one Chinese nursing faculty member, and one Chinese surgeon (Appendix A9).

***Demographic form.*** The series of forms were used by the researcher to collect demographic and medical data of the patients, as well as demographic data of the family caregivers and the nurses (Appendix A1-1, A1-2, A1-3).

***Interview (focus group discussion) guideline.*** The series of guidelines were used by the researcher to conduct in-depth interviews with the patients and their family caregivers, as well as focus group discussion with the nurses (Appendix A2-1, A2-2, A2-3).

***Reflection guideline.*** The guideline was used by the researcher to enlighten the participants' critical self-reflection and perform the researcher's self-reflection (Appendix A3).

***Observation record form.*** The form was devised to make field note by the researcher through participant observation (Appendix A4).

***Record form of ostomy-related complications.*** This form was used by the researcher to record the incidence, treatment and outcome of ostomy-related complications as necessary. Regularly, the researcher recorded at discharge, the 1st week, the 1st month, and the 3rd month after discharge (Appendix A5).

***Evaluation form on the skill of using ostomy appliances.*** The form was used by the researcher to assess the skill of patients and their family caregivers at pre-operation, discharge, the 1st and 3rd month after discharge (Appendix A6). Its content validity (CVI = 0.98) was evaluated by five experts using the Content Validity Form (Appendix 8).

***Satisfaction evaluation form.*** The series of self-report questionnaires were used by the researcher to investigate: (1) the final satisfaction with nursing service among patients and their family caregivers (Appendix A7-1), and (2) the final satisfaction with this family-based care model among nurses (Appendix A7-2). Evaluated by five experts using the Content Validity Form (Appendix 8), these questionnaires had adequate content validity (CVI 0.90 for patients/caregivers, CVI 1.00 for nurses). After the completion of this study, their internal coefficient was evaluated by using Cronbach's alpha (0.80 for patients, 0.59 for family caregivers, 0.76 for nurses).

***Researcher's diary.*** The diary was used by the researcher to write down the progression of this action research and the researcher's observation and self-reflection including operational, observational and theoretical memos.

***Digital audio-recording pen.*** The equipment was utilized by the researcher to collect narrative data during in-depth interview, focus group and group meeting after getting the participants' permission.

***Camera.*** The equipment was adopted by the researcher to capture and record the significant figures, actions, scenes, events and situations.

## Research Process and Data Collection

The research process consisted of three steps: preparation, action, and final evaluation. All of possible activities of participants and the researcher were listed in Table 1.

### Preparation step

This step aimed to recruit participants, build rapport with them and understand the context of patients with a permanent colostomy.

### *1. Building rapport and recruitment*

The researcher has kept in touch with the ET nurse for nearly two years before conducting this action research. Under the assistance of the ET nurse, the researcher contacted the head nurse and obtained her support. Then, the head nurse helped the researcher to organize a core working group composed of the head nurse, the ET nurse, four nursing team leaders and three senior nurses. The researcher asked these nurses of the core working group to sign the informed consent forms after the detailed introduction about this study.

Subsequently, the ET nurse introduced the researcher to the two groups of patients: (1) seven experienced patients, and (2) 14 novice patients. The researcher built rapport with these patients since the first visit of pre-operation through frequent visiting and providing information and inspirational support on colostomy care. Also, the researcher introduced the objective of this study and the tasks of participants. After getting verbal consent, the researcher asked the patients to get their written informed content. At the same time, their family caregivers got the same introduction about this study and were asked to sign on the written form of informed content.

### *2. Assessing the context*

Using participant observation, the researcher detected the patients' daily living with a colostomy, and investigated the actual care received by the patients in this hospital or at home, including care from the nurses and their family caregivers. Informal interview and reviewing medical record were used to understand the patients' present illness, health status, problems, concerns, needs, expectations and resources.

## Action step

This part was conducted following five phases of action research, i.e. the initiative reconnaissance phase, and the spiral of four phases (planning, acting, observing, and reflecting).

### 1. *Reconnaissance phase*

The researcher conducted in-depth interview and participant observation in three months with seven experienced patients who had been with a permanent colostomy less than one year to understand their lived experiences involving current illness/health status, self-care activities, received care from their family caregivers and the nurses, perception on meanings of successful living with a permanent colostomy, experienced problems/difficulties and coping, and suggestions/expectations about nursing care. Meanwhile, four of their family caregivers were jointly interviewed to understand their experiences of caring for colostomy patients. Moreover, the nurses' caring activities for colostomy patients in this surgical unit were explored through participatory observation and focus group discussion with the nurses of the core working group.

### 2. *Planning phase*

A systematic review of literature was performed to search existing research evidence related to ostomy care by (1) CIHNAL, (2) PubMed, (3) The Cochrane Library, (4) CNKI. The key words included quality of life, adaptation, adjustment, coping, self-management, self-care, self-efficacy, family-based care, social support and empowerment. Using Google, online resources were also assembled, such as the websites of International Ostomy Association and United Ostomy Associations of America.

A tentative care model was developed by integrating literature review, qualitative data from the reconnaissance phase, and suggestions from the ET nurse and the head nurse. The tentative care model was introduced to the nurses of the core working group in a group meeting.

### 3. *Acting and observing phase*

The tentative care model was implemented with 14 dyads of novice patients and their family caregivers over eight months. The proposed interventions were performed since pre-operation until three months after discharge. The duration was decided according to existing research evidence. Pittman et al. (2009) found that the impacts of ostomy formation mostly emerged in the early postoperative stage, and could be improved dramatically by three months after surgery. Data were collected through participatory observation, taking field note and in-depth interview.

### 4. *Reflecting phase*

Reflection was performed with all participants to evaluate the outcomes of implementing this model, and identify the factors influencing the patients' successful living with their colostomies. Further, following the spiral of four phases of action research, this model was constantly modified until generating an appropriative model for enhancing the patients' successful living with a colostomy.

### Final evaluation step

Process evaluation was to investigate the participants' satisfaction with the process of executing the family-based care model via participatory observation, in-depth interview, group meeting, and a series of satisfaction evaluation forms (Appendix A7),.

Outcome evaluation was to understand the impacts of this model on the patients and their family caregivers through both qualitative and quantitative methods using participatory observation, in-depth interview, the Record Form of Ostomy-Related Complications (Appendix A5), and the Evaluation Form on the Skill of Using Ostomy Appliances (Appendix A6).

The evaluation was performed at different time-points involving pre-operation, post-operation and post-discharge (Figure 3). The evaluation indicators primarily included:

(1) Patients demonstrated the feeling of living well with a permanent colostomy, e.g. getting used to and having adapted to.

(2) Patients demonstrated active self-care actions, e.g. performing the procedures of using ostomy appliances independently.

(3) Family caregivers demonstrated proper caregiving actions.

(4) Patients and family caregivers demonstrated mutual support in colostomy care and management.

(5) Patient/caregiver vocalized the understanding on disease, relevant surgery/treatment, colostomy and its effects on personal and family life.

(6) Patients had optimal ostomy site placement beneficial.

(7) Patients and family caregivers expressed satisfaction with received nursing service.

(8) Nurses expressed satisfaction with this model and stated to constantly use it.

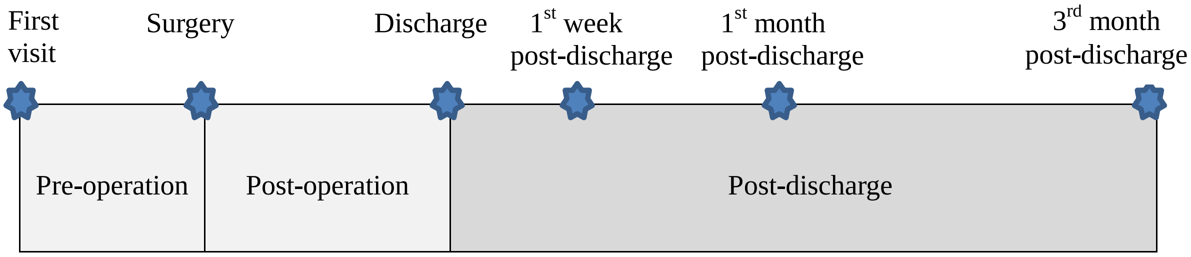


*Figure 3*. Time Frame of the Outcome Evaluation

Table 1

*Activities of the Researcher and Participants*

| **Actor** | **Preparation step** | **Action step** | | | | | **Final evaluation step** |
|---|---|---|---|---|---|---|---|
| | | **Reconnaissance phase** | **Planning phase** | **Acting, observing and reflecting phases** | | | |
| | | | | **Pre-op** | **Post-op** | **Post-discharge** | |
| Researcher (R) | Introducing this study<br>Building rapport and recruitment<br>Obtaining information relevant to the setting | Interviewing 7 experienced Ps & 4 of their Cs<br>Conducting FGD with Ns<br>Collecting and analyzing data | Reviewing research evidence<br>Developing a tentative care model and necessary materials<br>Introducing this model to participants | Testing and refining the tentative model among 14 dyads of novice Ps and their Cs<br>Collecting and analyzing data | Testing and refining the tentative model among 14 dyads of novice Ps and their Cs<br>Collecting and analyzing data | Testing and refining the tentative model among 14 dyads of novice Ps and their Cs<br>Collecting and analyzing data | Using qualitative and quantitative methods to evaluate impacts of the model on Ps and Cs<br>Investigating satisfaction with nursing service among Ps and Cs<br>Summarizing the actual care model and present it to Ns<br>Investigating Ns' satisfaction with this model |
| Nurse (N) | Understanding this study<br>Signing informed consent form<br>Assisting in recruiting Ps & Cs | Providing information on ostomy care | Providing suggestions on the tentative model<br>Mutual goal-setting and decision-making on care plan among Ns, Ps & Cs | Providing pre-op education to Ps & Cs<br>Providing counseling<br>Performing ostomy site marking | Providing post-op education to Ps & Cs<br>Training Ps & Cs the skill of using ostomy appliances<br>Providing counseling;<br>Preparing Ps & Cs for discharge | Providing continued support to Ps & Cs by ostomy clinic visit, telephone follow-up or home visit | Expressing satisfaction with this model and stating to constantly use it |
| Patient (P) | Understanding this study<br>Signing informed consent form | Providing information on experience of living with a colostomy | Mutual goal-setting and decision on care plan among Ns, Ps & Cs | Learning relevant knowledge<br>Receiving ostomy site marking | Learning relevant knowledge and skills<br>Preparing for discharge | Receiving continued support from Ns | Demonstrating feeling of living well with a colostomy and active self-care actions<br>Demonstrating mutual support with Cs<br>Having optimal ostomy site placement |
| Family caregiver (C) | Understanding this study<br>Signing informed consent form | Providing information on experience of caring for Ps with a colostomy | Mutual goal-setting and decision on care plan among Ns, Ps & Cs | Learning relevant knowledge<br>Providing support to Ps | Learning relevant knowledge and skills<br>Providing assistance and support to Ps | Receiving continued support from Ns<br>Providing assistance and support to Ps | Demonstrated proper caregiving actions<br>Demonstrating mutual support with Ps |

## Data Analysis

Qualitative and quantitative data were analyzed using qualitative content analysis, descriptive statistics and inferential data analysis.

Content analysis was applied to deal with qualitative data following the guidance by Hsieh and Shannon (2005), and Elo and Kyngas (2008). All narrative data were transcribed verbatim. The researcher read word by word and gained a sense of the whole. Next steps involved breaking data into analytic units, coding each unit, naming the units, grouping into categories, organizing categories into a hierarchical structure. The process of analysis helped the researcher to obtain necessary information to develop the family-based care model.

Descriptive statistics was used to analyze the quantitative data from the demographic characteristics of participants, the Evaluation Form on the Skill of Using Ostomy Appliances, and the satisfaction evaluation forms. Wilcoxon matched pair and signed rank test was used to compare the changes of skill of using ostomy appliances before with after participating in the first/second stages among the patients (the family caregivers).

## Trustworthiness

The trustworthiness of this study was evaluated following the general criteria for qualitative research proposed by Lincoln and Guba (1985) including credibility, dependability, confirmability and transferability. To integrate with the opinions of Holloway and Wheeler (2010), credibility is the criteria to evaluate the extent to which the findings correctly describe and interpret the studied phenomenon, namely the participants can recognize the truth of the findings in their own context. Dependability is a criteria of the extent to which the findings can be replicated and repeated, namely the reader can evaluate the accuracy of analysis following the decision-making process how the researcher achieved the conclusion. Confirmability is to evaluate the extent to which the findings are free from bias, namely the reader can judge that the findings and conclusions are from the data not the researcher’s preconceptions. Transferability refers to the extent to which the findings can be generalized to similar context, namely the findings in one context can be transferred to other similar population and situation.

### Credibility

The study tried to achieve credibility through long term engagement, triangulation, peer debriefing and member checking. The researcher has kept in touch with the ET nurse for nearly two years before conducting this study. During the process of this study, the researcher had worked with the participants together for 11 months. Data collection employed both qualitative and quantitative methods, such as in-depth interview, participatory observation, focus group discuss, using the skill evaluation form and the satisfaction evaluation form. Various types of data were triangulated by each other. During the analysis process, the ET nurse and the major advisor of the researcher performed peer debriefing in order to achieve consensus of analysis results. The member checking was used to verify the accuracy of analysis by the participants' recognition.

### Dependability

The dependability of this study was guaranteed by audit trail. All relevant documents were kept involving demographic forms, complication record forms, skill evaluation forms, satisfaction evaluation forms, field notes, audio-digital records of in-depth interviews, verbatim transcripts, photographs and the researcher's diary. The procedures of this study were described in detail. The research process was audited by the two advisors of the researcher.

### Confirmability

Except for the above audit trail, selecting diverse patients were used to ensure confirmability of this study. The patients with various personal characteristics and different situations were recruited, e.g. age, gender, occupational status, educational background, family income level and dwelling in rural or urban area. Importantly, the appropriate and adequate quotes of the participants' statements were reported to support that the findings were from the obtained data rather than the researcher's preconceptions. These strategies could correct or avoid the prejudice of data analysis by the researcher.

### Transferability

The strategy of ensuring transferability was to perform thick description about participants, context and the whole process of this study. Thick description provided the possibility that the reader completely understand the process of this study. Also, the readers were able to recognize other similar circumstances and thereby transfer the findings of this study into them.

## Summary

This study was designed to develop a family-based care model to enhance Chinese patients' successful living with a permanent colostomy using the approach of action research. The participants were recruited at an abdominal surgical unit of a university hospital in a southwestern province of China. The participants encompassed 21 patients (seven experienced patients and 14 novice patients), 18 family caregivers (four caregivers of experienced patients and 14 caregivers of novice patients), and nine nurses of the core working group (an ET nurse, a head nurse, four nursing team leaders and three senior nurses). The process of this study consisted of three steps: preparation, action and final evaluation. The step of preparation aimed at recruiting participants, building rapport with them and understanding the context of the patients with a permanent colostomy. The step of action followed the spiral of action research (i.e. reconnaissance, planning, acting, observing and reflecting) to develop a tentative family-based care model and refine it. The final evaluation step covered both process and outcome evaluation. The data were collected via both qualitative and quantitative methods, such as in-depth interview, participatory observation, focus group discussion, structural questionnaire and clinical observation. The data were analyzed by qualitative content analysis, descriptive statistics and inferential data analysis. Credibility, dependability, confirmability and transferability were utilized to evaluate and ensure the trustworthiness of this study.

# Chapter 4

## Findings and Discussion

The family-based care model to enhance Chinese patients' successful living with a permanent colostomy was conducted among the patients with a permanent colostomy, their primary family caregivers, the nurses and the researcher using the methodology of action research. The findings of this study were based on both qualitative and quantitative data analysis and presented as follows.

1. Demographic Characteristics of the Participants
2. Process of Developing the Family-Based Care Model
   2.1 Reconnaissance phase
      2.1.1 Self-care activities of the patients with a permanent colostomy
      2.1.2 Caregiving activities of the family caregivers
      2.1.3 Health care services for the colostomy patients
      2.1.4 Caring activities of the nurses for the colostomy patients
      2.1.5 Meanings of successful living with a permanent colostomy
      2.1.6 Main problems in the patients' situations of living with a permanent colostomy
   2.2 Spiral action research process to develop the family-based care model
      2.2.1 Stage 1: Accepting the reality of colostomy formation and learning colostomy care
      2.2.2 Stage 2: Adapting to living with a colostomy and returning to a normal family life
   2.3 Final evaluation
3. Components, Stages and Strategies of the Family-based Care Model
4. Discussion

## Demographic Characteristics of the Participants

The participants of this study included 21 patients with a permanent colostomy (seven experienced patients and 14 novice patients), 18 primary family caregivers (four caregivers of experienced patients and 14 caregivers of novice patients), and nine nurses of the core working group.

### Patients with a permanent colostomy

A total of 21 patients with a permanent colostomy took part in this study. Seven experienced patients who had already been with a permanent colostomy were recruited in the reconnaissance phase of this study, in order to understand their lived experience and suggest the tentative family-based care model. 14 novice patients who were newly-admitted and finally received a surgery resulting in a permanent colostomy were recruited before surgery to refine the tentative family-based care model.

Among seven experienced patients (Table 2), there were four men and three women aged 39 – 68 years ($M$ = 54.00, $SD$ = 9.56). All of them were Han people without any religion. Two were illiterate, three graduated from a primary school, one finished study in a middle school, and one got a diploma of high school. Two were retired, one was unemployed, and the remainder was peasants. All patients were married. Five lived in a nuclear family, and two lived in an extended family. Their primary family caregivers involved five spouses, one adult child and one sibling. Their monthly family incomes varied in a large range from no income to 5000 Yuan. All of them were covered by the national medical insurances: four were supported by the new rural cooperative medical insurance; three were included in the basic medical insurance for urban employees. All seven experienced patients had already been with a permanent colostomy for 2 – 11 months ($M$ = 4.86, $SD$ = 3.09) when they were recruited. All were diagnosed with rectal cancer. They received different surgical procedures: four endured Miles operation; two experienced Hartmann operation; one underwent laparoscopic radical rectectomy. Four received preoperative chemo/radiotherapy, and all undertook postoperative chemo/radiotherapy. Four reported comorbidity. Ostomy-related complications and other health-related problems reported by these patients involved itching and redness of peristomal skin, ostomy bleeding, loss of appetite, nausea, vomiting, dizziness and perineal wound pain.

Table 2

*Demographic Characteristics of the Experienced Patients (n = 7)*

| Characteristics | | n |
|---|---|---|
| Gender | Male | 4 |
| | Female | 3 |
| Age (*M* = 49.62, *SD* = 10.80) | 30 – 39 years | 1 |
| | 40 – 49 years | 1 |
| | 50 – 59 years | 3 |
| | 60 – 69 years | 2 |
| Ethnic | Han | 7 |
| Religion | None | 7 |
| Educational level | Illiteracy | 2 |
| | Primary school | 3 |
| | Middle school | 1 |
| | High school | 1 |
| Occupational status | Retired | 2 |
| | Unemployed | 1 |
| | Peasant | 4 |
| Marital status | Married | 7 |
| Family type | Nuclear family | 5 |
| | Extended family | 2 |
| Primary family caregiver | Spouse | 5 |
| | Adult child | 1 |
| | Sibling | 1 |
| Monthly family income | < 1000 Yuan | 2 |
| | 1000 – 2999 Yuan | 3 |
| | 3000 – 4999 Yuan | 0 |
| | ≥ 5000 Yuan | 2 |
| Medical insurance | New rural cooperative medical insurance | 4 |
| | Basic medical insurance for urban employees | 3 |

Table 2 *(Continued)*

| Characteristics | | n |
|---|---|---|
| Diagnosis | Rectal cancer | 7 |
| Surgical procedure | Miles | 4 |
| | Hartmann | 2 |
| | Laparoscopic radical rectectomy | 1 |
| Period of having a colostomy | < 3 months | 1 |
| (*M* = 4.86, *SD* = 3.09) | 3 – 5 months | 4 |
| | 6 – 8 months | 1 |
| | 9 – 12 months | 1 |
| Preoperative chemo/radio-therapy | Yes | 4 |
| | No | 3 |
| Postoperative chemo/radio-therapy | Yes | 7 |
| | No | 0 |
| Comorbidity | Yes | 5 |
| | No | 2 |
| Ostomy-related complications | Yes | 5 |
| | No | 2 |
| Other health-related problems | Yes | 6 |
| | No | 1 |

Among 14 novice patients (Table 3), there were eight men and six women aged 30 – 66 years (*M* = 47.43, *SD* = 11.03). Three were minority people (Hani, Miao and Yi), and 11 were Han people. Three were Buddhists, and the remainder had no any religion. One was illiterate, five graduated from a primary school, six finished their study in a middle school, and two got diplomas of high school. One was retired, two were unemployed, and the remainder was with various occupations (seven peasants, three businessmen and one worker). All patients were married. 10 lived in a nuclear family, and four lived in an extended family. Their primary family caregivers included 10 spouses, three children and one sibling. Their monthly family incomes varied in a large range from no income to more than 5000 Yuan. All of them were covered by the national medical insurances: eight were supported by the new rural cooperative medical insurance; two were included in the basic medical insurance for urban employees; four had the basic medical insurance for urban nonemployees. 12

were diagnosed with rectal cancer; one was rectal cancer recurrence; one was rectal stromal tumor. They received different surgical procedures: eight endured Miles operation; four experienced Hartmann operation; one underwent laparoscopic radical rectectomy; one undertook sigmoid colostomy. Five received preoperative chemo/radiotherapy, and nine underwent postoperative chemo/radiotherapy. Four had comorbidity.

Additionally, the demographic characteristics of each patient are shown in Appendix C1-C4.

Table 3

*Demographic Characteristics of the Novice Patients (n = 14)*

| Characteristics | | n |
|---|---|---|
| Gender | Male | 8 |
| | Female | 6 |
| Age (*M* = 49.62, *SD* = 10.80) | 30 – 39 years | 3 |
| | 40 – 49 years | 5 |
| | 50 – 59 years | 4 |
| | 60 – 69 years | 2 |
| Ethnic | Han | 11 |
| | Hani | 1 |
| | Miao | 1 |
| | Yi | 1 |
| Religion | None | 11 |
| | Buddhism | 3 |
| Educational level | Illiteracy | 1 |
| | Primary school | 5 |
| | Middle school | 6 |
| | High school | 2 |
| Occupational status | Retired | 1 |
| | Unemployed | 2 |
| | Peasant | 7 |
| | Businessman | 3 |
| | Worker | 1 |

Table 3 *(continued)*

| Characteristics | | n |
|---|---|---|
| Marital status | Married | 14 |
| Family type | Nuclear family | 10 |
| | Extended family | 4 |
| Primary family caregiver | Spouse | 10 |
| | Adult child | 3 |
| | Sibling | 1 |
| Monthly family income | < 1000 Yuan | 5 |
| | 1000 – 2999 Yuan | 4 |
| | 3000 – 4999 Yuan | 2 |
| | ≥ 5000 Yuan | 1 |
| | Unknown | 2 |
| Medical insurance | New rural cooperative medical insurance | 8 |
| | Basic medical insurance for urban employees | 2 |
| | Basic medical insurance for urban nonemployees | 4 |
| Diagnosis | Rectal cancer | 12 |
| | Rectal cancer recurrence | 1 |
| | Rectal stromal tumor | 1 |
| Surgical procedure | Miles | 8 |
| | Hartmann | 4 |
| | Laparoscopic radical rectectomy | 1 |
| | Sigmoid colostomy | 1 |
| Preoperative chemo/radio-therapy | Yes | 5 |
| | No | 9 |
| Postoperative chemo/radio-therapy | Yes | 9 |
| | No | 5 |
| Comorbidity | Yes | 4 |
| | No | 10 |

### Primary family caregivers

A total of 18 primary family caregivers participated in this study. In the reconnaissance phase, four family caregivers of experienced patients were interviewed jointly with respective patients. Other three family caregivers were not recruited because of the patients' reluctance. These patients considered that their family caregivers were with weak ability of oral expression, busy in working, or unable to provide more information. In the following phases, 14 family caregivers of novice patients were recruited by this way of one family caregiver versus one patient as a dyad, so as to refine the tentative family-based care model.

Among four family caregivers of experienced patients involved two spouses, one adult child and one sibling (Table 4). All were female, ranging in age from 37 years to 66 years (*M* = 52.75, *SD* = 1.20). All were married Han people without any religion. Two were retired, and two were peasants. One was illiterate, two finished their study in a middle school, and one got a diploma of high school. Two lived with the patients in the same houses, and two did not live in the same house but lived nearby.

Table 4

*Demographic Characteristics of the Family Caregivers of Experienced Patients (n = 4)*

| Characteristics | | n |
|---|---|---|
| Relationship with the patient | Spouse | 2 |
| | Child | 1 |
| | Sibling | 1 |
| Gender | Female | 4 |
| Age (*M* = 52.75, *SD* = 1.20) | 30 – 39 years | 1 |
| | 50 – 59 years | 2 |
| | 60 – 69 years | 1 |
| Ethnic | Han | 4 |
| Religion | None | 4 |
| Educational level | Illiteracy | 1 |
| | Middle school | 2 |
| | High school | 1 |
| Occupational status | Retired | 2 |
| | Peasant | 2 |
| Marital status | Married | 4 |
| Living with the patient in the same house | Yes | 2 |
| | No (but living nearby) | 2 |

Among 14 family caregivers of novice patients involved 10 spouses, three adult children and one sibling (Table 5). Ten were male, and four were female, ranging in age from 27 years to 60 years (*M* = 42.29, *SD* = 1.08). Three were minority people (Hani, Miao and Yi), and 11 were Han people. Two were Buddhists, and the remainder had no any religion. 13 were married, and only one was single. One was retired, one was unemployed, and the remainder was with various occupations (seven peasants, two businessmen, one worker, one physician and one soldier). One was illiterate, six graduated from a primary school, five finished their study in a middle school, one got a diploma of high school, and one had a bachelor degree. 13 lived with the patient in the same house, and one did not live with the patient in the same house but lived nearby.

Additionally, the demographic characteristics of each caregiver are shown in Appendix C5-C6.

Table 5

*Demographic Characteristics of the Family Caregivers of Novice Patients (n = 14)*

| Characteristics | | n |
|---|---|---|
| Relationship with the patient | Spouse | 10 |
| | Child | 3 |
| | Sibling | 1 |
| Gender | Male | 10 |
| | Female | 4 |
| Age (*M* = 52.75, *SD* = 1.20) | 20 – 29 years | 1 |
| | 30 – 39 years | 4 |
| | 40 – 49 years | 5 |
| | 50 – 59 years | 2 |
| | 60 – 69 years | 1 |
| Ethnic | Han | 11 |
| | Hani | 1 |
| | Miao | 1 |
| | Yi | 1 |
| Religion | None | 12 |
| | Buddhism | 2 |
| Educational level | Illiteracy | 1 |
| | Primary school | 6 |
| | Middle school | 5 |
| | High school | 1 |
| | University | 1 |
| Occupational status | Retired | 1 |
| | Unemployed | 1 |
| | Peasant | 7 |
| | Businessman | 2 |
| | Worker | 1 |
| | Soldier | 1 |
| | General practitioner | 1 |
| Marital status | Married | 13 |
| | Single | 1 |
| Living with the patient in the same house | Yes | 13 |
| | No (but living nearby) | 1 |

### Nurses of the core working group

Nine nurses working in this selected unit were organized into a core working group (Table 6). This group's members included one head nurse, one ET nurse, four nursing team leaders, and three senior nurses. All of them were married female without any religion, and aged 32 – 44 years (*M* = 37.22, *SD* = 4.02). One was minority people (Bai), and eight were Han people. All nine had a Bachelor degree with different professional titles (five with middle level and four with primary level). Their work experience as a registered nurse was 9 – 26 years (*M* = 17.78, *SD* = 5.45). Specifically, the work experience of engaging in ostomy care ranged from 4 months to 21 years (*M* = 10.70, *SD* = 6.41). Although the head nurse had only 4-month work experience of ostomy care while being recruited into this study, she had completed a 3-month study visit on ostomy care in the Beijing Tumor Hospital. Additionally, she had already been a head nurse for many years in another unit before she moved to this unit. Moreover, the ET nurse had 8-year work experience as a specialist nurse in ostomy care.

Additionally, the demographic characteristics of each nurse are shown in Appendix C7.

Table 6

*Summary of Demographic Characteristics of the Nurses (n = 9)*

| Characteristics | | n |
|---|---|---|
| Gender | Female | 9 |
| Age (*M* = 37.22, *SD* = 4.02) | 30 – 39 years | 6 |
| | 40 – 49 years | 3 |
| Ethnic | Han | 8 |
| | Bai | 1 |
| Religion | None | 9 |
| Educational level | Bachelor degree | 9 |
| Marital status | Married | 9 |
| Current work position | Head nurse | 1 |
| | Enterostomal therapist nurse | 1 |
| | Nursing team leader | 4 |
| | Senior nurse | 3 |
| Professional title | Middle level | 5 |
| | Primary level | 4 |
| Work experience as a registered nurse (*M* = 17.78, *SD* = 5.45) | 5 – 9 years | 1 |
| | 10 – 14 years | 2 |
| | 15 – 19 years | 2 |
| | 20 – 24 years | 3 |
| | 25 – 29 years | 1 |
| Work experience of engaging in ostomy care (*M* = 10.70, *SD* = 6.41) | < 5 years | 1 |
| | 5 – 9 years | 4 |
| | 10 – 14 years | 2 |
| | 15 – 19 years | 1 |
| | 20 – 24 years | 1 |

## Process of Developing the Family-Based Care Model

Following five phases of action research, i.e. the initiative reconnaissance phase and the spiral of four phases (planning, acting, observing, and reflecting), the process of developing the family-based care model to enhance Chinese patients' successful living with a permanent colostomy was reported through three sections: (1) reconnaissance phase; (2) spiral action research process to develop the family-based care model; and (3) final evaluation.

### Reconnaissance phase

Reconnaissance was conducted to understand the patients' situations and identify problems that needed to be resolved through in-depth interviews with seven experienced patients who had been with a permanent colostomy less than one year (Table 2) and four of their family caregivers (Table 4), and a focus group discussion with nine nurses who were working in the setting where this study was carried out (Table 6). The findings revealed that living with a permanent colostomy (zao kou, which is commonly verbalized by health care professionals) was both a stressful situation and a negative event for Chinese patients who newly received the fecal diversion (gai dao, which is universally called by lay persons). These patients coped with this situation largely through their own endeavors, receiving nursing care in hospital and family caregiving at home. Concretely, the findings in the reconnaissance phase were presented including: (1) self-care activities of the patients with a permanent colostomy; (2) caregiving activities of the family caregivers; (3) health care services for the colostomy patients; (4) caring activities of the nurses for the colostomy patients; (5) meanings of successful living with a permanent colostomy; and (6) main problems in the patients' situations of living with a permanent colostomy.

### ***1. Self-care activities of the patients with a permanent colostomy***

Following the formation of colostomy, the patients took care of themselves to cope with their stressful situations primarily through: managing defecation, handling bodily discomfort, struggling with mental distress, and reconciling with restrictions in life.

#### *1.1 Managing defecation*

The fecal diversion changed the normal defecation pattern into the new one which was frequently perceived as a strange, abnormal, inconvenient and troublesome pattern. The patients with a colostomy had to learn the skill of using ostomy appliances, the determination of timeliness to release gas in the pouch, empty feces in the pouch and change the ostomy appliance, and then gradually becoming familiar with their own routines of defecation.

##### *1.1.1 Performing the procedures of using ostomy appliances*

The skill of using ostomy appliances was a vital basis of good defecation management. In all procedures of this skill, there were four procedures emphasized by the participants, i.e. releasing gas in a pouch, emptying and cleaning the pouch, cutting the skin barrier, and attaching the skin barrier onto peristomal abdomen. The last two procedures could be called as changing the ostomy appliance.

However, only three in seven experienced patients usually performed the four procedures independently. These patients were willing to assume the responsibility of caring for their own colostomies. Meanwhile, they were pleasant that their family caregivers expressed concern and love to them through occasionally helping them to change ostomy appliances. Evidence could be seen in the following quotes:

> It is not good to let others clean, empty and change ostomy appliances for you, because they may feel your excrement dirty. It would be better if you can care for the colostomy by yourself, because the excrement is yours and you will not feel it dirty.
>
> (Experienced patient PE2)
>
> If you always rely on your family caregiver [to care for your colostomy], you will feel disgraceful and unacceptable.
>
> (Experienced patient PE5)
>
> I deal with ostomy appliances by myself. I usually handle them alone except when my wife is at home. While at home, she is glad to change the ostomy appliance for me to express her concern (guan xin) and lack of disgust (bu xian qi).
>
> (Experienced patient PE2)

Moreover, the other three experienced patients were responsible for only releasing gas, and emptying and cleaning pouches. Even though these patients would like to take the responsibility of caring for their own colostomies, they thought that the skin barriers attached by their family caregivers can be kept for longer time, or having no confidence in attaching the skin barriers well by themselves. As two experienced patients explained:

> I can attach the skin barrier by myself, but it will leak soon. Conversely, the skin barrier could be maintained for longer time if my family caregiver attached it for me.
>
> (Experienced patient PE3)
>
> I can see my ostomy while standing up or sitting down, but I feel that I cannot attach the skin barrier very well.
>
> (Experienced patient PE4)

Unfortunately, one elderly woman failed to care for the colostomy by herself, and completely relied on her family caregivers to deal with ostomy appliances due to her fatigue during chemotherapy. Moreover, owing to financial difficulty, she used the outdated type of ostomy appliance (binding a plastic around a rubber ring) which is easily leaking feces with weak airtightness. As a result, she was overwhelmed by both bodily and mental suffering. As she described:

> I have no energy. I cannot deal with the ostomy appliance by myself. My children or husband does this for me…Dealing with the pouch is very troublesome. When my feces came out, if my children were not aside, my husband had to deal with it for me. He felt bored with this…Nobody was nearby sometimes, so I had to hold my feces on my hands. I felt very smelly and really inconvenient. I felt suffering, and very suffering.
>
> (Experienced patient PE7)

*1.1.2 Learning what is a good time to release gas, empty a pouch and change an ostomy appliance*

Determining a good time to release gas, empty the pouch and change the ostomy appliance was very significant for the patients with a colostomy to manage their flatus and defecation, which could contribute to both the good management of body image through avoiding break-up, leakage and come-off of ostomy appliances, and the prevention of peristomal skin problems. Commonly, these individuals learned from the nurses, their family caregivers, fellow patients and their own experience. The nurses taught the basic principles, such as releasing gas in the pouch when the pouch is inflated by intestinal gas, emptying the pouch when it is one-third to one-half full, and generally changing the ostomy appliance in 5 – 7 days or when it is leaking. The family caregivers and fellow patients shared their tips, e.g. not letting water wash back over the skin barrier of one-piece ostomy appliance when flushing the pouch. Also, the patients learned from their own practice, as two patients introduced:

> Touch this pouch from time to time. I can feel whether it is inflated. Releasing gas in the pouch is fairly easier than emptying and cleaning the pouch. I just open the clip and let gas go out.
>
> (Experienced patient PE6)

> I may feel a little itching around the colostomy before I recognize that I should change my ostomy appliance. If no sense of itching, I may smell odor several days after attaching a new ostomy appliance, which implies that it is time to change.
>
> (Experienced patient PE6)

Unexpectedly, lack of timely education caused the negative experience related to the break-up of pouch among the patients and their family caregivers in the immediate post-operation, as two participants stated:

> At the third day after surgery, feces came out of the break-up pouch and dirtied the sheet. Nobody told us to observe the pouch to release gas in the pouch, or empty the pouch if necessary. How can we touch this pouch without the guidance of nurses? We have no any previous experience [about caring for a colostomy].
>
> (Family caregiver CE1)

> At that time, the pouch broke up, and feces came out with smelly odor. Flatus (fan pi, which is called by lay persons) is just intestinal exhaust (pai qi, which is verbalized health care professionals). When the pouch is full of intestinal gas, you must release it. We did not know what intestinal exhaust meant, so we did not timely release gas and the pouch broke up.
>
> (Experienced patient PE3)

*1.1.3 Becoming familiar with the own routine of defecation*

Eliminating feces from the surgical opening on the abdomen is very different from the common defecation pattern. It was hard for the patients to be familiar with the new defecation pattern. After discharge home, some of them were gradually able to master their own routines of defecation, and thereby get used to the new pattern. Evidence was from the following excerpt:

> When I just got this colostomy, I felt very inconvenient because I had to empty the pouch many times in one day. Now, I have gotten used to it. I have understood my routine of defecation. If being normal, I need to empty the pouch 2 – 3 times/day; if being abnormal, I have to empty it more times in one day…Usually, I empty the pouch in the morning like a normal person. However, it is different from the normal defecation. Feces come out a little by

> a little. After you empty the pouch for several minutes, feces may come out again. Commonly, I continue to empty the pouch about three times, and then feces will not come out again.
>
> (Experienced patient PE3)

*1.2 Handling bodily discomfort*

After discharge from hospital, the patients with a colostomy encountered the main bodily discomfort including peristomal skin problems, perineal wound pain, and side effects of postoperative adjunctive chemotherapy. Handling these issues became the parts of their daily lives.

*1.2.1 Dealing with peristomal skin problems*

Many patients suffered peristomal skin problems at the early stage of post-discharge including redness, itching, soreness and rash around their colostomies. They needed both the assistance of family caregivers and the guidance of nurses to perform the correct procedures of using ostomy appliances and accessories in order to deal with these skin problems. For example, one female explained:

> After the surgery was just done, I felt my peristomal skin itchy every day, and I had to scratch it. Ouch, it was too itchy. Once I really felt it unbearable, so my husband changed a new ostomy appliance for me. Then, I felt better. He reminded me not to let water wash the peristomal area when I put water into the pouch to clean it…At that time, I went back to hospital to see the ET nurse and then followed her suggestions: not cutting skin barriers so big; avoiding food which easily causes diarrhea; using ostomy skin barrier powder. After two months post-operation, I did not feel itchy again.
>
> (Experienced patient PE3)

However, unsolved peristomal skin problems could result in both bodily and mental discomfort among the patients with a colostomy. One elderly woman reflected:

> The skin barrier is sticky and airtight, so my skin under it becomes red and very itchy…I have to frequently clean the skin and change the ostomy appliance, which lets me feel very troublesome.
>
> (Experienced patient PE7)

### *1.2.2 Managing perineal wound*

The patients with a colostomy, who had a perineal open wound created from Miles operation, had to clean up the wound and perform the hip bath every day for several months in order to improve the healing of wound and reduce discomfort from the wound. Due to the particular position of perineal wound, their family caregivers universally took the responsibility of cleaning up the wound. Managing the perineal wound became an essential daily activity for these patients and their family caregivers after discharge home. As two experienced patients mentioned:

> When I just went home, I had to perform the hip bath daily. I dealt with the hip bath every day. Importantly, my wife assisted me to clean up my perineal wound before the hip bath.
>
> (Experienced patient PE3)

> Have the hip bath 3 – 4 times each day. I would feel dry and uncomfortable about my perineal wound if I had not performed the hip bath, so that I must have the hip bath every day.
>
> (Experienced patient PE7)

In particular, partial patients with a perineal open wound encountered unbearable perineal wound pain, which became an obstacle for these patients to perform the procedures of using ostomy appliances independently. As a male stated:

> I hadn’t tried to empty the pouch by myself at the initial post-discharge. At that time, I felt very painful [in my perineal wound] and no possibility to do this. At about one month after discharge, I just started emptying the pouch by myself.
>
> (Experienced patient PE6)

### *1.2.3 Enduring side effects of chemotherapy*

Most patients with a colostomy endured side effects of post-operative adjunctive chemotherapy involving: loss of appetite, nausea, vomiting, dizziness, fatigue and diarrhea/constipation. These side effects brought out bodily discomfort to these individuals, and also impacted their independence in performing the procedures of using ostomy appliances and their defecation management. As three participants described:

> I cannot empty the pouch by myself. I want to eat something but I am unable to really eat it. I feel nausea and no energy. It has been four months like this. (Sigh) No energy to empty it.
>
> (Experienced patient PE7)
>
> During my husband received the second postoperative chemotherapy, his response of vomiting was very serious. He was unable to eat anything. Even drinking some water, he would vomit them up at once. So I directly put a rubbish bin in front of him. I reported to the doctor, and then my husband got several injections. Due to irregular diet, his defecation was not regular.
>
> (Family caregiver CE5)
>
> I accumulated some heat in my body from chemotherapy, so I got constipation. I just defecated every 3 – 4 days…I felt difficult to eliminate, a little by a little, along with my bellyache.
>
> (Experienced patient PE4)

#### *1.3 Struggling with mental distress*

Due to the creation of colostomy, some bodily discomfort, and the cancer's feature of threatening life, the patients with a colostomy confronted a great deal of mental distress, such as sadness, anxiety, worry, fear, loss of control, sense of disability, sense of self-inferiority, sense of isolation and discrimination. They made great efforts to struggle with these suffering, which were presented in several aspects: having to accept the reality of colostomy formation, having to keep a normal body image in public, and obtaining emotional support from family members and fellow patients.

#### *1.3.1 Having to accept the reality of colostomy formation*

Having a colostomy was frequently associated with "being abnormal, inconvenient, being difficult to care for, a cause of being isolated, and affecting one's job". Thus, almost all patients before surgery hoped the surgeons to preserve their original anuses (bao gang), if possible. Even though it was hard for them to accept a colostomy, a Confucian realist belief in valuing the present life rather than the afterlife allowed these individuals to accept the reality of colostomy formation based on the thought of saving life (bao ming). Following the surgeon's suggestion, abiding by the own destiny (ting tian you ming), and the Taoist idea of being happy-go-lucky (sui yu er an) were the common coping strategies. As several patients articulated:

> Preoperatively, considering having a colostomy is different from an ordinary person, I do not want the fecal diversion. But, in order to save my life (bao ming), I had to listen to the surgeons and abide by my destiny (ting tian you ming).
>
> (Experienced patient PE1)
>
> It is my thinking that I can only be happy-go-lucky (sui yu er an) because thinking more is useless…I just do what the surgeons told me.
>
> (Experienced patient PE4)

Bitterly, one elderly female, who did not know the possibility of fecal diversion before surgery, was regretful and unacceptable about her colostomy. As she complained:

> If I knew I got this kind of disease (cancer), I would not come to take this surgery. But, my daughter and son concealed [this diagnosis and the possibility of colostomy] from me…Having this colostomy makes my mood rather bad. I asked my husband or adult children to help me to empty the pouch and clean up feces. At the beginning, it was OK for them. But now, they feel bored and don't want to help me. (Her daughter said: It would be better if my mother had not undertaken the fecal diversion) Yes. It would be better for me if I had not undertaken the fecal diversion. Ouch, I feel very sad.
>
> (Experienced patient PE7)

#### *1.3.2 Having to keep a normal body image in public*

Due to low level of awareness about a colostomy among Chinese people, the patients who have a colostomy to eliminate feces were often looked down upon. Similar to a traditional Chinese opinion, delivering a baby without an anus is a negative family affair. This family could be laughed at by other people. Moreover, the participants perceived their colostomies as "a surprising thing, a handicap, or making themselves different from common people". Hence, these patients had to conceal their colostomies from others to maintain a normal body image in public, and further avoid themselves and their families being isolated and laughed at. As several patients stated:

> About the fecal diversion, it is a surprising thing and makes me different from a normal person…I worry that I could be isolated by other people who know my colostomy.
>
> (Experienced patient PE1)
>
> Some people asked me, 'Are you defecating?' I answered no and then pulled up my clothes to show my partial abdomen to them. I asked them, 'You take a look at my abdomen. Where are the feces?'
>
> (Experienced patient PE5)
>
> Some friends would like to see my colostomy. I do not show it to them. It does not sound good if they spread the reality of my colostomy.
>
> (Experienced patient PE2)

*1.3.3 Obtaining emotional support from family members and fellow patients*

Chinese belief in restraining the own emotional expression hindered the patients with a colostomy to proactively seek emotional support from their significant others. Nevertheless, some patients could obtain emotional support from their family members and fellow patients. Evidence was showed in the excerpts:

> My husband did me a big favor. Also, my parents-in-law helped me a lot. In short, all of my family encouraged me…My mother-in-law said to me, "We accept the fate. Only if you are alive, can you enjoy your life…If you cannot do farming labor, you may look after children at home. Like this, your children will still feel happy."
>
> (Experienced patient PE3)
>
> Other patients said to me, "Relax, don't always think about it, don't care about it. Only if your mood is happy, can you be better"…Now I feel better after chemotherapy. I did always want to cry while going back home.
>
> (Experienced patient PE3)

*1.4 Reconciling with restrictions in life*

Although having a colostomy led to various restrictions in the patients' lives, these patients made efforts to reconcile with the restrictions through adjusting oneself to daily life in a family, reducing social activities, and putting sexual relationship aside.

### *1.4.1 Adjusting oneself to daily life in a family*

All seven experienced patients were living with their family members. These individuals endeavored to adjust themselves to personal and family lives every day involving: personal hygiene, dressing, sleeping, purchasing/preparing food, cooking, housekeeping (e.g. washing clothes, cleaning home, and making up a room), leisure activities, physical activities and productive homeworking/farming (e.g. feeding livestock and poultry, and planting vegetable). The common tendency was from the initial family-caregiving predominant to self-care (or collaborative care) predominant atmospheres over time. The family caregivers gradually reduced their involvement in colostomy care and daily living care, and then returned to their previous family lives. As several participants described:

> When I just came back home after discharge, I did not do any housework. I was just responsible for eating, because I was not required to cook by my family members. At that time, my daily life focused on dealing with feces and the hip bath. Even, at the beginning of discharge home, my husband assisted me to change the ostomy appliance and prepare the water of hip bath…Now, I can do some light housework, while my husband assumes those heavy ones. Every day, I send my children to school and pick them up. I prepare food for my family members. I have adjusted to my current life.
>
> (Experienced patient PE3)

> If I am at home, I am responsible for cooking. If I go to farm, my husband just has a cook. We are feeding several rabbits and twenty pigeons at home.
>
> Someone said that feeding pigeons is equal to regulating moods. Hope that my husband' mood may become better.
>
> (Family caregiver CE2)

Also, these individuals overcame some restrictions in life by means of choosing light and digestible food to improve regular defecation; averting spicy, deep-fried, pickled or grilled food to prevent cancer recurrence; choosing less gas-producing food to evade embarrassment of flatulence and flatus; releasing gas from the pouch before sleep to prevent it breaking; wearing larger clothes without a belt to avoid pressure on the colostomy; avoiding physical exercise which may damage the colostomy.

#### *1.4.2 Reducing social activities*

Due to the intention of keeping a normal body image in public, the individuals had to conceal their own colostomies from common others. Thus, many individuals worried about break-up, leakage, come-off, odor, and noise relevant to ostomy appliances and ostomy itself, and thereby reduced their social activities. For example, two participants explained:

> There is little time for me to play together with my friends after having a colostomy…My main worry is the leakage of ostomy appliances.
>
> (Experienced patient PE2)

> At present, I seldom go to public places because I cannot control this noise (flatus) which makes me awkward in public.
>
> (Experienced patient PE6)

#### *1.4.3 Putting sexual relationship aside*

Colostomy-related surgery and treatment often impacted some patients on their sexual lives, especially younger people with a colostomy. The restrictions in sexual life were generally with regard to female dyspareunia, male impotence, unattractive body image with a colostomy, and less sexual desire owing to long-term treatment. The embarrassment of talking about sexual topics with an outsider (wai ren, a person who is out of a family) was a barrier for these patients to proactively seek support from health care professionals. Likewise, the health care professionals seldom provided information on sexual issues to these patients and their spouses because of awkwardness.

Therefore, the patients and their spouses put their sexual relationship aside, and instead paid attention to their own responsibilities of keeping marital loyalty and family integrity which were rooted in Confucian ethic system of role relationships. As one young female reflected:

> [The surgery has] some impacts on our sexual life (fu qi sheng huo)…I feel shy to ask the surgeon when my husband and I may have sex (tong fang). Also, the surgeon has not proactively informed us about this issue…My husband said that he has become a male who is single (guang han zi) for nearly one

> year since I got sick. However, he did not mind this (no sexual intercourse with me) based on our many-year marriage with two children.
>
> (Experienced patient PE3)

### *2. Caregiving activities of the family caregivers*

The family caregivers played a major role in caring for their relatives with a permanent colostomy, especially in the first several months after surgery. The caregiving activities of family caregivers mainly included: assisting to perform the procedures of using ostomy appliances, helping to manage bodily discomfort, providing emotional support, and taking more family responsibilities.

#### *2.1 Assisting to perform the procedures of using ostomy appliances*

Assistance provided by the family caregivers in performing the procedures of using ostomy appliances varied with different need, ability, availability and preference among the patients and these family caregivers themselves. Some family caregivers gradually reduced their involvement in using ostomy appliances until their relatives were able to perform all procedures independently, while other family caregivers persisted to perform the procedure of changing the ostomy appliance for their relatives. As several participants described:

> After discharge home, I was unable to cut and attach the skin barrier of ostomy appliance, and my husband always helped me. Later, he said to me, “How will you do if I am not at home?” so, he taught me, and then I learned and mastered. Now I can cut and attach the skin barrier.
>
> (Experienced patient PE3)
>
> At that time, I was unable to empty or change my ostomy appliance due to unbearable [perineal wound] pain…I had started emptying my ostomy pouch after one month post-operation. Before that, I always relied on my wife to empty it. Until now, my wife still helped me to change the ostomy appliance.
>
> (Experienced patient PE6)
>
> My daughter changed my ostomy appliance in hospital. After discharge home, my husband, son or daughter-in-law change the ostomy appliance for me…I

> had never changed my ostomy appliance by myself because I was afraid that I cannot attach it onto my abdomen well.
>
> (Experienced patient PE4)

Importantly, changing the ostomy appliance every several days seemed to be acceptable for most family caregivers. However, frequent emptying the pouch every day easily caused that the family caregivers felt burden and burnout after performing this for a long time.

*2.2 Helping to manage bodily discomfort*

The family caregivers inevitably involved in managing the bodily discomfort of their relatives with a colostomy. They helped their relatives to deal with peristomal skin problems, perineal open wound and side effects of chemotherapy, such as performing peristomal skin care, cleaning up perineal wound, preparing water for the hip bath, and improving nutrition before the next chemotherapy. Examples could be seen as follows:

> In the first several days of discharge home, my husband felt discomfort with his peristomal skin. It seemed that something was gnawing at his skin. So, I removed the old ostomy appliance, cleaned the skin with clear water, exposed the skin in air for a while, and then attached the new ostomy appliance.
>
> (Family caregiver CE1)

> When I just discharged home, my main activities were to perform the hip bath and deal with feces every day, and my husband helped me to clean up my perineal wound, prepare water for the hip bath, and handle my ostomy appliance.
>
> (Experienced patient PE3)

> At the first chemotherapy, my husband’s response was serious. He was unable to eat anything, especially food with much fat and unpleasant smell. I had no way, and just waited until he felt better after chemotherapy. Then, I prepared food according his favorite and encouraged him to eat more for preparing the next chemotherapy.
>
> (Family caregiver CE1)

*2.3 Providing emotional support*

The family caregivers were an imperative source of emotional support for their relatives with a colostomy. They provided emotional support through consolation, encouragement, protecting the survival hope, and concealing the own worries to avoid hurting their relatives. Evidence was presented in the quotes:

> My mother-in-law consoled me, “We have to defecate hard after our bodies accumulate so much heat, while it is so easy for you to defecate. Don’t worry every day. You seem to be lucky. You know, a villager spent one million Yuan to treat her leukemia, but finally she was not saved. We all have abided by our destinies. Only when you are alive, can you enjoy your life.”
>
> (Experienced patient PE3)

> (Patient: I have received chemotherapy and just expect to be cured. If I am not be cured, I will have no choice except suicide) Do not think too much. You will be better. What is more, you have undertaken the surgery in which your tumor has been removed.
>
> (Family caregiver CE7)

> I had been nervous for one week during my husband’s surgery. Frankly speaking, I worried whether my husband could survive the surgery because he was so old. I had not told him my worry because I would like to influence his mood. Until the fifth day after surgery, our children came to hospital, and I was just able to be asleep well.
>
> (Family caregiver CE1)

*2.4 Taking more family responsibilities*

When a family member became a patient with a newly-formed colostomy, his/her family caregiver commonly took more responsibilities for maintaining their family.

Generally, Chinese people thought that a patient who just underwent a surgery needed a good rest to recuperate. Thus, the family caregivers assumed more housework to avoid the individuals’ tiredness and facilitate their recovery. As two participants described:

> All of daily housework, such as cooking, is taken by my wife. Also, my siblings concern me. What did they do like? Even lifting a barrel of water, they did not allow me to do. They just suggested me to have a walk outside.
>
> (Experienced patient PE2)

> I cook something my husband wants to eat. I do housekeeping. I hope him to become better soon, so I assume all housework. Besides, we had no farm labor, so I spend time in accompanying him to have fun.
>
> (Family caregiver CE1)

Among the families of seven experienced patients, except two families with the monthly income of more than 5000 Yuan, the other five families had lower monthly income and faced financial stress. The family caregivers in these families became the main breadwinner, and endeavored to make more money for paying family living costs, educational expenses of the children, ostomy appliance cost, and subsequent medical expenditure of the patients with a colostomy. As a female participant stated:

> …I worried that I spent so much money on my medical treatment, and how to repay our debt…My husband said to me, “You do not worry, and you just take good care of yourself. Let me deal with the matter of money”.
>
> (Experienced patient PE3)

### *3. Health care services for the colostomy patients*

In this study’s context, health care services for the colostomy patients were largely associated with the conventional Western medical service provided by the tertiary hospitals, along with both a small amount of service utilization of traditional Chinese medicine and paucity of community health care service.

#### *3.1 Being mainly provided by the tertiary hospitals*

In this province where this study was conducted, health care services for the patients requiring/with a permanent colostomy were mainly provided by the tertiary hospitals. Due to the requirement of surgical technology, most colostomy-related operations were performed in the tertiary hospitals.

Preoperatively, a number of patients had encountered hematochezia (blood in feces) and change in defecation habit for several months. After being diagnosed with rectal cancer by the surgeons of regional hospitals (secondary hospitals), most patients were referred to the tertiary hospitals.

Moreover, community health care providers were universally short of necessary knowledge and skills relevant to colostomy care. Thus, there was lack of health care services specific to the patients with a colostomy after discharge home in community.

### *3.2 Conventional Western medical service for the colostomy patients*

Conventional Western medical service for the patients requiring/with a permanent colostomy was chiefly with regard to the treatment methods including surgery, radiotherapy and chemotherapy.

According to different stages of large bowl cancer based on the TNM (T - tumor, N - node, M - metastasis) Classification of Malignant Tumors (seventh edition) by the American Joint Committee on Cancer (AJCC) and the Union for International Cancer Control (UICC), different treatment plans were selected involving colostomy-related surgery, radiotherapy and chemotherapy before/after operation.

Common surgical procedures for treating rectal cancer consisted of Miles operation (abdomino-perineal resection of the rectum and formation of an end colostomy), Hartmann operation (resection of the rectosigmoid colon with closure of the rectal stump and formation of an end colostomy), and laparoscopic radical rectectomy.

For preoperative radiotherapy, the total dose was generally 5000sgr, and simultaneously oral Xeloda (capecitabine) was recommended. Moreover, the protocol of postoperative adjuvant chemotherapy usually merged oxaliplatin, folinic acid, 5-fluorouracil (or Xeloda) and irinotecan for a maximum of 14 treatment cycles, and the duration of each cycle was two or three weeks.

With the trend of shortening hospital stays, most patients with a colostomy discharged about ten days after surgery in this hospital where this study was conducted. It was suggested to perform postoperative medical check-up every three months in the first three years, every six months after three years, and every year after five years.

### *3.3 Traditional Chinese medical service for the colostomy patients*

After the completion of relevant conventional Western medical treatment, some patients with a colostomy went to see the physicians of traditional Chinese medicine, and took herbal soups to supplement Qi and blood in order to facilitate physical recovery, improve gastrointestinal function and enhance immunity. As one patient stated:

> I am planning to see the physician of traditional Chinese medicine after completing chemotherapy, and get the prescription of herbal soup for enhancing my gastrointestinal function. Because the chemotherapy has damaged my stomach, intestine and liver, I need to take some herbal soups to repair them.
>
> (Experienced patient PE2)

## ***4. Caring activities of the nurses for the colostomy patients***

The creation of a permanent colostomy was mostly for treating rectal cancer through the surgical procedures of conventional Western medicine. Due to the task-orientated and nurse-directed climate, the nurses' caring activities for the patients with a colostomy were commonly described in technical rather than humanistic ways, involving performing education and perioperative nursing care, providing ostomy nursing care, carrying out radio/chemotherapy nursing care, and providing few opportunities for patients to obtain peer support.

### *4.1 Performing perioperative education and nursing care*

A permanent colostomy is created from relevant surgical procedures. Thus, performing perioperative education and nursing care is a part of caring activities of the nurses for the colostomy patients.

In this surgical unit where this study was conducted, the contents of routine perioperative education and nursing care included: (1) assessing the patients' general status while being admitted; (2) assisting and guiding the patients to complete relevant medical examination and treatment; (3) carrying out routine preoperative preparation and education (e.g. intestinal preparation); (4) implementing postoperative observation (e.g. vital signs, wound status, pain and complications); (5) guiding the hip bath of open perineal wound; (6) providing nursing care of various medical catheters (e.g. gastric tube, urinary catheter, and drainage tube); (7) guiding body position and activity; (8) proving dietary guidance; (9) performing treatment plan (e.g. medication, injection and infusion); (10) proving discharge education (e.g. time schedule of medical check-up or postoperative chemotherapy).

Routinely, the nursing team leaders organized several ward nurses in each nursing team to perform perioperative education and nursing care for the patients requiring/with a colostomy.

*4.2 Providing ostomy nursing care*

In this surgical unit, ostomy nursing care was mostly provided by the ET nurse, involving: preoperative ostomy site marking and education, postoperative ostomy care and education, and ostomy follow-up after discharge.

Preoperative ostomy education was generally provided while performing ostomy site marking. However, ostomy site marking was not a nursing routine and depended on the surgeons’ requirements. In seven experienced patients interviewed by the researcher, only two patients received preoperative ostomy site marking and education performed by the ET nurse, while the others understood the colostomy-related knowledge from their surgeons and fellow patients. For example, two participants mentioned:

> Before surgery, I went around this unit and knew some patients who received the fecal diversion, so I learned some knowledge about colostomy from them. In fact, the surgeons just told that it was possible for me to need the fecal diversion, but they had not provided more information about this. Besides, the nurses had not said anything about colostomy.
>
> (Experienced patient PE4)

> Generally, we tell the patients that we will teach them how to care for the ostomy after surgery. Thus, preoperative ostomy education is often superficial and insufficient. Without the demonstration of ostomy model and appliances, it is not easy for the patients to understand. Of course, if the ET nurse performed ostomy site marking to the patients, she would provide demonstration and more information to them.
>
> (Nursing team leader XD)

Postoperatively, the ET nurse commonly changed ostomy appliances for the patients 2 – 3 times, and simultaneously taught these patients and their family caregivers how to use ostomy appliances. Teaching practical ostomy care skills to both the patients and their caregivers was concerned by the ET nurse, because she thought that most patients were unable to care for their own colostomies and relied on their caregivers or the nurses before discharge. As an experienced patient (PE3) described, “When my pouch fills with too much gas and feces and then broke up, the ET nurse came to change it. She taught my husband while she was cleaning my skin, cutting and attaching the skin barrier, and sealing the opening of pouch.”

Additionally, when the ET nurse was unavailable in this surgical unit, other ward nurses would help the patients to deal with their ostomy-related problems, such as changing a leaking ostomy appliance at night shift.

After discharge, the ET nurse provided ostomy counselling service through answering the patients’ questions by telephone or by face-to-face in this surgical unit. Besides, the hospital administrators proposed to reduce hospital stays and thereby advocated the nurses to follow up the patients by telephone in the first month post-discharge. Thus, since June 2012, several senior nurses had got started providing telephone follow-up to the patients with/without a colostomy. However, the implementation of telephone follow-up was problematical. In seven experienced patients interviewed by the researcher, nobody had received telephone follow-up from the nurses of this surgical unit.

*4.3 Carrying out radio/chemotherapy nursing care*

Most patients requiring/with a colostomy might receive radio/chemotherapy before/after surgery. The ward nurses carried out corresponding nursing care involving: (1) guiding radiotherapy area skin care; (2) performing infusion or medication of chemotherapeutic medicine; (3) introducing common side effects, strategies of prevention and management; (4) observing side effects and reporting to the surgeons; (5) nursing care of the peripherally inserted central catheter (PICC) which is for infusing chemotherapeutic medicine.

*4.4 Providing few opportunities for patients to obtain peer support*

In this surgical unit, few opportunities were provided to the patients to obtain peer support in terms of some specific nursing interventions, such as ostomy group education, activities of ostomate club, and ostomate visiting. Due to the increase of patient beds after moving to the new in-patient building, the shortage of nurse manpower, and the shift of previous and current head nurse, the periodic ostomy group education and the activities of ostomate club had been ceased for a long time. Additionally, the ostomate visiting focused on the patients who felt difficult to accept ostomy-related surgery, which was occasionally provided according to the availability of the proper ostomate visitor who was present in this surgical unit.

### ***5. Meanings of successful living with a permanent colostomy***

Understanding the meanings of successful living with a permanent colostomy from the patients' perspectives was important to suggest the further actions. Data from in-depth interviews with seven experienced patients were extracted and presented including three aspects with seven components: (1) living with independence; (2) living without suffering; (3) living without self-inferiority. Besides, one component of surviving cancer emerged from in-depth interviews with novice patients in the spiral action research process. This component represented the patients' concern about survival, which can be interpreted by Confucian belief in valuing the present life rather than the afterlife, and also related to a Chinese idiom "Good death is not better than bad life" (hao si bu ru lai huo).

#### *5.1 Living with independence*

Almost every patient with a colostomy desired to live independently, and not to rely on the family caregiver too much and burden them. Through performing the procedures of using ostomy appliances independently, and getting used to the new defecation pattern, they could obtain the feeling of living with independence.

##### *5.1.1 Performing the procedures of using ostomy appliances independently*

The patients with a colostomy perceived being able to use ostomy appliances as an important basis. Through performing the procedures of using ostomy appliances independently, the individuals could get the sense of mastery, and gain confidence in adapting to a series of changes in their lives, such as body image, defecation pattern, dietary habit, and family affairs arrangement. Especially, these patients regarded opportunities to learn ostomy care as a key facilitator. Evidence could be seen in the following quotes:

> At the second post-operative day, the ET nurse came to change the ostomy appliance for me. My wife and I just looked at her operation. At the fifth post-operative day, she came again to teach how to change the ostomy appliance. After that, I change the ostomy appliance by myself. It is not difficult for me to master the skill.
>
> (Experienced patient PE2)

> It is essential for me that some people teach me how to use ostomy appliances. Otherwise, I do not know how to do. I need to learn from others, their experience, their guidance, about ostomy care. So, I can do by myself.
>
> (Experienced patient PE1)

#### *5.1.2 Getting used to the new defecation pattern*

The formation of colostomy changed the previous defecation pattern into the new one, which was unavoidably associated with uncontrolled sense of defecation (incontinence), irregular bowel movement, need to frequently empty the pouch, and altered toilet action (standing up to empty a pouch). As a consequence, the individuals often felt inconvenient and troublesome at the outset of living with a colostomy. However, through continuously learning and exercising the management of fecal elimination, many patients could obtain the sense of control, and get used to the new defecation pattern. As two participants stated:

> In one day, if normal, there are 2 – 3 times of defecation; if abnormal, there are 4 – 5 times of defecation…Different from the defecation of ordinary persons, the feces comes out a little every time, and I have to empty the pouch many times…I am afraid of diarrhea rather than constipation. If I get diarrhea, emptying the pouch becomes troublesome. I have to prepare water to flush feces attached on the pouch.
>
> (Experienced patient PE3)

> Before surgery, I worried that my defecation would become very inconvenient. Now I do not worry about it and let it be. I have already got used to it and feel it convenient.
>
> (Experienced patient PE1)

### *5.2 Living without suffering*

Suffering, with respect to the formation of colostomy, the life-threatened property of cancer, and the relevant medical treatment, surrounded the individuals and influenced their lives. The patients with a colostomy were expecting to be free from bodily discomfort, distance from mental distress, and meanwhile be able to gain support from family. Living without suffering was perceived as an essential aspect of successful living with a colostomy.

#### *5.2.1 Being free from bodily discomfort*

The patients with a colostomy, who encountered suffering from peristomal skin problems, perineal wound pain, or side effects of chemotherapy, frequently expressed their hope on being free from bodily discomfort. For example, three patients reflected:

> [When I just came back home], my feces was liquid and often irritated my peristomal skin, so that I felt very itchy. Then, I paid attention to timely empty, clean and change ostomy appliances…Currently, I do not feel my skin itchy, and I have adapted to being with a colostomy.
>
> (Experienced patient PE3)

> As long as my wound is not painful and itchy, I will have no any complaint. However, if any part of my body is painful and I cannot bear, I will feel that being alive is not better than being dead. Anyway, this type of idea is natural among common people.
>
> (Experienced patient PE6)

> I just feel nausea. I try to vomit but I cannot vomit anything. Unlike other patients who receive chemotherapy, they are always vomiting. (Sign) If no nausea and vomiting, it would be better for us.
>
> (Experienced patient PE2)

#### *5.2.2 Distancing from mental distress*

Although the formation of colostomy, along with the diagnosis of cancer, brought out a lot of negative emotions, the patients were always expecting and trying to distance from the mental distress in order to recover from the surgery and the disease as soon as possible. Based on a Taoist belief in the connection of body and mind, Chinese people universally believe that a negative mood may hinder the physical recovery from ill conditions. Thus, keeping a good mental state was concerned by the patients with a colostomy. Evidence could be seen in the following excerpts:

> Only when your mood is good, can your body immunity become better. I just think like this. I try to distance from bad moods.
>
> (Experienced patient PE3)

> No choice. You have to accept the fecal diversion. In fact, it is not a severe disease. Even though I defecate every several days, it seems normal. I just think like this. Let it be.
>
> (Experienced patient PE4)

> I am not worried and anxious now. I try not to think these [colostomy-related negative impacts]. Just have fun, play cards, or cook my favorite.
>
> (Experienced patient PE5)

#### *5.2.3 Getting support from family*

Getting support from family was perceived by the patients as an imperative component for their successful living with a colostomy. They expected and appreciated practical, informational, emotional and instrumental support from their families, such as assisting in cleaning up perineal wound, teaching how to cut and attach the skin barrier, encouragement to accept the reality of having a colostomy, and providing financial assistance to purchase the proper ostomy appliances and so on. As a participant commented:

> If no support from my family, I could not accept my colostomy and recover from the surgery so quickly.
>
> (Experienced patient PE3)

### *5.3 Living without self-inferiority*

Owing to the change of defecation pattern, the ostomy-related accidents (e.g. odor from leaking ostomy appliances), and no income after leaving work, the patients with a colostomy usually felt themselves inferior to others. Therefore, they endeavored to keep a normal body image in public and strived to contribute to their families, for the desire of living without self-inferiority.

### *5.3.1 Keeping a normal body image in public*

After all, the fecal elimination through a surgical opening on the surface of abdomen was different from an ordinary defecation. The patients with a colostomy were commonly expecting to keep a normal body image in public through avoiding leakage of fecal odor, noise of bowel movement, and come-off of ostomy appliances in front of other people, in order to maintain their own self-esteem and distance from the sense of self-inferiority. As several patients mentioned:

> If I smell the fecal odor while I am outside, I must go home to change my ostomy appliance. Otherwise, other people would be disgusted with me followed by unpleasant odor.
>
> (Experienced patient PE3)
>
> If I am making noise of bowel movement loudly when other people just come to me, they could hear this noise and be aware of having a colostomy with me. At the first several months after surgery, the noise from my bowel movement was loud. So I avoided eating gas-producing food and going outside. Now, it is lucky that the elimination of flatus is not loud with me.
>
> (Experienced patient PE3)
>
> A week after discharge, I found something in my trousers when I was walking on the street. So I picked up it, the clip of my ostomy appliance. It was fortunate for me that there were not feces in the pouch. Otherwise, I would be very embarrassed.
>
> (Experienced patient PE2)

### *5.3.2 Being able to contribute to family*

Being able to contribute to family is very significant for the patients with a colostomy to regain sense of self-worth and thereby avoid self-inferiority. They were expecting to share housework with their family members and do a productive work for their families. For example, several patients stated:

> Although I underwent the fecal diversion, I feel well now. (Her husband said: She lives well. She has been able to do some housework)…There are only two persons at home, my husband and me. It is easy for me to prepare our meal.
>
> (Experienced patient PE4)

> I have not done any work after getting sick. My family relies on only my wife’s income about 2000 Yuan/month at present. Our child is studying in university with high expenditure. I am anxious about our financial issue. So, I would like to look for a job to contribute to my family after I recover from the surgery.
>
> (Experienced patient PE2)
>
> At the beginning, I thought I might be unable to do anything due to being with this pouch. But now, I am expecting to do some farm labor if there is nothing wrong with me.
>
> (Experienced patient PE3)

### ***6. Main problems in the patients’ situations of living with a permanent colostomy***

Due to the distinction of the patients’ situations between before and after discharge, main problems were identified by the participants and divided into two aspects: (1) main problems before discharge (hospitalization), and (2) main problems after discharge (discharge home).

#### *6.1 Main problems before discharge (hospitalization)*

The main problems in the patients’ situations at hospitalization before discharge included: bodily and mental suffering before discharge, inadequate discharge preparedness of the patients and their family caregivers, and issues on communication between the patients and their family caregivers.

##### *6.1.1 Bodily and mental suffering before discharge*

Bodily and mental suffering was interconnected and interactive. Preoperatively, unpleasant disease-related symptoms and signs (e.g. pain and hemafecia), and the dilemmas between saving life (bao ming) and preserving the original anus (bao gang) were coexisting. At the immediate post-operation, fatigue and pain from the surgery, alteration of bodily appearance and defecation pattern, and sense of sadness about bodily changes were mixed together.

Particularly, lack of awareness about colostomy before surgery often caused difficulties in accepting colostomy-related surgery and colostomy itself. Among two in seven experienced patients who were unaware of the diagnosis of cancer and the possibility of colostomy, one patient (PE7) felt difficult to accept her colostomy and regret receiving the fecal diversion for a long time, and another patient (PE3) felt very sad about having a colostomy and was always crying at the early period of post-operation. One elderly male patient (PE1) had ever rejected to get the fecal diversion before surgery, because he had not known much about colostomy and imagined that having a colostomy would be very troublesome and isolated by others. At that time, his adult children replaced him to have a preoperative conversation with his surgeon, and also he had not received preoperative ostomy site marking and education from the ET nurse.

Additionally, among the patients with a colostomy and their family caregivers, insufficient knowledge and ability in using ostomy appliances and taking care of perineal wound, usually brought out unnecessary suffering. For example, cutting the opening of skin barrier too wide induced peristomal skin to be irritated by feces; making too high concentration of potassium permanganate solution for hip bath led to chemical burn.

### *6.1.2 Inadequate discharge preparedness of the patients and their family caregivers*

During hospitalization, the main concerns of the patients and their family caregivers were about receiving surgery for saving life and recovering from surgery (e.g. surgical excision healing, diet, rest and activities). The procedures of using ostomy appliances were mostly performed by the nurses and seemed rather simple. Therefore, these patients and their family caregivers often lack inadequate preparation for coping with possible difficulties in dealing with ostomy appliance, preventing and managing ostomy-related complications after discharge at home. There were the following reasons responsible for this.

#### *(1) Reluctant to learn colostomy care among the patients and their family caregivers before surgery*

Some patients and their family caregivers were reluctant to learn colostomy care before surgery. They paid more attention to treat their diseases and survive the coming surgery, while how to care for a colostomy was perceived as a task after it became a reality after surgery. As one experienced patient and the ET nurse reflected:

> It is unnecessary to understand how to care for the colostomy before surgery. Once the colostomy forms, I just do what I should do. Moreover, it is possible that I cannot survive surgery, so I can only abide by my destiny.
>
> (Experienced patient PE6)

> It is impossible to let the patients to learn how to use ostomy appliances before surgery. At this time, the patients have a lot of ideas with mental stress. They have no spare time and energy to learn the usage of ostomy appliances. I think the most important thing before surgery is to let the patients look at the ostomy appliance and know that they will use the ostomy appliance to manage their defecation after surgery.
>
> (ET nurse WQ)

*(2) Relying on nurses to deal with ostomy appliances after surgery*

A preconception, that is, the nurses should care for the hospitalized patients through directly doing for them, affected the patients and their family caregivers to actively participate in exercising the usage of ostomy appliances. Instead, most of them relied on the nurses to deal with ostomy appliances after surgery in hospital. Evidence was from the nurses' experience:

> Some patients said, "I stay in hospital. It is reasonable that the nurses help me to deal with my ostomy appliance".
>
> (Senior nurse SY)

> Many patients and their family caregivers relied on our nurses to deal with ostomy appliances in hospital. Although we encouraged them to change ostomy appliances at least once before discharge, but they had the idea of dependency on the nurses and were unwilling to do by themselves.
>
> (Nursing team leader XD)

*(3) Limited learning opportunities on ostomy care provided to the patients and their family caregivers before discharge*

Owing to short hospital stays and correspondingly limited learning opportunities, a certain number of patients and their family caregivers had not obtained adequate knowledge and skills on ostomy care before discharge, involving correct usage of ostomy appliances, prevention and management of ostomy-related complications, and information of ostomy care products (e.g. one/two-piece ostomy appliance, ostomy skin barrier powder, skin sealants, fillers, adhesive removers etc.). As the head nurse reflected:

> I consider the patients and their family caregivers have not mastered enough knowledge and skills on ostomy care and healthy lifestyle before discharge. At that day, we had a meeting with some patients and their family caregivers. They hoped that we could organize the periodic activities of group education to provide their more learning opportunities on ostomy care.
>
> (Head nurse SX)

> Most patients admitted in our unit were from various regions where are far from our hospital, usually with low level income and dependence on family caregiving. Some family caregivers reflected that they did not know how to deal with peristomal skin problems [after discharge at home]. When they consulted the professionals in local regional hospitals, these professionals did not know how to treat. Also, it was difficult for them to come to our hospital due to high expense of transportation and accommodation. One day, a patient told me that he cut two skin barriers wrong. Until the third one, it was just OK for using. Perhaps, these issues were resulting from our inadequate guidance at hospitalization. So let us discuss how to improve our ostomy nursing care, such as introduction of ostomy care products, and education on preventing and managing ostomy-related complications.
>
> (Head nurse SX)

### *6.1.3 Issues on communication between the patients and their family caregivers*

Effective communication between the patients and their family caregivers may improve mutual understanding and support. Otherwise, misunderstanding and conflict will emerge. For instance, one elderly woman (PE7) was concealed by her family members about her diagnosis of cancer and the possibility of colostomy formation before surgery. After surgery, she complained to them and regretted having this colostomy which was associated with dirtiness, odor and itching of peristomal skin.

Moreover, many patients and their family caregivers controlled to express their own negative emotions (e.g. worry and anxiety) in order to avoid hurting their relatives and maintain a positive mood in stressful situations. As a female family caregiver (CE1) mentioned, “I had worried for one week about whether my husband could survive and recover from surgery successfully because he is nearly seventy years old. But, I did not dare to tell him my worry because I would not like to bring negative impacts on his mood.”

### *6.2 Main problems after discharge (discharge home)*

The main problems in the patients’ situations after discharge at home involved: bodily and mental suffering after discharge, fewer social activities, insufficiency of continued nursing support for the patients and their family caregivers, and inappropriate family caregiving.

#### *6.2.1 Bodily and mental suffering after discharge*

After discharge at home, the patients frequently encountered bodily discomfort from ostomy-related complications, perineal wound, and side effects of chemotherapy, and mental distress related to difficulty in adapting to living with a colostomy. These bodily discomfort and mental distress were weaved together into their personal and family lives.

Moreover, insufficient knowledge and ability in managing peristomal skin problems and dealing with side effects of chemotherapy could worsen the patients’ situations, e.g. using alcohol to disinfect peristomal skin, which was actually irritating skin; not drinking water during chemotherapy due to vomiting, which was not beneficial for the elimination of chemotherapeutic drugs and thereby aggravating the response of vomiting.

#### *6.2.2 Fewer social activities*

It was common that the patients with a colostomy participated in fewer social activities than those they attended before surgery. Owing to both bodily discomfort and worry about isolation and stigma/discrimination from the public, the patients often reduced or gave up some of their previous social activities, which might worsen their sense of self-inferiority. Thus, these patients needed to be encouraged to actively try previous social activities on the basis of being able to managing body image and defecation well. Evidence could be reviewed in the quotes:

> At the initial period of discharge home, I almost stayed at home all the day without any going outside because I was unable to walk due to the severe perineal wound pain. Now, I can have a walk outside for a while. But, I

> seldom go to the public places, in order to avoid worry about the noise of my bowel movement in public.
>
> (Experienced patient PE6)
>
> Although I have sense of isolation and worry about my colostomy, I do not refuse to visit my relatives/friends. We talked and had fun together. Before surgery, I practiced dancing with some friends and neighbors every day. But now, I have not joined them. I consider I cannot go to dance with them again, because it easily happens that the pouch comes off while you are dancing and wriggling your body. My sister-in-law encouraged me, "You may go to play with them and also have a dance with slow rhythm. Spending some time in collective recreation activities may avoid that you think too much at home, and then you will feel better."
>
> (Experienced patient PE3)

*6.2.3 Insufficiency of continued nursing support for the patients and their family caregivers*

After discharge from hospital and go back home, the patients were really aware of the impacts of having a colostomy on their personal and family lives. These patients needed continued nursing support to facilitate their successful living with their colostomies, and also their family caregivers needed the nurses' guidance about proper caregiving. However, continued nursing support was actually insufficient for the patients and their family caregivers.

First of all, there was absence of ostomy nursing service in community. In this province where this study conducted, the present community nursing service mostly focused on injection and infusion, vaccination and health education activities in the settings of community health service units. Visit service involved only postpartum visit and infusion/dressing at home. Visiting ostomy patients at home was still absent due to various reasons, such as lack of necessary knowledge and skill of ostomy care among community health care professionals, shortage of personnel and cost issues.

Moreover, the actual implementation of telephone follow-up by ward nurses in this surgical unit was poor, even though it was required that the telephone follow-up call should be at least once in the 1st month after discharge. In this study, all seven experienced patients said that they had not received any telephone call from the nurses of this surgical unit. According to the nurses' explanation, the possible reasons were: the nurses could not contact them successfully due to wrong telephone numbers; the nurses omitted to follow up owing to their busy work. However, these nurses agreed that continued nursing support by telephone follow-up was feasible for themselves and helpful for the patients' successful living with their colostomies. These nurses proposed to generate an operational telephone follow-up form to guide and facilitate the implementation of telephone follow-up. As two nursing team leaders stated:

> Generally, a telephone follow-up spends about 5 – 10 minutes. We ask the patients about their ostomies, defecation, diet and activities. Then, we make a brief record…There has not been the standard of telephone follow-up in our unit at present…Of course, it would improve our telephone follow-up if there was an operational telephone follow-up form to guide us.
>
> (Nursing team leaders LS)
>
> Compared with to our competency and available work time, I think, it has been pretty good that we provide telephone follow-up. We cannot go to the patients' home to guide them.
>
> (Nursing team leader XD)

Additionally, the utilization of ostomy specialist counseling service was weak. Some patients did not understand the role of the ET nurse as a specialist nurse of ostomy care, and instead they knew the ET nurse as only a ward nurse who taught them to use ostomy appliances. Thus, they seldom telephoned the ET nurse for counseling about their ostomy-related issues except for going to see her in hospital.

### *6.2.4 Inappropriate family caregiving*

Appropriate family caregiving could improve the individuals' recovery from surgery, and ability of managing colostomy-related impacts, and thereby facilitate successful living with their colostomies. However, excessive and insufficient family caregiving often caused negative outcomes.

On the one hand, excessive family caregiving was relatively common in a Chinese family. Chinese people believed that caring for a sick relative was the moral obligation of other family members, which originates from Confucian ethical system of role relationships (Wong & Pang, 2000). Thus, many family caregivers assumed too much caring tasks for their sick relatives. As a consequence, excessive family caregiving could postpone/ impede the patients' independence in living with their colostomies. For example, one young participant (PE3) regained her energy soon after surgery, but she still relied on her husband to change her ostomy appliance until the third postoperative month. As she explained, "I just started to cut the skin barrier by myself three months after surgery. Before that, my husband replaced me to cut it. I always asked for his assistance, so that he followed me to cut and attach it for me because of his mild temper." Moreover, two participants (PE4, PE6) never tried to change ostomy appliances by themselves, because their family caregivers always did this for them.

On the other hand, insufficient family caregiving was not conducive for the patients to be free from suffering. For instance, one elderly woman (PE7) was concealed by her family members about her diagnosis of cancer and the possibility of colostomy formation before surgery. After surgery, she regretted having this colostomy which was associated with dirtiness, odor and itching of peristomal skin. Also, she was unable to deal with ostomy appliances by herself owing to fatigue during chemotherapy, and usually her family caregivers did not provided timely assistance. Consequently, this elderly woman felt very suffering about her colostomy and being disgusted by her family, and even produced the thought of suicide.

### Spiral action research process to develop the family-based care model

The findings in the reconnaissance phase, in terms of the meanings of successful living with a permanent colostomy and the main problems in the patients' situations, were used to develop a family-based care model to enhance these patients' successful living with their colostomies. The patients' feelings on successful living with a colostomy and their ability to perform the procedures of using ostomy appliances were utilized as criteria to evaluate the development of this care model.

The process of developing this care model employed the collaboration and communication among the researcher, 14 patients requiring/with a permanent colostomy (Table 3), 14 primary family caregivers (Table 5), and nine nurses (Table 6). Different from the seven experienced patients (PE1 – PE7) who were recruited in the reconnaissance phase and had been with a colostomy for 2 – 11 months, the 14 patients were recruited before surgery and followed up until the third month after discharge, and thus they were called as the novice patients (PN1 – PN14). Their primary family caregivers (CN1 – CN14) were recruited by the method of one patient to one caregiver as a dyad. The nine nurses were organized as a core working group, including one head nurse, one ET nurse, four nursing team leaders, and three senior nurses. The collaboration and communication focused on sharing knowledge and information, improving mutual understanding and support, determining caring needs and expectations, identifying problems and influencing factors, enhancing personal ability, and developing a family-based care model.

This family-based care model to enhance Chinese patients' successful living with their colostomies was developed in two stages: (1) accepting the reality of colostomy formation and learning colostomy care; and (2) adapting to living with a colostomy and returning to a normal family life.

### ***Stage 1: Accepting the reality of colostomy formation and learning colostomy care***

In the first stage during hospitalization (Table 9), the patients were admitted for receiving colostomy-related surgery and hospitalized until discharge. During the perioperative period at hospitalization, the patients experienced a difficult decision between saving life and preserving anus before surgery; colostomy-related surgery; postoperative fatigue, wound pain, alteration of bodily appearance and defecation pattern. In spite of provision of preoperative ostomy site marking and education, and postoperative ostomy nursing care and education, most of them felt hard to accept the reality of colostomy formation. Also, these patients and their family caregivers (the dyads) lacked ability of correctly using ostomy appliances, and knowledge about prevention/management of ostomy-related complications and perineal wound care.

Based on the findings of the reconnaissance phase, the main problems in the patients' situations during hospitalization were: bodily and mental suffering before discharge; inadequate discharge preparedness of the patients and their family caregivers; and issues on communication between the patients and their family caregivers.

Moreover, in this stage, the patients expressed their expectations about successful living with a permanent colostomy chiefly involving: performing the procedures of using ostomy appliances independently; distancing from mental distress; and getting support from family.

### *1. Planning phase*

According to the main problems in the patients' situations and their expectations, mutual care plan was developed for the overall goal of helping the patients to accept the reality of colostomy formation, and facilitating the dyads to learn colostomy care. Specific nursing aims included: empowering the patients to accept the reality of colostomy formation; developing the dyads' ability of performing the procedures of using ostomy appliances; and developing the dyads' awareness of preventing/managing ostomy-related complications and perineal wound. Several strategies were identified to guarantee the achievement of goals/aims involving:

(1) Building rapport of relationships with the dyads
(2) Facilitating mutual goal-setting and decision-making among the dyads and the nurses
(3) Empowering the dyads to perform colostomy care by providing information and inspirational support
(4) Encouraging the patients to accept the reality of colostomy formation and develop awareness and ability in colostomy self-care
(5) Encouraging the family caregivers to provide the patients proper assistance and support
(6) Providing preoperative ostomy site marking and education, and postoperative skill training and education
(7) Providing bedside and group education to the dyads
(8) Enhancing the nurses' professional confidence and competency in colostomy care by group learning and interaction with the dyads

### ***2. Acting and observing phases***

Mutual care plan were conducted among the patients, their family caregivers, the ET nurse, the nursing team leaders, the head nurse and the researcher. The actions of each group of participants were described and summarized as follows.

#### *2.1 The patients with a permanent colostomy*

In the first stage, the activities of patients requiring/with a colostomy involved four aspects in two time periods (pre-operation and post-operation).

#### *2.1.1 Participating in mutual goal-setting and decision-making with the family caregivers and/or the nurses*

The patients were inspired to acknowledge their situations before and after surgery, talk about their needs and concerns, set personal goals, make decision about their own plans, and take action through communication and interaction among the patients, their family caregivers, the nurses and the researcher. Especially, the ideas about the importance of the patients' independence in using ostomy appliances, and the collaborative efforts to achieve successful living with a colostomy were frequently mentioned to the dyads by the nurses and the researcher. Also, the patients were encouraged to communicate with their family caregivers about their feelings and thinking, and thereby improve mutual emotional support.

#### *2.1.2 Being aware of the phenomenon of living a permanent colostomy*

Preoperatively, the patients obtained information from the ET nurse and the researcher to be aware of the phenomenon of living a permanent colostomy. Also, they received ostomy site marking by the ET nurse and learned from the model of ostomy and the sample of ostomy appliance. All of these preparations were for facilitating the patients' acceptance about the reality of colostomy formation.

#### *2.1.3 Being active to participate in developing abilities in using ostomy appliances*

Postoperatively, the patients were encouraged to actively participate in developing their abilities in using ostomy appliances. Concrete activities involved: being encouraged to look at and touching their colostomies at the first time; learning to detect flatus and defecation in the pouch, release gas in the pouch, empty and clean the pouch, cut the suitable opening of skin barrier, and remove the used ostomy appliance and attach the new one.

*2.1.4 Being aware of preventing/managing ostomy-related complications and perineal wound*

Before discharge, the patients received information about how to identify whether colostomy and peristomal skin were normal, prevent and manage ostomy-related complications (e.g. peristomal skin irritation and ostomy bleeding), and prepare kalium permanganicum solution to perform hip bath around their perineal wounds. Particularly, relationship between the correct usage of ostomy appliances and the incidence of ostomy-related complications was also informed to raise the patients' awareness.

*2.2 The family caregivers*

The family caregivers were inspired to understand the phenomenon of living a permanent colostomy, participate in setting mutual goals for the patients' successful living with their colostomies, and learn how to deal with ostomy appliances, potential/actual ostomy-related complications and perineal wound. Their activities of caring for the patients were as follows.

*2.2.1 Providing emotional support to the patients*

The term of permanent colostomy was new and unfamiliar for majority of both the patients and their family caregivers, when they heard the possibility of fecal diversion from the surgeons before surgery. The responses of family caregivers influenced the patients' preoperative decision on receiving colostomy-related surgery and postoperative acceptance on the reality of colostomy formation. The family caregivers supported the patients through encouraging their survival will after being diagnosed with cancer and confidence in getting used to living with a colostomy. For example, one family caregiver encouraged his wife before surgery:

> I told my wife, 'Don't be anxious. Everything can gradually be understood.' If you do not let her know [about her diagnosis and colostomy-related surgery plan], she would be more anxious. You may let the elderly not to know, but the young would have more ideas and worries if you conceal from them. At the preoperative conversation, the surgeon asked me whether my wife should avoid listening to this. I answered that let her know…I asked the surgeons whether they have any way to avoid the fecal diversion from my wife. But, several surgeons all said no way, and the fecal diversion must be done. Thus, I

> said to my wife, ‘Don’t worry. You would be fine after you get used to it (colostomy). If you worry that you cannot do farm labor after surgery, that is OK for me, and you just do some housework at home. If you can be alive for more years after removing your tumor, you can do some housework and that will be fine.’
>
> (Family caregiver CN1)

### *2.2.2 Assisting the patients in using ostomy appliances and managing perineal wound*

Postoperatively, the family caregivers and the patients as dyads received face-to-face ostomy care education provided by the ET nurse 3 – 4 times. The family caregivers replaced the patients to release gas and empty the pouch until the patients could perform by themselves (usually, at discharge or in the 1st month post-operation). Also, they provided assistance in changing ostomy appliances until the patients could carry out independently (mostly, in three months post-operation). For instance, a family caregiver stated:

> (Before discharge) I asked the ET nurse to supervise that I changed the ostomy appliance for my wife. I considered that I am her husband, so that I should do for her when she cannot deal with ostomy appliances by herself.
>
> (Family caregiver CN1)

For the patients who had perineal open wound, their family caregivers assisted in cleaning up wound, preparing water of the hip bath, and helping the patients to move to the specific chair of hip bath. As a family caregiver mentioned:

> He has started having the hip bath since the dressings in his perineal wound were taken out by the surgeon yesterday. I prepare water and adjust the concentration of potassium permanganate. Then, I assist him in moving to the chair of hip bath.
>
> (Family caregiver CN12)

### *2.3 The ET nurse*

The ET nurse, as a specialist on ostomy care, stood on a key position to empower the dyads of patients and their family caregivers to acknowledge the phenomenon of living a permanent colostomy, perform the procedures of using ostomy appliances, prevent/manage ostomy-related complications, and manage perineal wound. Also, the ET nurse collaborated with surgeons and ward nurses in order to provide more comprehensive ostomy care and management.

*2.3.1 Facilitating the dyads' awareness about the phenomenon of living a permanent colostomy*

During implementing preoperative ostomy site marking, the ET nurse provided information to facilitate the dyads' awareness about the phenomenon of living a permanent colostomy, involving: how important for patients to accept the fecal diversion so as to remove their tumor; what a colostomy looks like; how to manage colostomy by using ostomy appliances; in what ways the colostomy could impact patients' lives. Also, the ET nurse displayed the model of ostomy and the sample of ostomy appliance to the dyads. Besides, the ET nurse introduced herself as a specialist on ostomy care who would provide more guidance and assistance for them after having a colostomy became true. Sometimes, if the ET nurse found that a patient felt difficult to accept the fecal diversion, she would try to advocate a hospitalized patient who is active to face his/her colostomy to perform preoperative ostomate visiting.

*2.3.2 Encouraging the dyads to actively participate in learning the usage of ostomy appliances*

At the 1st day post-operation, the ET nurse went to see the patients, check their colostomies, and teach the dyads about: (1) how to observe the status of colostomy; (2) how to observe flatus and defecation in the pouch; (3) how to release gas in the pouch and empty feces. At the 4rd – 6th day post-operation, the ET nurse changed the ostomy appliance for the patients (demonstrated the whole procedure from removing an old ostomy appliance to attaching a new one). During this process, the ET nurse encouraged the participation of the dyads in some steps, such as, removing the old ostomy appliance, and checking whether the opening of skin barrier is cut to fit the size of colostomy.

*2.3.3 Empowering the dyads to perform the procedures of using ostomy appliances independently*

Independent performance of the procedures of using ostomy appliances symbolized empowerment accomplishment among the dyads. Before discharge, about the 7th – 10th day post-operation, the ET nurse encouraged the dyads to actually perform the procedure of changing ostomy appliances under her supervision. This face-to-face teaching can timely detect and correct mistakes in using ostomy appliances, and thus contribute to prevent peristomal skin problems resulting from improper usage.

#### *2.3.4 Providing the dyads information about prevention/management of ostomy-related complications and perineal wound care*

During teaching how to use ostomy appliances, the ET nurse provided the dyads necessary information about prevention/management of ostomy-related complications, mostly involving: avoiding food that easily causes diarrhea; not using disinfectant to clean peristomal skin; timely changing the leaking ostomy appliance; choosing quality ostomy appliances; not lifting heavy things etc. Besides, if the patients required perineal wound care, she would teach them.

#### *2.3.5 Collaborating with surgeons and ward nurses*

Data from the reconnaissance phase reflected that many patients had not received preoperative ostomy site marking and education performed by the ET nurse. In order to solve this issue, collaboration with the surgeons was necessary. Thus, the head nurse negotiated with the director to set preoperative ostomy site marking as one part of ostomy nursing care routine, and require every surgeon to order preoperative ostomy site marking. Also, the ET nurse was active to collaborate with the surgeons. After the ward rounds every morning, the ET nurse went to detect the patients who might receive an ostomy-related surgery in the next day, and contacted the surgeons to understand the patients' medical conditions for preparing ostomy site marking.

The nursing team leaders reflected that most ward nurses lacked adequate knowledge and confidence in helping the patients to deal with ostomy-related issues. Therefore, in order to improve the ward nurses' competency in ostomy care, the ET nurse was responsible for organizing monthly nurse group learning. The discussion topics were identified according to the ward nurses' needs and suggestions, such as selection and application of ostomy care products (Figure 4).

*Figure 4.* The Group Learning on Selection and Application of Ostomy Care Products Among Ward Nurses on July 23, 2013 (The ET Nurse as Moderator)

### *2.4 The nursing team leaders*

Apart from organizing ward nurses in each team to perform routine perioperative nursing care, the nursing team leaders were to collaborate with the ET nurse in ostomy nursing care. The concrete activities were as follows.

#### *2.4.1 Encouraging the dyads to learn the usage of ostomy appliances*

Although most education on ostomy care and management was performed by the ET nurse, the nursing team leaders were active to encourage the dyads to learn the usage of ostomy appliances during daily nursing activities. They explained the importance of correctly using ostomy appliances to the dyads, which was with respect to reduce ostomy-related complications and adapt to living with a colostomy.

#### *2.4.2 Helping the patients to change ostomy appliances if necessary*

When the ET nurse was absent (e.g. night shift), the nursing team leaders and other ward nurses in the same team temporarily helped the patients to change their leaking ostomy appliances if the patients needed. Meanwhile, these nursing team leaders encouraged and taught the patients to change ostomy appliances by themselves.

#### *2.4.3 Organizing monthly ostomy group education activities for the dyads*

The nursing team leaders organized monthly ostomy group education activities for the dyads (Figure 5). There was an obvious progress after initiating this study, that is, more senior nurses were guided by the ET nurse and participated in ostomy group education activities as educators. In the past, these activities were performed by only the ET nurse and had been paused for half a year due to the relocation of this surgical unit and the shift of head nurse.

*Figure 5*. An Ostomy Group Education Activity for Patients and Family Members on July 28, 2013 (A Nursing Team Leader as Educator)

### *2.5 The head nurse*

As an administrator of nursing affairs in this unit, the head nurse played many vital roles in improving ostomy nursing care, such as coordinator, opportunity-creator, negotiator and facilitator.

#### *2.5.1 Coordinating nurses and surgeons*

As a coordinator, the head nurse actively coordinated surgeons, the ET nurse, nursing team leaders and ward nurses for the purpose of building up a team of ostomy care and management. The specific strategies included: improving performance of preoperative ostomy site marking by collaboration between surgeons and the ET nurse, enhancing implementation of bedside patient education and ostomy group education activities by collaboration between nursing team leaders and the ET nurse.

#### *2.5.2 Providing nurses more opportunities to learn ostomy care*

As an opportunity-creator, the head nurse not only encouraged ward nurses to learn more about ostomy care, but also provided opportunities to them, such as arranging in-house skill training (assigning ward nurses to practice in ostomy clinic under the guidance of the ET nurse), and sending ward nurses to study in other hospitals with excellent ostomy care.

### *2.5.3 Negotiating with the director of facilities management department*

According to the ET nurse' complaint that there were few ostomy care products in the hospital supply and payment system, the head nurse negotiated with the director of facilities management department to require more ostomy care products into the list of hospital payment system through open tender, in order to facilitate the patients' choices on ostomy appliances and accessories.

### *2.5.4 Preparing a specific ostomy care education room*

As a facilitator, the head nurse actively engaged in preparing a specific ostomy care education room to facilitate ostomy care education activities. Initially, the researcher reminded the head nurse that previous periodic ostomy group education activities had been ceased for several months since the surgical unit was moved to the new in-patient building. Thus, the head nurse decorated a meeting room as a specific ostomy care education room equipped with television, video player, reading materials and wall pictures about ostomy care, and samples of ostomy care products (Figure 6). Monthly ostomy group education activities have restarted to provide to patients and family caregivers during this study was conducted.

*Figure 6.* The Ostomy Care Education Room

Additionally, according to the head nurse's suggestions, the researcher searched useful online resources, and then downloaded and edited the following learning materials: (1) two videos of demonstrating the procedure of changing one-piece and two-piece ostomy appliances which were played to the patients and their family caregivers in monthly ostomy group education activities (Figure 7); (2)

four booklets which were provided to the patients and their family caregivers to read in the ostomy care education room including: (a) Becoming a Happy Ostomate; (b) New Life: Telling the Ostomates' Own Stories; (c) Who is an Enterostomal Therapist Nurse; (d) Ostomate Visitor: the Friend of Ostomate (Figure 8).

*Figure 7.* The Procedure of Changing Ostomy Appliances (Video)

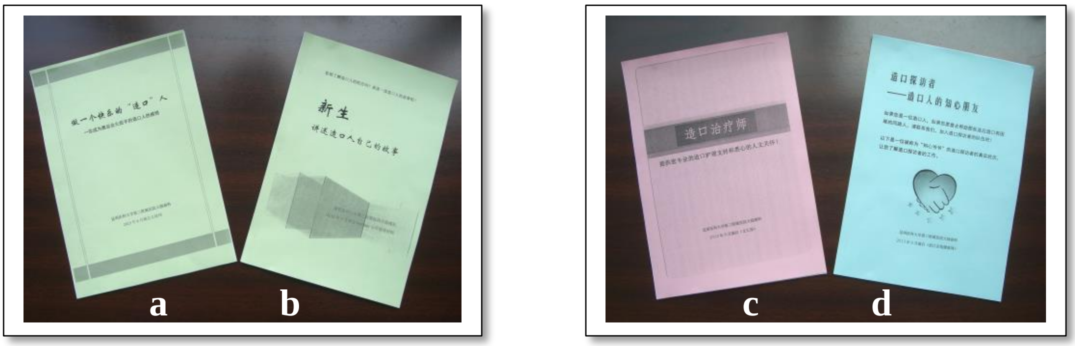


*Figure 8.* The Four Booklets for Ostomy Patients

*2.6 The researcher*

The activities of the researcher were to improve communication and collaboration among the patients, the family caregivers, and the nurses; to enhance the patients' confidence in independently performing the procedures of using ostomy appliances.

*2.6.1 Facilitating communication between the patients and their family caregivers*

The researcher facilitated communication between the patients and their family caregivers by gathering them together to understand the patients' situations, participate in decision-making, and set mutual goals, such as learning and mastering the usage of ostomy appliances, prevention and management of ostomy-related complications, and lifestyle adjustment etc. (Figure 9).

The first contact before surgery was significant to build up relationship rapport. The researcher was introduced by the ET nurse to the patients and their family caregivers. Through briefly introducing this study's objectives, contents and benefits to participants, the researcher prepared them to accept the formal invitation of taking part in this study after surgery. After the ET nurse completed preoperative ostomy site marking and education, the researcher dialogued with the patients and their family caregivers about their ideas, feelings and questions regarding the coming surgery and the possible colostomy. Meanwhile, the researcher answered their questions on colostomy care and encouraged them to positively face the situation of disease and treatment.

Postoperatively, the researcher gathered the patients and their family caregivers to set mutual goals involving both independent self-care and proper family caregiving for achieving successful living with a colostomy. Simultaneously, the researcher encouraged them to express respective feelings/concerns/questions with each other, and make decision together.

*Figure 9.* Facilitating Communication Between Patient and Family Caregiver

### *2.6.2 Promoting the patients' confidence in performing the procedures of using ostomy appliances independently*

The researcher facilitated the patients to promote their confidence in performing the procedures of using ostomy appliances independently through telling other patients’ stories of successful living with a colostomy, explaining the benefits of mastering the usage of ostomy appliances, and giving positive appraisals about their progress.

Additionally, in order to help the patients to get a direct experience that it is easy and convenient to use ostomy appliances, before surgery, the researcher advocated that they had a try to attach an ostomy appliance on abdomen skin where might be with a colostomy. However, both the patients and the ET nurse thought that it was unnecessary and wasteful, because the patients trusted that health care professionals would teach how to use ostomy appliances after surgery.

*2.6.3 Providing the dyads information about ostomy care by verbal and written methods*

The planned education of ostomy care was completed by the ET nurse. Hence, the researcher provided information mainly through answering questions of the dyads, distributing the written learning materials and guiding to read them. The written learning materials were edited by the researcher and reviewed by the ET nurse and the head nurse during the reconnaissance phase of this study, which were divided into two volumes and presented to the dyads at different time periods in order to avoid that they were overwhelmed by large knowledge and information.

At the first preoperative visit to the dyads, the researcher distributed the Self-care Manual for Colostomy Patients (Volume 1) which included six parts: background of ostomy care, acknowledging colostomy, how to care for colostomy, colostomy and life, considerations at the immediate post-operation, and the ET nurse’s roles and contact method.

Before discharge, the Self-care Manual for Colostomy Patients (Volume 2) was distributed to the dyads. This volume consisted of four parts: common ostomy-related complications, storing ostomy appliances, colostomy irrigation, and available resources from the suppliers of ostomy care products.

Additionally, the colostomy self-care kit was presented to the dyads, in which a tissue scissors (curved head) was appreciated by them (Figure 10).

*Figure 10.* The Colostomy Self-care Kit and the Self-Care Manual for Colostomy Patients (Volume 1 & 2)

#### *2.6.4 Encouraging the patients to seek peer support*

Communicating with fellow patients is a good way to obtain peer support. Both the researcher and the nurses encouraged the patients to share their experience and feelings with other colostomy patients when they were hospitalized or attended ostomy group education activities. For example, one 47-year-old female participant (PN4) told the researcher that she had made friendship with a fellow patient who conveyed her optimistic mood and shared tips about dressing and using ostomy appliances (Figure 11).

*Figure 11.* Peer Support Between a Novice Patient and an Experienced Patient

### ***3. Reflecting phase***

Reflection was carried out among the patients, the family caregivers and the researcher to assess the appropriateness of interventions, the patients' feeling of successful living with a colostomy, and relevant influencing factors.

### *3.1 Impacts of this family-based care model on the patients during the first stage*

This family-based care model in the first stage facilitated the patients to accept the reality of colostomy formation, and provided opportunities of learning ostomy care to the patients and their family caregivers.

#### *3.1.1 Accepting the reality of colostomy formation*

Most patients received preoperative ostomy site marking and education by the ET nurse, which prepared these patients well to face the coming colostomy formation. Moreover, before surgery, most patients perceived having a colostomy as becoming a disabled person, getting a trouble, and being a strange thing. However, after surgery, informational/emotional support from the nurses, the researcher, the family caregivers and fellow patients helped them to readily accept the reality of having a colostomy. As a female patient commented:

> Look at these surgeons and nurses who always support and care for me. Correspondingly, I should be strong to face the reality of having a colostomy. How well the society treats me! Correspondingly, I should hold on persistently. In other words, let things take their own courses (sui qi zi ran)…Although I have to receive the fecal diversion, I feel well as if I can survive cancer…This colostomy was staying with me. Once I form a habit of living with a colostomy, it becomes natural to me (xi guan cheng zi ran).
>
> (Novice patient PN4)

#### *3.1.2 Developed ability to perform the procedures of using ostomy appliances*

The researcher guided the patients and family caregivers to assess their abilities using the Evaluation Form on Skill of Using Ostomy Appliances (Appendix A6), which possible range was 16 – 48 points. Both 14 novice patients and their family caregivers obtained the significant improvement of ability to perform the procedures of using ostomy appliances, comparing before with after participating in the first stage of this family-based care model (Table 7). Also, the abilities of the family caregivers were commonly better than those of the patients (Table 8). After participating in the first stage of this model, about half of patients could empty the pouch independently while all of caregivers could do this; no patient could change the ostomy appliance independently while nearly half of caregivers could do this.

Table 7

*Comparison on the Patients' Skill of Using Ostomy Appliances Between Before and After Participating in the First Stage*

| | *n* | Median | Interquartile Range | Z | *p* |
|---|---|---|---|---|---|
| Before participating in the first stage (pre-operation) | 14 | 20.00 | 1.50 | -3.072 | .002* |
| After participating in the first stage (at discharge) | 14 | 27.00 | 6.00 | | |

Note. * Wilcoxon matched pair and signed ranks test

Table 8

*Comparison on the Family Caregivers' Skill of Using Ostomy Appliances Between Before and After Participating in the First Stage*

| | *n* | Median | Interquartile Range | Z | *p* |
|---|---|---|---|---|---|
| Before participating in the first stage (pre-operation) | 14 | 20.00 | 1.50 | -3.299 | .001* |
| After participating in the first stage (at discharge) | 14 | 32.00 | 13.00 | | |

Note. * Wilcoxon matched pair and signed ranks test

#### *3.1.3 Developed awareness of preventing/managing ostomy-related complications and perineal wound*

Information provided by the nurses and the researcher helped the patients and their family caregivers to be aware of the importance of both proper usage of ostomy appliances and correct preparation of hip bath solution. They expressed confidence to manage colostomy and perineal wound well. For instance, they understood that the reason not to use disinfectant on peristomal skin is to avoid irritating skin; they knew that too hot water will resolve kalium permanganicum and make its solution lose efficacy.

#### *3.1.4 Fulfilling partial expectations of successful living with a permanent colostomy*

The meanings of successful living with a permanent colostomy perceived/expected by the patients were partially fulfilled after they participated in the first stage of this family-based care model (Table 13). Different from the seven experienced patients in the reconnaissance phase, surviving cancer was concerned by these novice patients; 5 in 14 patients had not expressed the expectation of being able to contribute to family, who were financially supported by their adult children or had a pension.

### *3.2 Factors influencing the patients' successful living with a colostomy*

During the first stage of this family-based care model, several main factors influenced the patients to achieve successful living with their colostomies, including: (1) belief in self-care as the own responsibility; (2) physical and emotional status; (3) available family support; (4) information and encouragement provided by the nurses; (5) impacts of fellow patients; and (6) family financial status.

#### *3.2.1 Belief in self-care as the own responsibility*

Almost all patients in this study believed that taking care of their own colostomies was a reasonable and unescapable responsibility, although it is much emphasized that caring for the sick relatives is a moral obligation of other family members in a Chinese traditional culture concerning Confucianism. These patients made efforts to manage colostomy itself and colostomy-related impacts both before and after discharge. The belief in self-care as the own responsibility was beneficial for the patients' participation and performance in ostomy care and management, and also was linked to their confidence and ability about self-care. For example, one 50-year-old male expressed his opinion:

> Feces are dirty. I should empty them by myself and should not rely on others…I have confidence in taking good care of my colostomy. No confidence is bad…I am already able to deal with my ostomy appliance by myself completely…Now I care for my own colostomy every day. I have got used to it.
>
> (Novice patient PN2)

#### *3.2.2 Physical and emotional status*

The patients' physical and emotional status influenced their feeling of living with a colostomy. On the one hand, physical fatigue due to surgery, abdominal wound pain, perineal wound pain often hindered them to achieve the feeling of living well with a colostomy. On the other hand, negative emotions were not conducive for the patients to adapt to living with a colostomy, e.g. the sense of burden while thinking (si xiang bao fu), and the sense of being equal to a disabled person. Nevertheless, they always made efforts to keep a peaceful emotional status by means of abiding by the destiny, being happy-go-luck, letting things take their own courses (sui qi zi ran), not thinking too much, and saving life as a most important thing. As one 58-year-old male patient expressed:

> I cannot become happy now, but I can say that my mood is peaceful…I do not want to encounter this kind of thing (having a colostomy). However, I have encountered it. Anyway, I have to face these difficulties, I must overcome them.
>
> (Novice patient PN8)

#### *3.2.3 Available family support*

During hospitalization, many family members, especially the primary family caregivers, provided the patients both practical and emotional support, which was helpful for them to recover from surgery and accept the reality of colostomy formation. Commonly, the family caregivers not only assisted the patients in diet, activities, comfort improvement, and ostomy care, but also inspired the patients to struggle with the adversity, maintain the hope on surviving cancer, and think in a positive way.

#### *3.2.4 Information and encouragement provided by the nurses*

The patients and their family caregivers appreciated that information and encouragement provided by the nurses. Information from preoperative ostomy site marking and education, ostomy group education, postoperative bedside education performed by the nurses was useful for them to learn and master ostomy care and management. Although emotional support from the nurses was not much, the patients and their family caregivers were grateful for the nurses’ encouragement in ostomy care, and also expressed their understanding about the nurses’ difficulty (e.g. the nurses were busy in physical care and had no much time to communicate with them). As one family caregiver explained:

> This hospital is large with a great number of patients. It is easy to understand the nurses’ difficulty…For my wife, I may console her and needn’t spend the time of nurses…Of course, it would be better that someone can enlighten and teach you when you are not aware of something.
>
> (Family caregiver PN1)

### *3.2.5 Impacts of fellow patients*

Although peer support from fellow patients was a helpful resource for the patients' successful living with their colostomies, several patients reflected that some opinions and experiences of fellow patients had negative impact on their awareness on the phenomenon of having a colostomy. One patient narrated his experience:

> When I just heard I had to receive a permanent colostomy, I felt that I would become disabled owing to my awareness about having a colostomy learned from other ostomy patients' experiences…An ostomy patient has told me something ridiculous that he can see rice out from his ostomy after having meal. Also, I have seen another ostomy patient that he was very dirty with horrible odor. He used the outdated type of ostomy appliance [which is non-adhesive and easily leaking].
>
> (Novice patient PN2)

### *3.2.6 Family financial status*

Family financial status impacts the patients' choice about the types of ostomy appliances. In this study, around half of the patients had low family income, mostly from rural areas. Despite the increased reimbursement rate of the new rural cooperative medical insurance had reduced their financial burden, they still concerned the monthly expense of ostomy appliances. The ET nurse often recommended a cost-effective one-piece ostomy appliance to them. The expense is about 50 Yuan when there spend four pieces each month. However, this type of ostomy appliance was not proper for some patients who were sensitive for the material of its skin barrier.

Table 9

*Stage 1: Accepting the Reality of Colostomy Formation and Learning Colostomy Care (Hospitalization)*

| | | |
|---|---|---|
| Reconnaissance | | |
| Problems | | Bodily and mental suffering before discharge<br>Inadequate discharge preparedness of Ds<br>Issues on communication between Ps and Cs |
| Planning | | |
| Overall goal | | Accepting the reality of colostomy formation<br>Learning colostomy care |
| Ps' expectations of successful living | | Performing the procedures of using ostomy appliances independently<br>Distancing from mental distress<br>Getting support from family |
| Specific nursing aims | | Empowering Ps to accept the reality of colostomy formation<br>Developing Ds' ability of performing the procedures of using ostomy appliances<br>Developing Ds' awareness of preventing/managing ostomy-related complications and perineal wound |
| Strategies | | Building rapport of relationships with Ds<br>Facilitating mutual goal-setting and decision-making among Ds and Ns<br>Empowering Ds to perform colostomy care by providing information and inspirational support<br>Encouraging Ps to accept the reality of colostomy formation and develop awareness and ability in colostomy self-care<br>Encouraging Cs to provide Ps proper assistance and support<br>Providing pre-op ostomy site marking and education, and post-op skill training and education<br>Providing bedside and group education to Ds<br>Enhancing Ns' professional confidence and competency in colostomy care by group learning and interaction with Ds |
| Acting and observing | | |
| Actions of Ps | | Participating in mutual goal-setting and decision-making with Cs and/or Ns<br>Being aware of the phenomenon of living a permanent colostomy<br>Being active to participate in developing abilities in using ostomy appliances<br>Being aware of preventing/managing ostomy-related complications and perineal wound |
| Actions of Cs | | Providing emotional support to Ps<br>Assisting Ps in using ostomy appliances and managing perineal wound |
| Actions of Ns | ET | Facilitating Ds' awareness about the phenomenon of living a permanent colostomy<br>Encouraging Ds to actively participate in learning the usage of ostomy appliances<br>Empowering Ds to perform the procedures of using ostomy appliances independently<br>Providing Ds information about prevention/management of ostomy-related complications and perineal wound care<br>Collaborating with surgeons and ward Ns |
| | TLs | Encouraging Ds to learn the usage of ostomy appliances<br>Helping Ps to change ostomy appliances if necessary<br>Organizing monthly ostomy group education activities for Ds |
| | HN | Coordinating Ns and surgeons<br>Providing Ns more opportunities to learn ostomy care<br>Negotiating with the director of facilities management department<br>Preparing a specific ostomy care education room |
| | R as a surgical nurse | Facilitating communication between Ps and Cs<br>Promoting Ps' confidence in performing the procedures of using ostomy appliances independently<br>Providing Ds information about ostomy care by verbal and written methods<br>Encouraging Ps to seek peer support |
| Reflecting | | |
| Impacts of this model | | Accepting the reality of colostomy formation<br>Developed ability to perform the procedures of using ostomy appliances<br>Developed awareness of preventing/managing ostomy-related complications and perineal wound<br>Fulfilling partial expectations of successful living with a permanent colostomy |
| Factors influencing successful living | | Belief in self-care as the own responsibility; physical and emotional status; available family support; information and encouragement provided by Ns; impacts of fellow Ps; family financial status |

Note. P: patient; C: family caregiver; D: dyad of P and C; N: nurse; ET: enterostomal therapist nurse; TL: nursing team leader; HN: head nurse; R: researcher.

### *Stage 2: Adapting to living with a colostomy and returning to a normal family life*

In the second stage (Table 14), the patients were discharged from hospital back to their home. In spite of having been prepared before discharge, these patients still faced a number of problems and difficulties in adapting to living with a colostomy, such as, non-proficiency in using ostomy appliances; insufficient ability in managing ostomy-related complications, perineal wound and side effects of chemotherapy; restrictions in daily life; and worry about ostomy-related accidents in social activities. Also, their family caregivers often encountered the challenge to take good care of these patients at the same time of assuming most housework and getting more income.

According to the findings of the reconnaissance phase, the main problems in the patients' situations after discharge at home were: bodily and mental suffering after discharge; fewer social activities; insufficiency of continued nursing support for the patients and their family caregivers (the dyads); and inappropriate family caregiving.

Also, in this stage, the patients expressed their expectations about successful living with a permanent colostomy largely involving: getting used to the new defecation pattern; being free from bodily discomfort; keeping a normal body image in public; being able to contribute to family; and surviving cancer.

#### *1. Planning phase*

Considering the main problems in the patients' situations and their expectations, mutual care plan was developed for the overall goal of empowering the patients to adapt to living with a colostomy and return to a normal family life. Specific nursing aims were identified: improving the dyads' ability to perform the procedures of using ostomy appliances; improving the dyads' awareness of preventing/managing ostomy-related complications, perineal wound and side effects of chemotherapy; developing the patient' ability of managing defecation and body image for improving their social participation; and encouraging the patient' active participation in family affairs. Some strategies were set up to ensure the fulfillment of goals/aims encompassing:

(1) Constantly facilitating mutual goal-setting and decision-making among the dyads and the nurses
(2) Encouraging the patients to improve awareness and ability in colostomy self-care
(3) Encouraging the family caregivers to provide the patients proper assistance/support and gradually withdraw from colostomy care
(4) Providing continued nursing support by telephone follow-up, counseling, ostomy clinic visit, and home visit
(5) Improving communication and sharing among the dyads by the activity of an ostomate club
(6) Applying supportive communication technique to provide informational and emotional support to the dyads
(7) Constantly enhancing the nurses' professional confidence and competency in colostomy care by group learning and interaction with the dyads

### *2. Acting and observing phases*

Mutual care plan were carried out among the patients, their family caregivers, the ET nurse, the nursing team leaders, the head nurse and the researcher. The actions of each group of participants were summarized and reported as follows.

#### *2.1 The patients with a permanent colostomy*

In three months after discharge, the patients' activities could be divided into two time periods, namely, the 1st month post-discharge and the 2nd-3rd month post-discharge.

The 1st month of post-discharge was the fairly difficult period for the patients to adapt to their usual lives with a newly-formed colostomy after departure from the professionally-supportive hospital environment. Many patients experienced difficulties and problems related to the new defecation pattern, peristomal skin problems, perineal wound pain, and side effects of chemotherapy. Support from family caregivers and nurses were required.

Later, at the 2nd-3rd month post-discharge, involvement of both the family caregivers and the nurses was gradually reduced, while the patients performed more self-care actions with increased abilities in using ostomy appliances, preventing/managing ostomy-related complications, caring for perineal wound, dealing with side effects of chemotherapy, managing body image and defecation, and sharing housework.

These patients gained access to continued nursing support through the telephone follow-up program, home visit, the specialist counselling service by telephone or ostomy clinic, and the activity of an ostomate club.

#### *2.1.1 Constantly participating in mutual goal-setting and decision-making with family caregivers and/or nurses*

The patients were constantly inspired to talk about their needs and concerns, identify problems they encountered after discharge, set individualized goals, consider provisional solutions, and make decision to take action. Furthermore, the ideas about the importance of the patients' independence in using ostomy appliances, and the collaborative efforts to achieve successful living with a colostomy were reinforced among the dyads. Also, the dyads' mutual emotional support was still encouraged.

#### *2.1.2 Improving/developing ability in using ostomy appliances, preventing/ managing ostomy-related complications, perineal wound care, and handling side effects of chemotherapy*

With assistance and support from family caregivers and nurses, the patients actively participated in improving their abilities in using ostomy appliances, preventing/managing ostomy-related complications, and perineal wound care. Moreover, some patients endeavored to develop their ability of handling side effects of chemotherapy.

#### *2.1.3 Developing abilities in managing defecation and body image*

The patients made efforts to being familiar with their new defecation pattern through developing their ability of managing defecation, such as understanding the appropriate time to empty and change ostomy appliances, the usual number of emptying the pouch daily, and the time interval of changing each ostomy appliance. When the patients were familiar with their defecation pattern, managing their body images became easier. There were some tips of body image management used by the patients, e.g. wearing wide clothes to avoid pressing colostomy and pouch visualization, checking ostomy appliances before going outside, and usually stroking the stomach to check the content volume in pouch.

#### *2.1.4 Sharing family affairs*

The patients shared family affairs with their family caregivers by taking some housework and joining some productive work, e.g. preparing food, cleaning and making up house, and assisting in the family’s business of restaurant. In the early period of post-discharge, most patients did not take housework because their family caregivers would like them to have enough rest for recovering from surgery. About one month after discharge, many patients were able to fully participate in housework.

### *2.2 The family caregivers*

The family caregivers continued to provide necessary assistance and emotional support to the patients comprising: inspiring the patients to perform the procedures of using ostomy appliances independently; assisting the patients in managing ostomy-related complications, perineal wound, and side effects of chemotherapy; sharing housework with the patients.

#### *2.2.1 Inspiring the patients to perform the procedures of using ostomy appliances independently*

With the patients’ recovering from surgery, the family members gradually reduced their involvement in using ostomy appliances and inspired the patients’ independent performance. As one family caregiver narrated:

> When she was just discharged from hospital, I had helped her to change ostomy appliances for a period of time. Now, she always changes ostomy appliances by herself. Also, she can go to hospital for chemotherapy alone, because I am busy in the farm labor of flue-cured tobacco and unable to accompany her.
>
> (Family caregiver CN5)

#### *2.2.2 Assisting the patients in managing ostomy-related complications, perineal wound, and side effects of chemotherapy*

Through detecting, mutual decision making and taking action, the family caregivers assisted the patients to manage ostomy-related complications, perineal wound, and side effects of chemotherapy, for example, using skin protection powder and light saline water to handle the itching of peristomal skin; utilizing syringe to irrigate the perineal wound that was healing and becoming narrower; encouraging food intake during the intermission of chemotherapy.

#### *2.2.3 Sharing housework with the patients*

When the patients became better over time, their family caregivers were glad to share housework with them. The principle of avoiding lifting heavy things was paid attention by both the patients and family caregivers. As a family caregiver stated:

> Now, my wife is already able to do some housework, e.g. washing clothes and making up the rooms. Importantly, she cannot lift heavy things.
>
> (Family caregiver CN1)

### *2.3 The ET nurse*

After discharge, the ET nurse provided ostomy counseling service to the dyads, and facilitated the patients to obtain ostomy appliances and accessories.

#### *2.3.1 Providing the dyads ostomy counseling service*

The ET nurse provided ostomy counseling service to the dyads by telephone or interview in ostomy clinic, even though she was too busy to perform regular telephone follow-up.

Thanks to introduction about the ET nurse’s roles and contact method, some dyads proactively called the ET nurse to get advice from her. The ET nurse reflected that active communication with the dyads at hospitalization may build up mutual respectful and trustful relationship which was beneficial for them to proactively seek support from the ET nurse.

After the head nurse made efforts to lobby the hospital administrators, a nurse-led ostomy clinic was formally open in the new outpatient building during this study was conducted. In this clinic, there were two rooms, i.e. dressing room and interview room, which was in charge of the ET nurse and brought a lot of convenience to the patients who had been discharged from hospital and needed further specialist service on ostomy care (Figure 12).

*Figure 12.* The Nurse-led Ostomy Clinic in the Outpatient Building

*2.3.2 Facilitating the patients to obtain the proper ostomy appliances and accessories*

The ET nurse suggested the patients to choose proper ostomy appliances and accessories according the patients' conditions of ostomy and peristomal skin, their preferences and financial situations. Many patients purchased ostomy appliances in this hospital when they came to take medical check-up, due to: trust in the ET nurse's expertise, unavailability of ostomy appliances in local regional hospitals, and failed experience of purchasing ostomy care products in other places.

*2.4 The nursing team leaders*

The nursing team leaders collaborated with the researcher to develop a telephone follow-up program for the dyads. Under the assistance of the head nurse, the researcher organized an activity of literature learning on nurse-led telephone follow-up with the nursing team leaders, the ET nurse and the head nurse (Figure 13). Six selected articles were critiqued about the contents, methods and effects of nurse-led telephone follow-up for ostomy patients. Knowledge from literature learning was applied into discussing the Record Form of Telephone Follow-Up for Colostomy Patients, which was designed by the researcher and had been reviewed by the ET nurse and the head nurse. Finally, along with a discharge assessment, the 3-time telephone follow-up program in three months post-discharge was included into the ostomy care routine of this unit. The three time points were respectively at the 1st week, 1st month, and 3rd month after discharge. Additionally, a discharge assessment was conducted to gain the baseline information and make appointments with the patients and their family caregivers. This record form was revised and ready to use, which consisted of seven parts: (1) demographic information; (2) self-care level and skill of using ostomy appliances; (3) defecation condition; (4) colostomy care knowledge; (5) ostomy-related nursing problems; (6) feeling of living with a colostomy; (7) satisfaction with nursing service. Besides, a manual of questions and answers about colostomy nursing care was edited by the researcher and the ET nurse and provided to the nurses who would take part in the telephone follow-up program (Figure 14).

*Figure 13.* The Activity of Literature Learning on Nurse-Led Telephone Follow-up

*Figure 14.* The Manual of Questions and Answers (a) and the Record Form of Telephone Follow-Up for Colostomy Patients (b)

### *2.5 The head nurse*

The head nurse facilitated provision of continued nursing support for the dyads through organizing the activity of an ostomate club and setting up the ostomy clinic, and meanwhile improved the development of ostomy nursing team through sending a young nurse to attend the ET education program.

#### *2.5.1 Organizing the activity of an ostomate club*

Collaborating with the ostomy care products suppliers, the head nurse initiated the first activity of ostomate club on June 18, 2013 (Figure 15). More than 20 discharged patients and their families were invited to participate in this activity. The theme of this activity was *Living with an Ostomy Like an Ordinary Person*. All speakers (including the director, the head nurse, and the ET nurse) encouraged the patients to actively participate in ostomy care and management, overcome physical and psychological distress, return a normal life and reintegrate society. Three patient representatives shared their experience and especially introduced some tips in ostomy care. For example, a patient utilized the second-hand skin barrier of two-piece ostomy appliance with a belt to fix the one-piece ostomy appliance, which can completely avoid the come-off of ostomy appliance and strengthen the adhesiveness of skin barrier.

*Figure 15*. The Activity of an Ostomate Club on June 18, 2013

### *2.5.2 Lobbying the hospital administrator to set up the ostomy clinic*

The head nurse lobbied the hospital administrator to set up the ostomy clinic in the new out-patient building. This clinic was appreciated by the outpatients with an ostomy. These patients felt more convenient to obtain assistance and guidance by the ET nurse.

### *2.5.3 Sending a young nurse to attend the ET education program*

With the increasing number of outpatients in ostomy clinic, the ET nurse would spend more time on outpatients, and correspondingly devote less time to inpatients. This suggested that there was a need to produce another ET nurse who was chiefly in charge of inpatients. Thus, the head nurse negotiated with the director of this unit to financially support a young nurse with potentials to attend the ET education program for becoming a certificated ET.

### *2.6 The researcher*

In this stage, the researcher's activities were to provide necessary information and active encouragement to support the dyads to return to a normal family life.

*2.6.1 Providing the dyads informational and emotional support using the technique of supportive communication*

Using the technique of supportive communication, the researcher provided informational and emotional support to the dyads by various methods. Commonly, the researcher telephoned the dyads at the 1st week, the 1st month and the 3rd month after discharge, in order to provide support at the same of collecting data. Among partial patients, the researcher also followed up them by home visit (Figure 16, 17), face-to-face interview in a park/ward. During the initial three months after discharge, the problems/difficulties frequently mentioned by the dyads were related to: (1) at the 1st week: usage of ostomy appliances, irregular defecation, abdominal/perineal wound pain, and reduced daily activity due to fatigue/pain; (2) at the 1st month: usage of ostomy appliances, peristomal skin problems, irregular defecation, reduced daily/social activities due to fatigue/worries, perineal wound pain, and negative feelings about living with a colostomy; (3) at the 3rd month: irregular defecation, colostomy-related worries in social activities, side effects of chemotherapy, peristomal skin problems, and financial stress (Table 10). Additionally, the researcher reminded the young patients and their spouses to set out their intimate activity at the end of follow-up, i.e. about three months after discharge. The information was initially provided to them before surgery in the Self-Care Manual for Colostomy Patients (Volume 1).

*Figure 16.* Visiting Patient and Family Caregiver at Their Home

*Figure 17.* Emptying and Cleaning the Pouch Performed by the Patient

Table 10

*Problems/Difficulties Frequently Mentioned by the Patients and Their Family Caregivers During Telephone Follow-Up*

| | 1st week after discharge | 1st month after discharge | 3rd month after discharge |
|---|---|---|---|
| Usage of ostomy appliances | √ | √ | |
| Irregular defecation | √ | √ | √ |
| Abdominal wound pain | √ | | |
| Perineal wound pain | √ | √ | |
| Peristomal skin problems | | √ | √ |
| Reduced daily activity due to fatigue/pain | √ | √ | |
| Reduced social activities due to colostomy-related worries | | √ | |
| Colostomy-related worries in social activities | | | √ |
| Negative feelings about living with a colostomy | | √ | |
| Side effects of chemotherapy | | | √ |
| Financial stress | | | √ |

According to Gibb’s (1961) theory on interpersonal defensiveness and the researcher’s practice, the elements and strategies of supportive communication with colostomy patients were summarized. The four elements were respect, description, empathy and empowerment. The nursing strategies included: (1) developing a collaborative relationship with patients and families; (2) understanding patients’ concerns and problems; (3) discussing potential solutions; (4) encouraging patients to take action; (5) bringing out emotional expression; (6) normalizing negative emotions; (7) protecting hope.

For example, a middle-aged female patient (PN1) consulted the researcher whether she may take a job of ticket seller in a microbus. She wanted to get income to support her children’ education but she worried about any impact of long-time sitting-down on her perineal wound. The researcher discussed with her about her current state: having a good coalescence of perineal wound, being able to deal with ostomy appliances independently, and having the experience of traveling alone after discharge. Thus, the researcher encouraged her to have a try but she needed to concern her conditions of wound and ostomy at the outset.

#### *2.6.2 Facilitating the patients to utilize resource from the ostomy care products suppliers*

Some patients reported that it was not convenient for them to go back to this hospital to purchase ostomy appliances because they lived very far. Hence, the researcher introduced the hotline number of customers' service center of ostomy care products suppliers, suggested to purchase by post, and asked for the reading materials and the samples of ostomy care products.

### *3. Reflecting phase*

Reflection was conducted with the patients and their family caregiver to appraise the impacts of interventions, the patients' feeling of successful living with a colostomy, as well as pertinent influencing factors.

#### *3.1 Impacts of this family-based care model on the patients during the second stage*

This family-based care model in the second stage was to facilitate the patients to adapt to living with their colostomies and return to a normal family life mainly through providing continued nursing support.

#### *3.1.1 Improved ability to perform the procedures of using ostomy appliances*

The patients and family caregivers were guided to assess their abilities using the Evaluation Form on Skill of Using Ostomy Appliances (Appendix A6) at the 3rd month post-discharge. The abilities of performing the procedures of using ostomy appliances among 14 novice patients were significantly increased between before and after participating in the second stage of this family-based care model (Table 11). Likewise, the abilities of the family caregivers had significant improvement (Table 12). At the end of 3rd month post-discharge, 10 in 14 patients could change the ostomy appliance independently, while all of caregivers could do this. One novice patient's (PN9) performance of changing the ostomy appliance independently was presented at Figure 18.

Table 11

*Comparison on the Patients' Skill of Using Ostomy Appliances Between Before and After Participating in the Second Stage*

| | *n* | Median | Interquartile Range | Z | *p* |
|---|---|---|---|---|---|
| Before participating in the second stage (at discharge) | 14 | 27.00 | 6.00 | -3.303 | .001* |
| After participating in the second stage (3rd month post-discharge) | 14 | 46.00 | 8.50 | | |

Note. * Wilcoxon matched pair and signed ranks test

Table 12

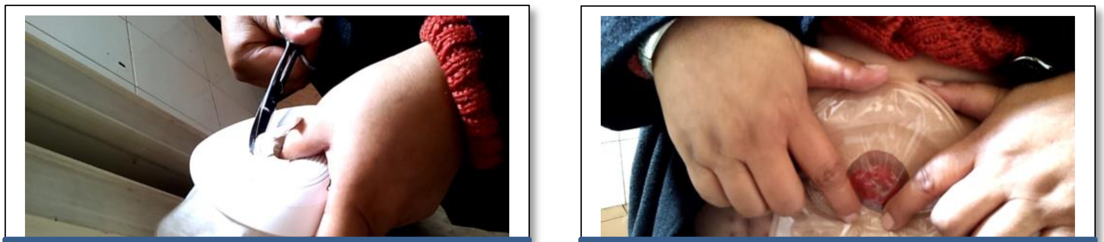
*Comparison on the Family Caregivers' Skill of Using Ostomy Appliances Between Before and After Participating in the Second Stage*

| | *n* | Median | Interquartile Range | Z | *p* |
|---|---|---|---|---|---|
| Before participating in the second stage (at discharge) | 14 | 32.00 | 13.00 | -3.194 | .001* |
| After participating in the second stage (3rd month post-discharge) | 14 | 46.00 | 2.00 | | |

Note. * Wilcoxon matched pair and signed ranks test

**1. Removing old ostomy appliance**

**2. Cleaning peristomal skin**



**3. Cutting skin barrier**

**4. Attaching new ostomy appliance**

*Figure 18.* Changing the Ostomy Appliance Independently Performed by the Patient

### *3.1.2 Improved ability of preventing/managing ostomy-related complications, perineal wound and side effects of chemotherapy*

After discharge, a lot of patients encountered problems/difficulties concerning ostomy-related complications, perineal wound and side effects of chemotherapy. Continued nursing support provided necessary information to enhance these patients' abilities of solving these problems.

Ten in 14 patients experienced the itching of peristomal skin in the 1st month post-discharge, and most alleviated later except four patients who were with sensitive skin, obesity, or loose feces due to chemotherapy. Nursing suggestions for these patients included: cutting a proper opening in the skin barrier of ostomy appliance, timely changing ostomy appliances, using skin protection powder, adjusting diet to avoid diarrhea, or choosing other types of ostomy appliances. Among other ostomy-related complications, two patients suffered bowel obstruction owing to eating corn and were readmitted; one patient underwent ostomy bleeding slightly and learn solution from the ET nurse.

Eight in 14 patients had an open perineal wound and needed the hip bath for several months. Especially, two patients encountered unbearable wound pain and must take painkillers. The researcher visited one of them at his home and guided his pain management, such as, adherence to painkiller prescription, persisting with the hip bath, increasing nutrition for the healing of wound, listening to preferred music, and going out for a walk every day. Another patient was guided by telephone follow-up. After one month post-discharge, their wound pain became bearable.

Nine in 14 patients received postoperative chemotherapy. Among the nine patients, three suffered loss of appetite, nausea and vomiting; three encountered disordered bowel movement and thereby felt difficult in defecation management; the others experienced mild diarrhea or constipation during chemotherapy. Informational and emotional supports were provided by the nurses and the researcher, e.g. increasing nutrition during intermission, using two-piece ostomy appliances, and dietary adjustment.

### *3.1.3 Developed ability of managing defecation and body image*

The patients' abilities of managing defecation and body image were developed and improved over time through constant practice and learning from the family caregivers, fellow patients, the nurses and the researcher.

After three months post-discharge, most patients were familiar with their routines of defecation and aware of the good time to empty and change the ostomy appliance. Commonly, they emptied the pouch 1 – 4 times per day, and changed the ostomy appliance every 3 – 7 days.

The ability of defecation management was beneficial for keeping a good body image in public. The patients who had more confidence in dealing with ostomy appliances were better in managing their body image in social activities without many worries about odor and leakage of ostomy appliances. As the patients said:

> Other people cannot find that I am a person with a colostomy and a pouch. I do not worry about my colostomy when I attend social activities. The ostomy appliance is of high quality without odor.
>
> (Novice patient PN2)

> Covering the pouch under your clothes, you would look like a normal person. This colostomy is my own, so that I must protect and manage it. I do not feel self-inferiority. If it becomes dirty, that should be due to your own reason. This ostomy appliance is fairly good and airtight without leakage.
>
> (Novice patient PN4)

### *3.1.4 Active participation in family affairs*

The patients were encouraged to actively participate in family affairs, such as taking some housework, and attending some productive work. Like this, they may contribute to their families. Thus, they obtained a kind of sense of self-worth and simultaneously distanced from self-inferiority. One patient proudly told me:

> At present, I have already worked in the restaurant of my family, in charge of cooking and cleaning tables. Additionally, I also do some housework (e.g. washing vegetable and sweeping the floor) except for heavy manual labor.
>
> (Novice patient PN14)

### *3.1.5 Fulfilling most expectations of successful living with a permanent colostomy*

After participating in the second stage of this family-based care model, the patients had mostly fulfilled their expectations in relation to seven/eight components of successful living with a permanent colostomy. To summarize, the results from two stages were presented together in Table 13.

### *3.2 Factors influencing the patients' successful living with a colostomy*

In the second stage of this family-based care model, the main factors influencing the patients to achieve successful living with their colostomies involved: (1) independence in using ostomy appliances; (2) physical and emotional status; (3) available family support; (4) continued nursing support; (5) roles of the patients in their family.

### *3.2.1 Independence in using ostomy appliances*

Independence in using ostomy appliances is a basic factor contributing to successful living with a colostomy. Both body image and defecation management required independence in using ostomy appliances, which could strengthen the patients' confidence in attending social activities and avoid self-inferiority. As one patient explained:

> It is important that I can cut and attach the ostomy appliance independently. If I have checked my ostomy appliance and made sure that it is normal before going outside, I will not worry about its leakage. I am confident in managing my colostomy. Thus, I have not the sense of self-inferiority.
>
> (Novice patient PN6)

### *3.2.2 Physical and emotional status*

The patients' physical and emotional status had unavoidable impacts on their feeling of living with a colostomy. After three months post-discharge, although having been independent in using ostomy appliances, three (PN 5, 6, 7) in 14 patients still felt that they had not got used to the new defecation pattern. The explained reasons were: irregular defecation with fluctuating frequency among two patients; constant worry about come-off of ostomy appliances and feeling about inconvenience to release gas in the pouch in social activities.

Table 13

*Successful Living With a Permanent Colostomy Among the Novice Patients After Participating in the Family-Based Care Model (n = 14)*

| Patient code | Stage | Successful living with a permanent colostomy | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | a | b | c | d | e | f | g | h |
| PN1 | S1 | √* | | √ | | | | | |
| | S2 | √ | √ | √ | √ | √ | √ | √ | √ |
| PN2 | S1 | √* | √ | √ | | | | ** | |
| | S2 | √ | √ | √ | √ | √ | √ | ** | √ |
| PN3 | S1 | √* | | √ | | | | | |
| | S2 | √* | √ | √ | √ | √ | √ | √ | √ |
| PN4 | S1 | √* | √ | √ | | | | | |
| | S2 | √ | √ | √ | √ | √ | √ | √ | √ |
| PN5 | S1 | √* | | √ | | | | | |
| | S2 | √ | | √ | | | | √ | √ |
| PN6 | S1 | √* | | √ | | | | | √ |
| | S2 | √ | √ | √ | | √ | √ | | |
| PN7 | S1 | √* | | √ | | | | ** | |
| | S2 | √ | √ | √ | | | | ** | √ |
| PN8 | S1 | √* | √ | √ | | | | ** | |
| | S2 | √ | √ | √ | √ | √ | √ | ** | √ |
| PN9 | S1 | √* | √ | √ | | | | | |
| | S2 | √ | √ | √ | √ | | √ | √ | |
| PN10 | S1 | √* | √ | √ | | | | | |
| | S2 | √ | √ | √ | √ | √ | √ | √ | √ |
| PN11 | S1 | √* | | √ | | | | ** | |
| | S2 | √* | √ | √ | √ | | √ | ** | √ |
| PN12 | S1 | √* | √ | √ | | | | ** | |
| | S2 | √* | √ | √ | √ | √ | √ | ** | √ |
| PN13 | S1 | √* | √ | √ | | | | | |
| | S2 | √ | √ | √ | √ | | √ | √ | √ |
| PN14 | S1 | √* | √ | √ | | | | | |
| | S2 | √* | √ | √ | √ | √ | √ | √ | √ |

Note. S1: After participating in the first stage of this model (at discharge)
S2: After participating in the second stage of this model (3rd month post-discharge)
* Performing the procedures of using ostomy appliances with partial independence
** Being able to contribute to family was not expected by the patient.
a: Performing the procedures of using ostomy appliances independently
b: Distancing from mental distress
c: Getting support from family
d: Getting used to the new defecation pattern
e: Being free from bodily discomfort
f: Keeping a normal body image in public
g: Being able to contribute to family
h: Surviving cancer

### *3.2.3 Available family support*

After three months post-discharge, there were still four patients who relied on their family caregivers to change ostomy appliances for them. Except one patient (PN3) was owing to fatigue during chemotherapy, other patients (PN11, 12, 14) were chiefly attributed to easily-obtained family caregiving from their spouses or adult children. As one 51-year-old male explained:

> My spouse or adult children helped me to change the ostomy appliance. If I do this by myself, it is not very convenient for me because I cannot see my colostomy sometimes. My children often stay home. There are five persons in my home.
>
> (Novice patient PN14)

### *3.2.4 Continued nursing support*

After discharge, the patients and their family caregivers perceived continued nursing support was useful. Whether living with a colostomy or caring for a person with a colostomy was a new experience for the patients or their family caregivers. They need professional information to handle ostomy-related issues. Besides, emotional consolation and encouragement were beneficial. For example, one patient and one family caregiver reflected:

> I write down the cellphone number of the ET nurse, so I may ask for help when I need, e.g. purchasing ostomy appliances. You are very warm-hearted to usually tell us and teach us.
>
> (Novice patient PN4)

> I telephoned to ask the ET nurse when I had any question after my wife discharged home. There is something that we never saw or experienced before, so I have to telephone the ET nurse for seeking help. For instance, I called the ET nurse when my wife felt her peristomal skin itchy and burning…I felt satisfied with her reply…It is beneficial that someone enlightens me when I am unaware of something.
>
> (Family caregiver CN1)

### *3.2.5 Roles of the patients in their family*

The patients' roles in their family affected their expectations on being able to contribute to family. Relatively-young patients had strong expectations to get income for their family, at least share housework, which was commonly due to their roles as parents to assume educational expense of their young children. Differently, relatively-old patients who could obtain financial support from their adult children had not expressed expectations to get income for their family or share housework, but they intended to care for their own colostomies and not to burden their families. For instance, one middle-aged female and one elderly male expressed their different ideas:

> The financial condition of my family is weak. I don't know whether I can go to have a medical check-up three month after surgery. I want to be a ticket seller in a microbus because we need money to support our children' education.
>
> (Novice patient PN1)

> I am an elderly and come to my later years (wan nian). Frankly speaking, if I can maintain my own hygiene, I would be excellent as an elderly. I just live from one day to the next day and do not think too much about tomorrow (guo yi tian suan yi tian).
>
> (Novice patient PN12)

Table 14

*Stage 2: Adapting to Living With a Colostomy and Returning to a Normal Family Life (Discharge Home)*

| | | |
|---|---|---|
| Reconnaissance | | |
| Problems | | Bodily and mental suffering after discharge<br>Fewer social activities<br>Insufficiency of continued nursing support for Ps and Cs<br>Inappropriate family caregiving |
| Planning | | |
| Overall goal | | Adapting to living with a colostomy<br>Returning to a normal family life |
| Ps' expectations of successful living | | Getting used to the new defecation pattern<br>Being free from bodily discomfort<br>Keeping a normal body image in public<br>Being able to contribute to family<br>Surviving cancer |
| Specific nursing aims | | Improving Ds' ability to perform the procedures of using ostomy appliances<br>Improving Ds' awareness of preventing/managing ostomy-related complications, perineal wound and side effects of chemotherapy<br>Developing Ps' ability of managing defecation and body image for improving their social participation<br>Encouraging Ps' active participation in family affairs |
| Strategies | | Constantly facilitating mutual goal-setting and decision-making among Ds and Ns<br>Encouraging Ps to improve awareness and ability in colostomy self-care<br>Encouraging Cs to provide Ps proper assistance/support and gradually withdraw from colostomy care<br>Providing continued nursing support by telephone follow-up, counseling and ostomy clinic visit<br>Improving communication and sharing among Ds by the activity of an ostomate club<br>Applying supportive communication technique to provide informational and emotional support to Ds<br>Constantly enhancing Ns' professional confidence and competency in colostomy care by group learning and interaction with Ds |
| Acting and observing | | |
| Actions of Ps | | Constantly participating in mutual goal-setting and decision-making with Cs and/or Ns<br>Improving/developing ability in using ostomy appliances, preventing/managing ostomy-related complications, perineal wound care, and handling side effects of chemotherapy<br>Developing abilities in managing defecation and body image<br>Sharing family affairs |
| Actions of Cs | | Inspiring Ps to perform the procedures of using ostomy appliances independently<br>Assisting Ps in managing ostomy-related complications, perineal wound, and side effects of chemotherapy<br>Sharing housework with Ps |
| Actions of Ns | ET | Providing Ds ostomy counseling service<br>Facilitating Ps to obtain the proper ostomy appliances and accessories |
| | TLs | Developing and performing a telephone follow-up program for Ds in collaboration with R |
| | HN | Organizing the activity of an ostomate club<br>Lobbying the hospital administrator to set up the ostomy clinic<br>Sending a young N to attend the ET education program |
| | R as a surgical nurse | Providing Ds informational and emotional support using the technique of supportive communication<br>Facilitating Ps to utilize resource from the ostomy care products suppliers |
| Reflecting | | |
| Impacts of this model | | Improved ability to perform the procedures of using ostomy appliances<br>Improved ability of preventing/managing ostomy-related complications, perineal wound and side effects of chemotherapy<br>Developed ability of managing defecation and body image<br>Active participation in family affairs<br>Fulfilling most expectations of successful living with a permanent colostomy |
| Factors influencing successful living | | Independence in using ostomy appliances; physical and emotional status; available family support; continued nursing support; roles of the patients in their family |

Note. P: patient; C: family caregiver; D: dyad of P and C; N: nurse; ET: enterostomal therapist nurse; TL: nursing team leader; HN: head nurse; R: researcher.

### Final evaluation

The final evaluation was to appraise: (1) the process of developing the family-base care model; (2) the outcomes of implementing this model. The latter (outcome evaluation) had been accomplished during performing nursing interventions in each stage, while the former (process evaluation) was reported as follows.

When each patient and family caregiver had been followed up for three months after discharge, they were asked about their satisfaction on nursing service during the process of implementing this model. Finally, after completing all the nursing interventions for 14 novice patients, the researcher presented the actual family-base care model through a group meeting, in which the nine nurses of the core working group evaluated this model. Moreover, the main organizational changes during conducting this study were summarized here.

#### 1. *Patients' satisfaction with nursing service*

All the patients expressed satisfied with the provision of overall nursing service. Using the Evaluation Form of Satisfaction With Nursing Service (Appendix A7-1) with 12 items (total score range: 12 – 60 points), the patients were asked to evaluate the nursing service provided by the nurses in this surgical unit. The total satisfaction scores ranged from 36 to 48 with the mean score of 42.29±4.25. Item mean scores of less than 3.0 emerged in the aspects of teaching how to train regular defecation, guiding sexual life, and providing opportunities of emotional expression. After each patient completed this form, the researcher provided extra guidance according to the inadequate aspects that the patient thought. For instance, one patient commented:

> Compared to our local regional hospital with weak condition and service, this hospital generally treated the patients fairly well. Before surgery, the surgeon explained the fecal diversion to me using a picture of human body structure. After surgery, the ET nurse treated me with a warm attitude. When my wound became purulent, she helped me to clean up it. In a word, I was satisfied with postoperative nursing. Besides, I have read this manual of self-care and understand some considerations about diet, activity and ostomy-related complications. However, I have not got many words of consolation and

> encouragement from the nurses of this surgical unit because they were too busy.
>
> (Novice patient PN12)

### 2. *Family caregivers' satisfaction with nursing service*

All the family caregivers felt satisfied with the overall nursing service. Using the Evaluation Form of Satisfaction With Nursing Service (Appendix A7-1) with 12 items (total score range: 12 – 60 points), the family caregivers evaluated the nursing service provided by the nurses in this surgical unit. The total satisfaction scores were from 39 to 47 with the mean score of 43.29±2.64 among these family caregivers. Item mean scores of less than 3.0 emerged in the aspects of teaching how to train the patients' regular defecation, and guiding the patients' sexual life. After completing this form, the researcher provided additional guidance about these inadequate aspects. An example about the appraisal of family caregiver was as follows:

> I felt satisfied with the nursing service of this unit very much, due to their good service attitude and patience. Although we have not received much consolation and encouragement from nurses, we can understand that they are so busy. Also, I have no any suggestion or complaint.
>
> (Family caregiver CN12)

### 3. *Nurses' satisfaction with the family-based care model*

At the end of this study, the researcher presented the complete family-based care model to the nine nurses of the core working group, and then asked them to fill out the Evaluation Form of Satisfaction With the Family-based Care Model (Appendix A7-2) with 7 items (total score range: 7 – 35 points). The total satisfaction scores ranged from 29 to 35 with the mean score of 31.75±2.25. These nurses expressed satisfied with this model, and commented that it was easily-understandable, applicable and sustainable to be used. They felt confident and competent to improve quality of care and communicate with patients and their families. As the nurses reflected:

> I feel, sometimes, doing more for patients is not better than verbally communicating more with them. In the past, we often helped the patients to

> empty their pouches because they had not mastered how to do. At present, we just teach them. They look like happier about learning how to do by themselves. Like this, our workload is also reduced, and the patients seem to feel more satisfied with our service.
>
> (Nursing team leader LL)

> Recently, patient education has been strengthened through our nurses' efforts after participating in this action research. Many patients often say that they have mastered how to deal with their ostomy appliances and need not our nurses to do for them. They want to rely on themselves. This is a real change and improvement which is attributed to our every nurse's efforts and the theoretic guidance from Teacher Tao (the researcher).
>
> (Head nurse SX)

### 4. *Main organizational changes during conducting this study*

During conducting this study, some organizational changes have generated to support the sustainability of this family-based care model to enhance successful living with a colostomy encompassing:

(1) Including preoperative ostomy site marking and bedside education, and the 3-time telephone follow-up program into the routine of ostomy care in this surgical unit;
(2) Preparing a specific ostomy care education room in this surgical unit;
(3) Restarting the periodic ostomy group education activities organized by the nursing team leaders;
(4) Initiating the first activity of ostomate club in June 2013;
(5) Setting up a nurse-led ostomy clinic in September 2013 in the new out-patient building;
(6) Selecting a young nurse to attend the ET nurse education program for being equipped as a certificated ET;
(7) Assigning a ward nurse to have a study visit on ostomy care in the Beijing Tumor Hospital;
(8) Persisting with monthly group learning and in-house skill training among ward nurses guided by the ET nurse.

After the completion of this study, the nurses make constant efforts to ameliorate their working situation and provide better ostomy care service to the patients and their family caregivers. Since November 2013, this surgical unit has become the provincial training center of ostomy nursing care, which is mainly responsible for training the nurses from regional hospitals. The head nurse is actively applying for the research grand on ostomy nursing care in order to improve the quality of care in this unit and the ability of research among ward nurses. The ET nurse in charge of the ostomy clinic has become popular among the patients who received ostomy-related surgery in this hospital or other hospitals since this clinic was built up. Another ET nurse, who has got the certificate of ET nurse in December 2013, has engaged in the ostomy nursing care in this surgical unit.

## Components, Stages and Strategies of the Family-based Care Model

The family-based care model to enhance Chinese patients' successful living with a permanent colostomy (Figure 19) was generated from the findings of this study using the methodology of action research. The time periods were from hospitalization (pre-operation and post-operation) to discharge home (initial three months of post-discharge).

The initial 3-component model (family-based care, empowerment and successful living with a permanent colostomy) was slightly modified into a 4-component model which comprises self-care with a proper degree of independence, proper family caregiving, active empowerment, and successful living with a permanent colostomy. This modification was to emphasize that self-care with a proper degree of independence is the core component of this family-based care model. This model's uniqueness was rooted at the interpretation of relationship between this core component and other components in a Chinese sociocultural context where this study was conducted.

Firstly, lack of ostomy nursing care in community advocated the hospital nurses (the ET nurse and other ward nurses) to take main responsibilities to prepare the patients and their family caregivers (the dyads) before discharge, and provide continued nursing support after discharge. The concept of empowerment guided the nurses to build up partnership with the dyads, facilitate the development of the dyads' awareness and ability on colostomy care, and encourage self-care actions of the patients and caregiving actions of the family caregivers. Based on the improvement in awareness and ability, the changes in actions could be sustained.

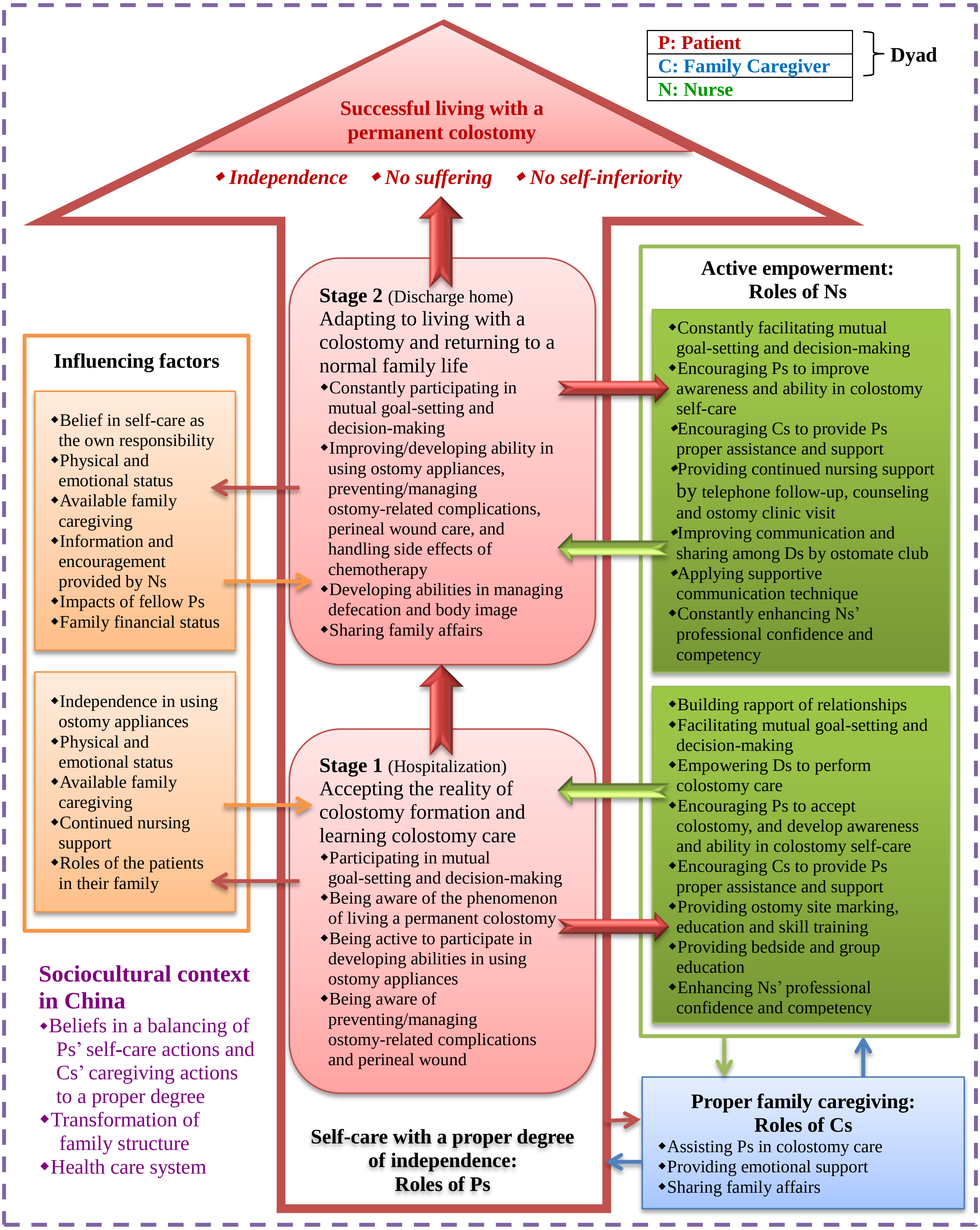
Secondly, different from a strong emphasis on caring for the sick relatives as a moral obligation of family members in the context of numerous extended families, the weakening of family caregiving function due to the trend of Chinese family nuclearization required the patients to take more responsibility in colostomy care rather than relying on family caregiving. Through assuming the responsibility of self-care and making possible contributions to family, the patients could feel independence and self-worth, obtain respect from family members, and thus avoid self-inferiority and mental distress.

Thirdly, grounded on the Doctrine of the Golden Mean of Confucian philosophy, a balancing of self-care actions of the patients and caregiving actions of the family caregivers to a proper degree was advocated in order to maintain the harmony of family. The proper degree implied that the patients performed self-care with a certain independence without sense of being a burden of family, and meanwhile their family caregivers had opportunities to care for the patients and thereby fulfill their obligation of caregiving without any sense of burden. Moreover, a Taoist idea of being happy-go-luck was frequently employed by the dyads to get through their stressful situations with a positive mood.

Finally, through the patients' own efforts, assistance and support from their family caregivers and the nurses, the patients could live well with independence, no suffering, and no self-inferiority. The process of become successful in living with a permanent colostomy was fulfilled over two distinct stages including: stage 1: accepting the reality of colostomy formation and learning colostomy care (hospitalization); and stage 2: adapting to living with a colostomy and returning to a normal family life (discharge home).

In the first stage (hospitalization), the overall goal was to help the patients to accept the reality of colostomy formation, and facilitating the dyads to learn colostomy care. The nursing strategies were carried out encompassing: (1) building rapport of relationships with the dyads; (2) facilitating mutual goal-setting and decision-making among the dyads and the nurses; (3) empowering the dyads to perform colostomy care by providing information and inspirational support; (4) encouraging the patients to accept the reality of colostomy formation and develop awareness and ability in colostomy self-care; (5) encouraging the family caregivers to provide the patients proper assistance and support; (6) providing preoperative ostomy site marking and education, and postoperative skill training and education; (7) providing bedside and group education to the dyads; (8) enhancing the nurses' professional confidence and competency in colostomy care by group learning and interaction with the dyads. The main factors influencing successful living with a colostomy consisted of: (1) belief in self-care as the own responsibility; (2) physical and emotional status; (3) available family support; (4) information and encouragement provided by the nurses; (5) impacts of fellow patients; (6) family financial status.

In the second stage (discharge home), the overall goal was to empower the patients to adapt to living with a colostomy and return to a normal family life. The nursing strategies were performed including: (1) constantly facilitating mutual goal-setting and decision-making among the dyads and the nurses; (2) encouraging the patients to improve awareness and ability in colostomy self-care; (3) encouraging the family caregivers to provide the patients proper assistance/support and gradually withdraw from colostomy care; (4) providing continued nursing support by telephone follow-up, counseling, ostomy clinic visit, and home visit; (5) improving communication and sharing among the dyads by the activity of an ostomate club; (6) applying supportive communication technique to provide informational and emotional support to the dyads; (7) constantly enhancing the nurses' professional confidence and competency in colostomy care by group learning and interaction with the dyads. The major factors influencing successful living with a colostomy involved: (1) independence in using ostomy appliances; (2) physical and emotional status; (3) available family support; (4) continued nursing support; (5) roles of the patients in their family.



**Successful living with a permanent colostomy**

- *Independence*
- *No suffering*
- *No self-inferiority*

**Influencing factors**

- Belief in self-care as the own responsibility
- Physical and emotional status
- Available family caregiving
- Information and encouragement provided by Ns
- Impacts of fellow Ps
- Family financial status

- Independence in using ostomy appliances
- Physical and emotional status
- Available family caregiving
- Continued nursing support
- Roles of the patients in their family

**Sociocultural context in China**

- Beliefs in a balancing of Ps' self-care actions and Cs' caregiving actions to a proper degree
- Transformation of family structure
- Health care system

**Stage 2** (Discharge home)
Adapting to living with a colostomy and returning to a normal family life

- Constantly participating in mutual goal-setting and decision-making
- Improving/developing ability in using ostomy appliances, preventing/managing ostomy-related complications, perineal wound care, and handling side effects of chemotherapy
- Developing abilities in managing defecation and body image
- Sharing family affairs

**Stage 1** (Hospitalization)
Accepting the reality of colostomy formation and learning colostomy care

- Participating in mutual goal-setting and decision-making
- Being aware of the phenomenon of living a permanent colostomy
- Being active to participate in developing abilities in using ostomy appliances
- Being aware of preventing/managing ostomy-related complications and perineal wound

**Self-care with a proper degree of independence: Roles of Ps**

**Active empowerment: Roles of Ns**

- Constantly facilitating mutual goal-setting and decision-making
- Encouraging Ps to improve awareness and ability in colostomy self-care
- Encouraging Cs to provide Ps proper assistance and support
- Providing continued nursing support by telephone follow-up, counseling and ostomy clinic visit
- Improving communication and sharing among Ds by ostomate club
- Applying supportive communication technique
- Constantly enhancing Ns' professional confidence and competency

- Building rapport of relationships
- Facilitating mutual goal-setting and decision-making
- Empowering Ds to perform colostomy care
- Encouraging Ps to accept colostomy, and develop awareness and ability in colostomy self-care
- Encouraging Cs to provide Ps proper assistance and support
- Providing ostomy site marking, education and skill training
- Providing bedside and group education
- Enhancing Ns' professional confidence and competency

**Proper family caregiving: Roles of Cs**

- Assisting Ps in colostomy care
- Providing emotional support
- Sharing family affairs

*Figure 19* . The Family-Based Care Model to Enhance Chinese Patients' Successful Living With a Permanent Colostomy

## Discussion

Compared to previous relevant studies, the findings of this study revealed some similarities and differences, which were discussed in seven aspects: (1) characteristics of the patients with a permanent colostomy; (2) meanings of successful living with a permanent colostomy; (3) main problems in the patients' situations of living with a permanent colostomy; (4) process and impacts of the family-based care model; (5) factors influencing successful living with a permanent colostomy; (6) contributions to knowledge development; and (7) lessons learned.

### Characteristics of the patients with a permanent colostomy

In comparison with prior studies, the characteristics of the colostomy patients were discussed composed of: (1) demographic characteristics of the patients; (2) changing concerns and needs of the patients over time; (3) self-care actions of the patients.

#### *1. Demographic characteristics of the patients*

According to demographic characteristics of seven experienced patients (four men and three women) and 14 novice patients (eight men and six women), respectively, the ages were 39 – 68 years (*M* = 54.00, *SD* = 9.56), and 30 – 66 years (*M* = 47.43, *SD* = 11.03). Rectal cancer was the main cause of the formation of permanent colostomy.

These findings were similar to those of previous studies conducted in China. The average age of colostomy patients was mainly from 40 to 60 years. For example, Hu and colleagues (2010) reported the average age of 58.66±12.85 years; Xu and associates (2010) indicated the average age was 48.33±9.80 years. Also, the majority was male, and the formation of permanent colostomy was mostly for treating rectal cancer.

#### *2. Changing concerns and needs of the patients over time*

The colostomy patients' concerns and needs were changing over time from pre-operation to post-discharge.

Initially, a coming surgery was the patients’ main concern and associate with whether their original anuses could be preserved after surgery. The patients needed to understand the surgery’s importance in saving life and be aware of the phenomenon of living with a permanent colostomy, such as what the fecal diversion (the colostomy) is like, how to care for the colostomy, what impacts of the colostomy on their lives will be. Through preoperative provision of necessary information and inspiration, the patients could be prepared well to accept the reality of colostomy formation after surgery.

Postoperatively, the patients’ chief concerns were recovering from surgery and learning colostomy care on the basis of accepting their own colostomies. The patients needed timely professional guidance on managing pain, resuming normal diet, and performing proper activities in order to recover from surgery. Meanwhile, they needed detailed education and vivid demonstration about the procedures of using ostomy appliances. Earlier they got rid of fatigue, more possibly they participated in learning and exercising the skill of using ostomy appliances. At this time, it was essential for the patients to understand the importance of independence in using ostomy appliances for the purpose of successful living with their colostomies, and thereby produce/reinforce the motivation (intention) of performing self-care actions. Also, encouragement and assistance from family caregivers were necessary to facilitate the process that the patients learned and mastered the skill of using ostomy appliances, because most patients were able to perform the procedures of using ostomy appliances with only partial independence during the initial post-operation.

After discharge from hospital, the patients commenced adapting themselves to a colostomy in their usual living condition in order to return to a normal family life. The patients’ needs were in relation to four aspects of problems and difficulties. Firstly, various restrictions became extrusive in their daily, social and sexual lives, such as being unable to lift heavy things, embarrassment about odor and noise in front of others, sexual dysfunction or inactiveness in marital relationship. Secondly, owing to non-proficiency in using ostomy appliances, peristomal skin problems frequently occurred in the first month post-discharge. Thirdly, some patients encountered obvious perineal wound pain in this first month, which would be gradually alleviated in next several months. Lastly, at about one month after discharge, some patients returned to hospital to receive postoperative chemotherapy. The side effects of chemotherapy became a barrier in adaptation to living a colostomy, e.g. reduced food intake due to loss of appetite, nausea, vomiting, diarrhea or/and constipation, which disturbed the patients' bowel movement and caused difficulty in being familiar with their own routine of defecation. At this stage, the family caregivers played a key role to encourage and assist the patients to adapt the changes in body and life. With increased ability of the patients in managing defecation, body image, peristomal skin problems, perineal wound, and side effects of chemotherapy, the family caregivers gradually reduced their involvement in colostomy care and management. Moreover, continued nursing support was beneficial for the patients to improve their ability of managing the colostomy itself and colostomy-related impacts, and handle future problems with regard to long-term life with a permanent colostomy.

Furthermore, changing concerns and needs of the patients over time were with respect to a dynamic and temporal process of becoming successful living with a permanent colostomy through constant development and improvement of self-care actions from peri-operation to post-discharge. Correspondingly, from unacceptance to acceptance is the turning point between pre-operation and post-operation; from learning to mastering is the turning point between before and after discharge; from maladaptation to adaptation is the turning point between the trajectory of colostomy-related surgery and returning to a normal family life. In this study, at three months after discharge, most patients expressed that they had got used to the new defecation pattern and adapted to living with their colostomies, namely, achieved successful living with a permanent colostomy.

Also, previous studies reported that time since ostomy-related surgery was a significant factor related to positive patient outcomes, such as general health among Iranian ostomy patients (Mahjoubi, Mohammadsadeghi, Mohammadipour, Mirzaei, & Moini, 2009), psychosocial adaptation among Taiwanese colostomy patients (Li, Rew, & Hwang, 2012), quality of life and life satisfaction among American ostomy patients (Smith, Loewenstein, Jankovic, & Ubel, 2009).

### *3. Self-care actions of the patients*

In this study, the patients' self-care actions were explored into details and further defined as individuals' efforts to manage the colostomy itself and colostomy-related impacts on personal and family lives. Concretely, the self-care actions of colostomy patients consisted of 12 components in four aspects: (1) managing defecation, including: performing the procedures of using ostomy appliances, learning what is a good time to release gas, empty a pouch and change an ostomy appliance, and becoming familiar with the own routine of defecation; (2) handling bodily discomfort, comprising: dealing with peristomal skin problems, managing perineal wound, and enduring side effects of chemotherapy; (3) struggling with mental distress, containing: having to accepting the reality of colostomy formation, having to keep a normal body image in public, obtaining emotional support from family members and fellow patients; and (4) reconciling with restrictions in life, involving: adjusting oneself to daily life in a family, reducing social activities, and putting sexual relationship aside.

Compared to previous studies, this study provided a comprehensive structure about self-care actions of colostomy patients. For instance, Xu and colleagues (2010) explored the relationship between psychosocial adaptation and self-care among Chinese patients with a permanent colostomy. In their study, self-care was measured and classified into three levels: (1) complete self-care, i.e. the patient performs the procedures of both cleaning and changing the ostomy appliance independently; (2) partial self-care, i.e. the patient performs the procedure of cleaning the ostomy appliance independently, but performs the procedure of changing the ostomy appliance with others' assistance; (3) complete dependence, i.e. the patient depends on others to perform the procedures of both cleaning and changing the ostomy appliance. However, performing the procedures of using ostomy appliances is only a basic part in the self-care actions of colostomy patients. According to Orem (2001), self-care refers to the actions of deliberately performing health maintenance, functioning, and well-being optimization. This study described and interpreted the patients' self-care actions involving physical, psychological, and social domains.

Moreover, the patients' self-care actions were developed and improved with their increased abilities, and finally led to positive patient outcomes. Based on the opinion of Orem (1995), self-care is a series of learned, goal-oriented actions generated by actively participating in taking care of oneself. During the process of learning and practicing, the individuals' abilities to perform these actions are developed for achieving the wholeness of bodily and mental functioning. In this study, most patients had gradually adapted to living with a permanent colostomy, along with their increased abilities in: (1) performing the procedures of using ostomy appliances, (2) managing defecation and body image, (3) preventing/managing ostomy-related complications and other health-related issues, and (4) participating in family affairs. Similarly, Hu and colleagues (2010) reported that the score of self-care ability was positively correlated with the score of adaptation among patients with a permanent colostomy. However, they used a general instrument, the Exercise of Self-Care Agency Scale developed by Kearney and Fleische (1979), which was weak to detect colostomy-specific self-care issues. Hence, owing to paucity of well-developed instruments specific to the self-care actions/abilities of colostomy patients, further research was needed in order to improve the patients' self-care actions/abilities and achieve better outcomes.

### Meanings of successful living with a permanent colostomy

Initially, in this study, successful living with a permanent colostomy was defined as the feeling of living well with a permanent colostomy perceived by the patients. Grounded in data from seven experienced patients, its meanings were extracted into three aspects with eight components: (1) living with independence: performing the procedures of using ostomy appliances independently, and getting used to the new defecation pattern; (2) living without suffering: being free from bodily discomfort, distancing from mental distress, and being able to gain support from family; and (3) living without self-inferiority: keeping a normal body image in public, and being able to contribute to family. The component of surviving cancer emerged from the data of interviewing with the novice patients. It was categorized into the aspect of living without suffering, because the life-threatening trait of cancer elicited the concern about survival which was more relevant to bodily discomfort or mental distress than independence and self-inferiority.

Compared with prior studies, the meanings of successful living with a colostomy were described in similar ways (Table 15). Firstly, in this study, the feeling of living with independence was obtained through performing the procedures of using ostomy appliances independently, and getting used to the new defecation pattern. Likewise, prior studies emphasized that the acquisition of independence and autonomy was based on skills of using ostomy appliances, practical ostomy self-care and management, and getting used to colostomy (Andersson et al., 2010; Dazio et al., 2009; Deeny & McCrea, 1991; Honkala & Berterö, 2009; Kelly, 1992; McVey et al., 2001; Nicholas et al., 2008). Secondly, in this study, living without suffering was mainly associated with survival, being free from bodily discomfort and mental distress, and gaining support from family. Similar expressions were found in other studies, such as getting through the thread of death, accepting ostomy, feeling comfortable, returning to normal state, and gaining support from significant others (Deeny & McCrea, 1991; Honkala & Berterö, 2009; Li & Zou, 2008; Manderson, 2005; McVey et al., 2001; Salter, 1992; Simmons et al., 2009). Thirdly, in this study, the patients endeavored to keep a normal body image in public and contribute to their families in order to obtain the sense of self-worth and thereby being far from self-inferiority. Comparably, previous studies also stressed satisfactory impression management, normalization of body image by others, and being able to work which can be related to contribute to family (Andersson et al., 2010; Dazio et al., 2009; Kelly, 1992; Li & Zou, 2008; Manderson, 2005; Nicholas et al., 2008; Salter, 1992; Simmons et al., 2009).

Apparently, independence, no suffering, and absence of self-inferiority expressed the patients' expectations about successful living with a permanent colostomy. These expectations became the individuals' goals/motivations in making efforts to adapt to changes due to having a colostomy, in other words, "striving toward a normal life" (Honkala & Berterö, 2009, p. 21).

Table 15

*Comparison About Meanings of Successful Living With a Permanent Colostomy With Findings of Prior Studies*

| Meanings of successful living with a permanent colostomy | Similar descriptions about meanings of successful living with a permanent colostomy in prior studies |
|---|---|
| Aspect 1: Living with independence | Looking after stoma independently (Deeny & McCrea, 1991)<br>Regaining autonomy (McVey et al., 2001) |
| Performing the procedures of using ostomy appliances independently | Practically dealing with ostomy appliances (Honkala & Berterö, 2009)<br>Managing ostomy confidently and independently (Nicholas et al., 2008)<br>Learning hand-skills of using stoma appliances (Kelly, 1992)<br>Becoming skilled at stoma self-care (McVey et al., 2001) |
| Getting used to the new defecation pattern | Accepting and having a good life with colostomy (Andersson et al., 2010)<br>Getting used to colostomy (Dazio et al., 2009) |
| Aspect 2: Living without suffering | Returning to the approximately normal state (McVey et al., 2001) |
| Being free from bodily discomfort | Feeling comfortable about having a stoma (Manderson, 2005) |
| Distancing from mental distress | Accepting stoma (Deeny & McCrea, 1991; Honkala & Berterö, 2009; McVey et al., 2001)<br>Being able to set aside reactions of disgust (Manderson, 2005)<br>Accepting own feelings regarding stoma (Salter, 1992) |
| Getting support from family | Being able to gain information and support from significant others (Li & Zou, 2008) |
| Surviving cancer | Getting through life-threatening experience (Simmons et al., 2009)<br>Rescuing from the jaws of death and returning to life (Honkala & Berterö, 2009) |
| Aspect 3: living without self-inferiority | Overcoming the sense of self-inferiority (Li & Zou, 2008) |
| Keeping a normal body image in public | Becoming highly skilled in impression management (Kelly, 1992)<br>Adapting to changes of appearance and life (Manderson, 2005)<br>Adjusting to body changes, and being accustomed to the appearance of stoma (Nicholas et al., 2008)<br>Managing satisfactorily the figure with stoma, and attempts at normalization made by others on behalf of the patient (Salter, 1992)<br>Accepting the appearance changes caused by the ostomy (Simmons et al., 2009) |
| Being able to contribute to family | Being able to work again (Andersson et al., 2010)<br>Going back to work (Dazio et al., 2009) |

### Main problems in the patients' situations of living with a permanent colostomy

In the reconnaissance phase, the main problems in the patients' situations of living with a permanent colostomy were identified and divided into two aspects, i.e. before and after discharge. The main problems at hospitalization before discharge included: bodily and mental suffering before discharge, inadequate discharge preparedness of the patients and their family caregivers, and issues on communication between the patients and their family caregivers. The main problems after discharge at home involved: bodily and mental suffering after discharge, fewer social activities, insufficiency of continued nursing support for the patients and their family caregivers, and inappropriate family caregiving.

Compared with previous studies, some problems have been commonly-discussed, while others were seldom mentioned in relation to the Chinese sociocultural context where this study was conducted.

### ***1. Problems commonly-discussed by previous studies***

Several commonly-discussed problems were: bodily/mental suffering before/after discharge, fewer social activities, inadequate discharge preparedness, and insufficient continued nursing support. These issues were discussed as follows.

#### *1.1 Bodily/mental suffering before/after discharge*

A great number of studies revealed that having an ostomy brought out both physical and psychosocial negative impacts on the patients who were living with it. Physically, incontinence of defecation and flatus, changed body image, odor and leakage related to the usage of ostomy appliances, and ostomy-related complications were common problems (Brown & Randle, 2005; Thorpe et al., 2009). These problems could further induce psychosocial distress, e.g. anxiety and depression (Boyles, 2010); worry and fear about leakage, odor and noise (Popek et al., 2010); loss of control (McVey et al., 2001); sense of disability (Honkala & Berterö, 2009); sense of self-inferiority (Li & Zou, 2008); and social isolation and discrimination (Williams, 2008).

#### *1.2 Fewer social activities*

Fewer social activities were frequently reported by previous studies, such as avoiding social and leisure activities due to the consideration about the need of changing pouches (McKenzie et al., 2006); reducing activities of going outside resulting from worry about leakage (Richbourg, Thorpe, & Rapp, 2007).

### *1.3 Inadequate discharge preparedness of the patients and their family caregivers*

Previous studies stated that there was inadequate discharge preparedness in the present ostomy nursing care, especially for the family caregivers. Cameron and associates (2004) revealed that the family caregivers of ostomy patients often lack preparation of caregiving at home. Studies reported that the family caregivers of ostomy patients felt anxiety and depression mainly owing to their own inadequate preparation of knowledge and skills on ostomy care (Cotrim & Pereira, 2008; Persson et al., 2004).

### *1.4 Insufficiency of continued nursing support for the patients and their family caregivers*

Insufficient continued nursing support was also a major problem in the present ostomy nursing care. This was resulting from: paucity of adequate knowledge on ostomy care among community nurses (Skingley, 2004), and difficult access to continued support from ET nurses (D'Orazio & Ozorio, 2008). Similar to the findings of this study, in the first month after discharge at home, the patients were overwhelmed by a lot of problems and difficulties involving: fatigue, dietary issues, disordered bowel movement, incorrect usage of ostomy appliances, ostomy-related complications, access to professional and peer support, and life adaptation (Burch & Taylor, 2012; Zhang, Wong, You, & Zheng, 2011).

## ***2. Problems specific to Chinese sociocultural context***

Issues on communication between the patients and their family caregivers, and inappropriate family caregiving were the specific problems identified in this study and related to Chinese sociocultural context. The two issues were discussed as follows.

### *2.1 Issues on communication between the patients and their family caregivers*

This issue can be associated with Chinese interdependent self-construal, and implicitness of emotional expression. Influenced by the belief of interdependent self-construal which refers to define oneself in relationships with others, Chinese people universally tend to pursue the harmonious interdependence with each other (Markus & Kitayama, 1991). In order to maintain the harmony of family in stressful situations, Chinese patients and their family caregivers get used to control their own emotions and employ implicit expression (Liu, Mok, & Wong, 2005). This is mainly due to the idea of valuing moderation with respect to all the seven emotions (qiqing) in the Doctrine of Golden Mean (Lin, 2009), and the belief that personal emotions are private and must be restrained (jiezhi) to express and controlled to proper degree (Liu, Mok, & Wong, 2005). In brief, attention to interpersonal harmony and implicit emotional expressions could negatively affect open communication between the patients and the family caregivers, and further become a cause of misunderstanding and insufficient mutual emotional support.

#### *2.2 Inappropriate family caregiving*

Inappropriate family caregiving can be linked to the family members' moral obligation to care for their sick relatives in Confucian ethic system of role relationships (Wong & Pang, 2000). If a family caregiver has not fulfilled this obligation, he/she would encounter the sense of moral frustration. Thus, in the initial period after the patients got sick, family caregiving could be beyond the actual needs of the patients and hinder development of their self-care ability. However, as time goes by, family caregiving could become insufficient when the family caregivers feel bored or burnout to provide care to the patients. This can be explained by a Chinese proverb, “A son's filial piety stops at his parent's prolonged sickbed” (jiu bing chuang qian wu xiao zi). Additionally, inappropriate family caregiving also can be related to technical errors in colostomy care. For example, the family caregivers use alcohol to clean peristomal skin of the patients. Therefore, appropriate family caregiving should be advocated to facilitate development of the patients' self-care ability and prevent from the family caregivers' sense of boredom and burnout, and thereby improve the harmony of family.

### Process and impacts of developing the family-based care model

The family-based care model to enhance successful living with a permanent colostomy among Chinese patients was developed and refined in nursing practice on the basis of a preliminary theoretical framework produced by literature review. This model shortened the gap between nursing theory/research and practice/application, as well as integrated holistic view into nursing practice involving physical, psychological, sociocultural, and spiritual aspects in relation to human life.

This model encompassed four key components, i.e. active empowerment, proper family caregiving, self-care with a proper degree of independence, and successful living with a permanent colostomy. The first three components were interconnected and interactive for the mutual purpose of enhancing the patients' successful living with their colostomies. Moreover, self-care actions of the patients and caregiving actions of the family caregivers became an inseparable dyad with respect to the family-based feature of this care model.

Firstly, the component of active empowerment was used to guide the determination and implementation of nursing strategies for the dyads of the patients and their family caregivers, based on Gibson's (1991) empowerment model for nursing which proposed nine roles of nurses in the empowering process including helper, supporter, counselor, educator, resource consultant, resource mobilizer, facilitator, enabler and advocator. These roles of nurses had been practiced broadly in this model, which could be divided into primary and secondary roles according to the importance for the dyads of colostomy patients and family caregivers (Table 16). Meanwhile, transforming previous professional-layman relationship into equal partnership relationship was advocated, as well as the notion of teamwork in ostomy care was emphasized among the head nurse, the ET nurse, and the nursing team leaders. Furthermore, these nurses in the core working group collaborated with all ward nurses and generated changes desired by the nurses in this surgical unit. As a result, the nurses felt more confidence and self-actualization in colostomy care. They reflected that practically doing more for the patients and their family caregivers (e.g. changing ostomy appliances for the patients) was not better than providing necessary information and support to facilitate them to master colostomy care (e.g. the usage of ostomy appliances). Like this, the patients would feel happier about their ability and independence; the family caregivers would feel capable to care for their sick relatives and satisfied with nursing care; the nurses' workload would be reduced.

Table 16

*Roles of the Nurses in Empowering Process at the First and Second Stages of the Family-Based Care Model*

| | Stage 1 Accepting the reality of colostomy formation and Learning colostomy care | | | | Stage 2 Adapting to living with a colostomy and returning to a normal family life | | | |
|---|---|---|---|---|---|---|---|---|
| | ET | TL | HN | R | ET | TL | HN | R |
| Primary roles: | | | | | | | | |
| Helper | √ | √ | | √ | √ | √ | | √ |
| Educator | √ | √ | | √ | √ | √ | | √ |
| Counselor | √ | √ | | √ | √ | √ | | √ |
| Supporter | √ | √ | √ | √ | √ | √ | √ | √ |
| Enabler | √ | | | | √ | | | |
| Facilitator | √ | | √ | √ | √ | | √ | |
| Secondary roles: | | | | | | | | |
| Resource consultant | √ | | | √ | √ | | | √ |
| Resource mobilizer | | | √ | √ | | | √ | √ |
| Advocator | √ | √ | √ | √ | √ | √ | √ | √ |

Note. ET=Enterostomal therapist nurse; TL=Nursing team leader; HN=Head nurse; R=Researcher as a surgical nurse.

Secondly, the component of proper family caregiving was one of the dyad in family-based care. Influenced by Confucian ethical system of role relationships, Chinese people universally believe that caring for the sick relatives is a moral obligation of other family members. Once the caring obligation has not been accomplished, relevant family members would confront the moral disappointment (Wong & Pang, 2000). Therefore, in this kind of cultural context, family caregiving for colostomy patients is relatively easy to be obtained. In the reconnaissance phase, this study found that both excessive and insufficient family caregiving existed, and usually brought negative impacts on self-care actions of the patients and their successful living with a colostomy. Accordingly, in the action phase, the properness of family caregiving was emphasized among the family caregivers, the patients and the nurses. The common consensus was that the core of colostomy care is to cultivate the patients' self-care ability for successful living with their colostomies, while the principle of family caregiving is to provide necessary assistance and support rather than to do all caring tasks for the patients. Finally, at the end of three-month follow-up, 10/14 novice patients had performed the procedures of using ostomy appliances with complete independence. All their family caregivers mastered the usage of ostomy appliances and felt satisfied with nursing service provided by the nurses of this surgical unit.

Thirdly, the component of self-care with a proper degree of independence was another one of the dyad in family-based care. Different from the Western viewpoint of regarding self-care as the individuals' responsibility for their own growth and development (Richard & Shea, 2011), a Chinese cultural belief emphasizes that the individuals take good care of themselves is for the purpose of taking better care of others, especially their parents and other family members grounded on Confucian thought of filial piety. Therefore, most Chinese colostomy patients intended to take colostomy care tasks by themselves. However, the improvement of self-care ability was a progressive and individualized process, which was influenced by both professional nursing care and available family support. In this study, the patients reached complete independence in performing the procedures of using ostomy appliances at different time periods. About one third patients achieved this in the first month after discharge; around one third accomplished after three months post-discharge; the rest still relied on their family caregivers partially.

Lastly, the component of successful living with a permanent colostomy embodied the individuals' expectations and actual feelings about living with their colostomies. The goal of successful living motivated the patients to actively involving in self-care practice. Through the patients' own efforts, proper family caregiving and nursing empowerment, the patients could obtain the feeling of successful living with their colostomies. Initially, the meanings of successful living with a permanent colostomy were extracted from data of in-depth interviews with the experienced patients, and then was flexibility used to guide goal-setting and outcome evaluation among the novice patients with the consideration of individual diversity and subjectivity. Especially, eight components about the meanings of successful living under three aspects served as a relatively-comparable standard to evaluate the actualization of successful living (Table 12). As a result, most of the novice patients thought that they had achieve successful living with a permanent colostomy after participating in the two stages of this model, except three patients still felt that they had not got used to the new defecation pattern.

### Factors influencing successful living with a permanent colostomy

The main factors influencing successful living with a permanent colostomy were discussed in two parts: (1) main influencing factors in the first stage (hospitalization); and (2) main influencing factors in the second stage (discharge home).

#### *1. Main influencing factors in the first stage (hospitalization)*

Several factors influencing successful living with a colostomy in the first stage were discussed, involving: (1) belief in self-care as the own responsibility; (2) physical and emotional status; (3) available family support; (4) information and encouragement provided by the nurses; (5) impacts of fellow patients; (6) family financial status.

##### *1.1 Belief in self-care as the own responsibility*

The belief in self-care as the own responsibility was regarded as a facilitator influencing successful living with a permanent colostomy. Despite the Confucian emphasizes caring for the sick relatives as a moral obligation of their family members (Wong & Pang, 2000), most colostomy patients believed that self-care is a reasonable responsibility for their own, and thus endeavored to manage their own colostomies and colostomy-related impacts. The possible explanation was as follows.

According to Confucianism, only when a person takes good care of himself/herself, can he/she take better care of his/her family members. Like this, it becomes possible that he/she fulfills filial piety to parents (jin xiao), and assumes obligations to other family members. As Confucius stated, “The body and hair and skin are received from the parents, and may not be injured: this is the beginning of filial piety” (Lin, 2009, p. 186). Therefore, it is understandable that a motivation of Chinese patients to perform self-care actions is to fulfill their moral obligations to other family members, on the basis of maintaining their own health.

In this study, many middle-aged patients stated that they would like to perform the procedures of using ostomy appliances by themselves instead of relying on their family caregivers. They thought that their own illness and treatment had brought a considerable burden to family, and also their family caregivers had assumed more responsibilities in family than those before they got sick. Therefore, they made efforts to take good care of themselves, in order to lighten the family caregivers' burden, become better soon, and then be able to contribute to family.

### *1.2 Physical and emotional status*

Few previous studies separately discussed the impacts of physical and emotional status based on the two different stages (before and after discharge). Thus, this factor would be put into the next part to make discussion.

### *1.3 Available family support*

Available family support influenced the patients to accept and adapt to their colostomies involving both before and after discharge. Prior studies generally reported the impacts of family support without the distinction between before and after discharge. Hence, this factor would be discussed in the next part.

### *1.4 Information and encouragement provided by the nurses*

This study revealed that the colostomy patients and their family caregivers valued information and encouragement provided by the nurses, which were helpful for them to be aware of the phenomenon of living with a colostomy, and develop ability of colostomy care and management. Previous studies reported that access to ET nurses in pre-operation and early post-operation was positively correlated with QOL of patients (de la Quintana Jimenez et al., 2010; Marquis et al., 2003). Moreover, professional self-care education and psychological support could facilitate successful self-care management and health-related QOL (Symms et al., 2008).

### *1.5 Impacts of fellow patients*

Previous studies revealed that peer support from fellow patients had positive impacts on the patients with an ostomy (Bui et al., 2002; Cross & Hottenstein, 2010; McMullen et al., 2008). In these studies, ostomy visitor and ostomy support group were common modes to provide peer support, which could contribute lesson learned and inspiration to the patients who will receive ostomy-related surgery or have a newly-formed ostomy. However, this study found some negative impacts from fellow patients which should be paid attention. For example, when a patient requiring ostomy-related surgery saw an ostomy patient who is dirty and odorous owing to awful ostomy management, he/she might reject surgery.

### *1.6 Family financial status*

This study found that family financial status had a noticeable impact on the patients’ choices of ostomy care products. Owing to the long-term trait of using ostomy appliances, the patients had to consider their family financial capacity. In spite of being covered by various public health insurances, they still had to pay for ostomy appliances by pocket money. Also, the patients who were from rural area and with low family income tended to choose cheap one-piece ostomy appliances. Once it was detected that this kind of ostomy appliances were inappropriate for them, e.g. incidence of contact dermatitis of peristomal skin, they would encounter the dilemma in selecting ostomy care products.

Similarly, Somani and associates (2009) have found that financial difficulty about payment of ostomy appliances affected the patients’ health-related quality of life. Moreover, a study concerning quality of life conducted in western China reported that the scores of financial difficulty of colostomy patients were obviously higher than those of common people (Yang et al., 2012). The estimated reasons were low income, high medical expense (e.g. surgery and radio-chemotherapy), and payment of ostomy care products (averagely 256 Yuan/month by pocket money). Further suggest was presented that ostomy care products should be included into the payment system of public health insurance in order to lighten the patients’ financial stress and improve quality of life (Yang et al., 2012).

## ***2. Main influencing factors in the second stage (discharge home)***

Main factors influencing successful living with a colostomy in the second stage were discussed here, including: (1) independence in using ostomy appliances; (2) physical and emotional status; (3) available family caregiving; (4) continued nursing support; (5) roles of the patients in their family.

### *2.1 Independence in using ostomy appliances*

The independence in using ostomy appliances was a positive factor of facilitating the patients to build up confidence in managing defecation, body image and engagement into social activities, and also gain respect from others and avoid self-inferiority.

On the one hand, independence in using ostomy appliances was beneficial for the patients to develop their confidence in ostomy care and management. McVey and colleagues (2001) found that, different from dependence which is an uncomfortable experience accompanied by negative emotions (e.g. fear and depression), becoming independent at ostomy care may lead to positive emotions, such as feeling confidence to attend and enjoy social activities. Likewise, Xu and associates (2010) revealed that more independence in performing the procedures of using ostomy appliances predicted better psychosocial adaptation to a permanent colostomy.

On the other hand, independence in using ostomy appliances was helpful for the patients to acquire senses of being respected and self-worth. Influenced by Confucianism, Chinese people usually employ the mean of interdependent self-construal to define themselves based on others' appraisals and in relationships with others (Markus & Kitayama, 1991). For example, in order to obtain respect from others and sense of self-worth, and also maintain harmonious relationships, Chinese elderly people universally tried their best to take care of themselves and shouldered certain housework and family tasks, at the same time of appreciating filial piety from their adult children (Chen, 2001).

### *2.2 Physical and emotional status*

This study found that the patients' physical status affected their feeling of living with a colostomy, chiefly involving: physical fatigue owing to surgery, irregular defecation (disordered bowel movement), ostomy-related complications (mainly itching of peristomal skin), perineal wound pain and side effects of chemotherapy.

Similarly, previous studies revealed that fatigue, issues on diet and bowel movement, and ostomy-related complications were concerned by ostomy patients in the first month after discharge at home, along with other issues on usage of ostomy appliances, access to ET nurses and peer supporters, and adaptation to personal and social life (Burch & Taylor, 2012; Zhang et al., 2011).

Moreover, consistent with this study's finding, Sung and colleagues (2010) discovered that irritant contact dermatitis was the most frequent peristomal skin complication through conducting a retrospective analysis of medical records of 1170 end colostomy patients. The similar result was reported by Persson and associates (2010) that the most common ostomy-related complications were peristomal skin problems which usually happed in two weeks after discharge.

However, few studies mentioned issues related to perineal wound after abdomino-perineal resection of the rectum (Miles operation). In this study, among 8/14 novice patients with perineal open wound, two who received preoperative radiotherapy encountered unbearable perineal wound pain in the first month after discharge. This finding was consistent with the report of Chadwick and associates (2006) that the patients who experienced Miles operation were largely more possible to suffer a perineal wound complication if they had preoperative radiotherapy than those had not. Also, they were more likely to have a delayed perineal wound healing than those who had not received preoperative radiotherapy.

In addition, Wallace and Taylor (2011) commented that there has been less work on how the side effects of chemotherapy affect ostomy patients, although its common side effects (e.g. fatigue, nausea and diarrhea) have been well known. Fortunately, this study disclosed that the impacts of side effects of chemotherapy on ostomy care were associated with (1) fatigue and reduced fecal output which was caused by less food intake due to loss of appetite, nausea and vomiting; (2) irregular defecation induced by diarrhea or/and constipation during taking/infusing chemotherapeutic medicine. Furthermore, irregular defecation led to the patients' difficulty in being familiar with their own routine of bowel movement. Also, owing to the periodic feature of postoperative adjuvant chemotherapy, the impacts of its side effects on ostomy care were cyclically fluctuating between feeling uncomfortable and becoming better.

Also, this study discovered that emotional status with a great quantity of negative emotions (e.g. sadness, worry, sense of normality and isolation) were experienced by the patients, mainly resulting from their altered defecation pattern and body image in relation to the formation of colostomy. These negative emotions became an inhibitor to hinder the patients to accept and adapt their lives with a colostomy.

On the one hand, due to defecation by an opening on abdomen as being abnormal, strange, inconvenient and troublesome, many colostomy patients worried about becoming a disabled person, and thus felt difficult to accept the fecal diversion before surgery. On the other hand, most patients perceived a colostomy as a surprising thing, a handicap, and a distinction from ordinary people, and also associated it with ugliness, dirtiness, odor and noise. Hence, they often presented a negative appraisal about their body image, and especially worried about being isolated and laughed at when their body image with a colostomy was exposed in front of other people.

Furthermore, they commonly felt hard to adapt to living with a colostomy, and tended to keep their colostomies secret from common others by careful body image management, reducing social activities, or quitting previous jobs. This action of concealing the existence of colostomy can be interpreted and understand by citing a Chinese curse, “Birth to a child with no rectum!” (Zhang et al., 2011, p. 1412). Having a colostomy means lack of a normal anus, which is universally considered as a negative and awkward condition by Chinese people.

The individuals’ emotional responses were frequently included into the items of existing research instruments which were to examine quality of life or psychosocial adaptation among ostomy patients, such as the Stoma Care Quality of Life (SCQLI) (Marquis et al., 2003) and the Ostomy Adjustment Inventory-23 (OAI-23) (Simmons et al., 2009). This meant an inherent connection between personal emotional status and their adaptation to living with a colostomy.

Moreover, Smith and colleagues (2007) deeply explored the relationship between a negative emotional response (disgust) to colostomy and individuals’ adaptation to a colostomy (a physical disability, or an offensive event). They discovered that higher disgust sensitivity predicted lower life satisfaction and colostomy adaptation, and stronger sense of stigma. Besides, another research confirmed that an ostomy has a negative impact on the body image of patients with colorectal cancer, and more body image disturbance predicted more emotional distress (Sharpe, Patel, & Clarke, 2011).

### *2.3 Available family support*

Generally, more available family support was linked to better care for the colostomy patients and contributed to positive patient outcome. Previous studies reported that family support was positively correlated with the patients’ ostomy adaptation (Hu et al., 2010; Piwonka & Merino, 1999). Common family support involved practical assistance in ostomy care, tangible support, encouragement and acceptance (McMullen et al., 2008).

Similarly, in this present study, most patients received timely and proper family caregiving, so that they could gradually develop from dependence to complete independence in performing the procedures of using ostomy appliances, and further obtain the feeling of successful living with a colostomy three months after discharge. However, availability of family caregiving might lead to incomplete independence in using ostomy appliances. 4/14 novice patients always relied on their family caregivers to change ostomy appliances in three months after discharge, in which there were two patients living in an extended family. According to the two patients' explanation, there were a lot of family members in their home; apart from their primary family caregivers, other family members could also help them to change ostomy appliances. As a result of high availability of family caregiving, these patients presented the partial independence in using ostomy appliances.

#### *2.4 Continued nursing support*

In this study, continued nursing support for the patients and their family caregivers was mainly delivered by the ET nurse and the researcher as a surgical nurse in three months after discharge, which functioned in improving healthy lifestyle and correct usage of ostomy appliances, timely handling ostomy-related complications, constantly encouraging active self-care of the patients and proper caregiving of the family caregivers. The delivery methods involved telephone counseling and ostomy clinic visit by the ET nurse, as well as telephone follow-up and home visit by the researcher as a surgical nurse.

Previous studies have verified the positive effects of post-discharge follow-up chiefly provided by ET nurses. A retrospective study of reviewing medical records of 204 ostomy patients revealed the protective effects of ET nurses in improving prevention and management of stomal and peristomal complications (Duchesne, Wang, Weintraub, Boyle, & Hunt, 2002). Compared with traditional home visit by home health nurses, telehealth interactions with ET nurses might contribute to positive patient outcomes, such as, more satisfaction with nursing care, improved quality of life, and reduced quantity of monthly-used ostomy appliances (Bohnenkamp et al., 2004). Moreover, a randomized controlled trial conducted among

Chinese colostomy patients has examined effects of ET nurse telephone follow-up on higher scores about ostomy adjustment, stoma self-efficacy and satisfaction with nursing care, as well as reduced ostomy-related complications among the patients in experimental group who received 2 - 3 ET nurse telephone calls in the first month after discharge (Zhang et al., 2013).

However, during conducting this action research, the researcher realized that it was impossible and infeasible to require the ET nurse to assume all of follow-up tasks, because she was a unique ostomy specialist nurse in this hospital and responsible for both hospitalized ostomy patients and ostomy/wound patients in the outpatient department. Combination the ET nurse with other ward nurses as a team was required for practical implementation of continued nursing support after discharge by means of telephone follow-up, telephone counseling, and ostomy clinic visit. Temporarily, the researcher played as a surgical nurse to collaborate with the nurses to accomplish continued nursing support in three months after discharge.

Moreover, through organizing the activity of literature learning on nurse-led telephone follow-up and designing the Telephone Follow-Up Record Form for Colostomy Patient in the core working group, a 3-time telephone follow-up program has been included into the ostomy care routine of this surgical unit as well as initiated to be implemented by the nursing team leaders. The three time points were respectively at the 1st week, 1st month, and 3rd month after discharge. During the initial three months after discharge, the problems/difficulties frequently mentioned by the patients and their family caregivers were related to: (1) at the 1st week: usage of ostomy appliances, irregular defecation, abdominal/perineal wound pain, and reduced daily activity due to fatigue/pain; (2) at the 1st month: usage of ostomy appliances, peristomal skin problems, irregular defecation, reduced daily/social activities due to fatigue/worries, perineal wound pain, and negative feelings about living with a colostomy; (3) at the 3rd month: irregular defecation, colostomy-related worries in social activities, side effects of chemotherapy, peristomal skin problems, and financial stress.

Similarly, Zhang and associates (2011) conducted 2 - 3 telephone follow-up calls to the patients with a permanent colostomy at the 1st month post-discharge, and found that the common problems mentioned were relevant to usage of ostomy appliances, peristomal dermatitis, defecation (involving stool character, diarrhea and constipation), personal and social life, and general postoperative problems (including chemotherapy, pain and medical fees). However, Zhang and associates (2011) realized that a few patients talked to nurses about their psychological issues. In this study, the researcher proactively asked the patients' feelings of living with a colostomy and found: (1) negative feelings were frequently expressed at the 1st month after discharge; (2) most patients felt that they had achieved successful living with their colostomies at the 3rd month after discharge; (3) emotional support from the researcher was appreciated by both the patients and their family caregivers.

#### *2.5 Roles of the patients in their family*

This study found that the roles of the patients in their family could influence their expectations about being able to contribute to family, such as sharing housework and doing a productive work to get income. Commonly, middle-aged patients seemed to have stronger expectations about this than older patients. In the Chinese sociocultural context, middle-aged adults have the double roles in family, i.e. feeding young children and nurturing elderly parents, while elderly parents may reasonably receive practical care and financial support from adult children based on the role ethic of filial piety. Thus, the different role requirements induce the distinction of expectations about being able to contribute to family.

## **Contributions to knowledge development**

This study's contributions to knowledge development can be summarized into four aspects: (1) generating a situation-specific theory; (2) improving the understanding about Chinese cultural impacts on colostomy self-care and family caregiving actions; (3) verifying the applicability of empowerment in colostomy nursing care; (4) confirming the acceptability of empowerment in Chinese cultural context.

### ***1. Generating a situation-specific theory***

This action research integrated theoretical knowledge and research evidence into the practice of colostomy care, addressed clinical problems of the nurses and thematic concerns of the dyads of patients and their family caregivers, and generated practical solutions in a specific illness journey (becoming successful living with a permanent colostomy), a particular setting (a university hospital of southwestern China), and a certain context (Chinese sociocultural context).

Correspondingly, a family-based care model to enhance Chinese patients' successful living with a permanent colostomy were developed and refined through mutual efforts among the patients, the family caregivers, the nurses and the researcher. According to Im and Meleis (1999), "situation-specific theories that developed in nursing must reflect a nursing perspective encompassing a focus on health, caring, holism, subjectivity of clients, a dialogued approach, and lived experiences" (p. 21). This family-based care model has reflected understanding about lived experiences of the colostomy patients; respect for subjectivity of the patients' perception on their living; focus on physiological, psychosocial and spiritual domains of successful living with a colostomy; provision of holistic nursing care through communication and interaction among the patients, their family caregivers and the nurses. Thus, this model could be used as a situation-specific theory to contribute to an integrated framework for nursing practice and research.

For example, in the reconnaissance phase, insufficiency of continued nursing support for the patients and their family caregivers was identified. Previous studies showed that ET nurse telephone follow-up had positive effects on patient outcomes, e.g. ostomy adjustment, reduced ostomy-related complications and satisfaction with nursing care (Duchesne, Wang, Weintraub, Boyle, & Hunt, 2002; Zhang et al., 2013). However, in this study, the ET nurse considered that she could not assume the task of telephone follow-up because she had been overwhelmed by visiting all of hospitalized ostomy patients and ostomy/wound outpatients. Therefore, combining the telephone counseling and ostomy clinic visit provided by the ET nurse with the telephone follow-up performed by the nursing team leaders were proposed and implemented by the nurses in the core working group under the assistance and guidance of the researcher. Finally, this study generated a 3-time telephone follow-up program in three months after discharge, which facilitated the patients and their family caregivers to deal with specific problems/difficulties and expressed their feelings, and thereby constantly supported the patients to achieve their expectations of successful living with a permanent colostomy.

### *2. Improving the understanding about Chinese cultural impacts on colostomy self-care and family caregiving actions*

The findings of this study have improved understanding about the impacts of Chinese Confucian and Taoist philosophies on individuals' self-care and family caregiving actions in colostomy care.

On the one hand, Confucianism emphasizes responsibility and obligation between man and man (Lin, 2009). The patients should take good care of themselves (self-care responsibility) in order to take better care of their family members; meanwhile, the family members have the moral obligation to care for their sick relatives (family caregiving obligation). Therefore, the patients obtained respect and self-worth through making efforts to manage their own colostomies and relevant impacts; simultaneously, the family caregivers provided assistance and support to the patients for accomplishing their obligation.

Furthermore, Chinese people believe in interdependent self-construal which refers to define oneself in relationships with others, and thus strive to maintain harmonious interdependence with each other (Markus & Kitayama, 1991). In the case of colostomy care, it is a key concern to maintain a harmony between the patients and their family caregivers through a balancing of self-care actions of the patients and caregiving actions of the family caregivers to a proper degree. The proper degree means that the patients may feel themselves capable in colostomy care and not being a burden of family, and meanwhile the family caregivers may have opportunities to fulfill their moral obligation of caring for the sick relatives and also express their concern and love to the patients without any sense of burden. Also, the proper degree can be explained by the idea of "too much is as bad as too little (guo you bu ji)" from the Doctrine of the Golden Mean of Confucian philosophy.

Hence, considering the relationship between self-care and family caregiving, the nurses could empower the two to positively interact with each other, and thus facilitate the patients to achieve successful living with their colostomies.

On the other hand, when the patients were unable to take care of themselves owing to bodily fatigue, discomfort or mental distress, they also adopted the Taoist view of being happy-go-lucky to safeguard self-esteem and accept family caregiving. Being happy-go-lucky signifies rebellion against the responsibility of Confucianism and compliance with the law of nature (dao) in Taoism. As Lin (2009) maintained, “The naturalism of Taoism is the balm that smoothes the wounded Chinese soul” (p. 120). Likewise, the Taoist ideas of xi guan cheng zi ran (once you form a habit of living with a colostomy, it becomes natural to you), and sui qi zi ran (let things take their own courses) are consistent with the view of being happy-go-lucky.

Besides, Chinese people believe the connection of body and mind from Taoism, that is, bodily and mental health are interactional, and pursue the harmony between the two. Because negative moods may slow down bodily recovery while positive moods may speed up it, keeping positive moods becomes a universal strategy to cope with stressful situations among Chinese people.

In brief, as Lin (2009) stated that Confucian realism and Taoist romanticism stand for the two sides of Chinese character. This kind of character benefits Chinese people to courageously assume responsibility and also keep a peaceful mood in adverse and stressful situations.

### *3. Verifying the applicability of empowerment in colostomy nursing care*

The development process of this model and its positive impacts provided evidence about the applicability of empowerment in colostomy nursing care. This was consistent with the opinion of specialists to empower patients through teaching practical ostomy management skills (Gesaro, 2012; Metcalf, 1999), and also the effect of one quasi-experimental study which proposed to employ the strategy of empowerment to increase patients’ knowledge about the fecal diversion and then improve their self-care actions (Kittinouvarat et al., 2011).

According the findings of this study and other studies (Hu et al., 2010; Xu, Cheng, Dai, et al., 2010) in the area of colostomy care, most patients at the outset of colostomy formation were middle-aged adults and elderly people who are lower than 70 years old. The majority of patients in this age range have potential to perform self-care actions in colostomy care and management. Thus, it is possible for nurses to empower them to manage colostomy itself and colostomy-related impacts by themselves. Furthermore, accurately speaking, nurses cannot empower patients, and instead patients can empower themselves through being aware of constraints in their lives and developing ability to gain control over these constraints, that is, patients are both subjects and objects of their empowerment (Gibson, 1991). However, nurses can facilitate patients' awareness and ability development, and thereby help patients to gain power of changing their living situations. In this study, the nurses have played multiple roles in improving the dyadic endeavor of the colostomy patients and their family caregivers in order to help the patients to obtain control over their living, that is, successful living with a colostomy.

### *4. Confirming the acceptability of empowerment in Chinese cultural context*

Although the concept of empowerment was developed in Western cultural context, the nurse participants in this study were commonly interested in this concept. Through the researcher's introduction and explanation about the concept of empowerment, these nurse participants expressed that it was acceptable and understandable.

Based on the philosophy of critical social theory, the nature of empowerment is to make people able to do something and improve their living conditions through critical self-reflection and interactions between the individuals and environment around them, others and self. This is compatible with a Chinese ancient proverb of "to teach one how to fish rather than just giving one a fish", and contemporary Marxist application in China.

On the one hand, the proverb of "to teach one how to fish rather than just giving one a fish (sou ren yi yu bu ru sou zi yi yu)" is from Taoism, which emphasizes the importance of mastering methods and developing ability. Likewise, related to the performance of using ostomy appliances in colostomy nursing care, teaching the patients to be able to perform by themselves is more significant than directly doing for them. As a nurse participant reflected that the patients were happier when you taught them and enabled them to empty the pouch by themselves than when you just did for them. According to the opinion of Habermas, people have cognitive interests and needs which further serve their behavioral choices (as cited in Holloway & Wheeler, 2010). This is the reason why the patients felt more satisfied with their own development in cognition and ability (action) than directly receiving care provided by the nurses.

On the other hand, Marxism opposes oppression and advocates oppressed groups to take action to obtain the own emancipation and change the own living conditions. Zedong Mao led Chinese people to win the class struggle, and acquire national liberation and independence. Xiaoping Deng guided Chinese people developed national economy to improve people's living conditions. The idea that people have potential to liberate themselves and obtain control over their living conditions has been rooted into Chinese mind. This is actually a vital antecedent of empowerment, i.e. belief in personal capacity for growth.

### Lessons learned

During conducting this action research study, the researcher gained the first-hand experience about how to integrate philosophic, theoretical, evidence-based and methodological knowledge held by the academic members, with clinical experience possessed by the nursing practitioners into nursing research and practice. The main lessons learned were presented in three aspects.

#### *1. Conducting an action research study*

Since choosing the realm of colostomy care as a focus of the researcher in this doctoral research two years before formally conducting this study, the researcher's competency in colostomy care and research was developed through learning from relevant literatures, the ET nurse, the colostomy patients and their family caregivers interviewed in pilot study. Meanwhile, the researcher gradually realized that living with a permanent colostomy is a very stressful situation, especially in the early period of colostomy formation. The patients needed to obtain external assistance and support, and be motivated their internal strength, in order to adapt themselves to bodily changes and return to a normal life. However, helping the patients to become successful living with their colostomies is a complicated and complex work influenced by social, cultural, economic and personal factors.

Subsequently, the process of conducting this action research study among three groups of participants (e.g. patients, family caregivers and nurses) provided the researcher both challenges and opportunities to: deeply understand the participants' experiences, concerns, needs, expectations, problems and difficulties; to gather the participants together to seek possible solutions and resolve actual problems; facilitate communication and interaction among the participants; improve their self-care actions, family caregiving actions, or nursing empowering actions by individual and collective critical refection; follow the procedures of action research methodology; finally, help the patients to achieve successful living with their colostomies. At the end of this study, most patients had obtained the feeling of living well with a colostomy, which brought the researcher the feeling of self-actualization and professional pride.

### *2. Self-development of the researcher*

Although it was a hard task for the researcher to conduct this action research study, she has acquired professional and personal development in terms of: colostomy care competency, research competency, communication skills, ability of teamwork, and personality development.

*Colostomy care competency.* Before formal data collection, the researcher learned colostomy care by various ways, e.g. reading literatures, interviewing with two Thai ET nurses and three Chinese ET nurses, communicating with colostomy patients and their family caregivers. In the reconnaissance phase of this study, the researcher observed the ET nurse’s activities of caring for ostomy patients, and simultaneously learned practical knowledge and skills of ostomy care at least once weekly in three months. Also, the researcher edited a self-care manual for colostomy patients, which was reviewed by the ET nurse and the head nurse. In the subsequent phases, the researcher constantly developed the competency in colostomy care, which became a wealth to conduct the future relevant research.

*Research competency.* During data collection and analysis, the researcher was overwhelmed by a large quantity of qualitative data. The nursing students’ assistance in the verbatim transcripts of interview audio-records, and the suggestions and comments from critical friends and advisors helped the researcher to overcome the obstacles in data analysis. Through constant reflection and learning, the researcher developed the ability of analyzing qualitative data.

*Communication skills.* Collaborating with three groups of participants required that the researcher have good communication skills. Especially, when providing professional information to the laypersons, the researcher should use the easily-understand language. Also, delivering psychological support needed to master some basic principles and strategies. Through learning the technique of supportive communication and exercising in practice, the researcher improved her communication skills.

*Spirit of teamwork.* During conducting this action research study, the researcher perceived the importance of spirit of teamwork, which means respect, trust, empathy, mutual understanding, sharing, communication, negotiation, cooperation, collaboration and coordination.

*Personality development.* Reflecting the process of conducting this study, the researcher has encountered a series of negative emotions, e.g. anxiety, tension, loss of confidence, disappointment and frustration. Thanks to inspiration and guidance from the advisors as well as support and encouragement from family, colleagues and friends, the researcher has gained the development in personality with more patience, courage and grit, and thereby successfully accomplished this study.

### ***3. Development of nursing science knowledge***

The nursing science knowledge acquired from this study reflected a need of conducting more action research in the settings of nursing practice in order to better translate theoretical and evidence-based knowledge into practice and improve practice. Action research focuses on taking action to solve practical problems in the real world through the cycle of planning, acting, observing and reflecting. The promoted awareness on a certain situation would trigger proper rationales and actual solutions which could be continuously tested and revised in nursing practice. As a result, these proper rationales and actual solutions would contribute to changes in practice and the formation of a new situation-specific theory.

# Chapter 5

# Conclusion and Recommendations

This chapter presents the conclusion, implications for nursing profession, recommendations for further research, and limitations of the study.

## Conclusion

The methodology of action research was employed in this study to develop a family-based care model to enhance Chinese patients' successful living with a permanent colostomy through a spiral action research process over eleven months with seven experienced patients, four primary family caregivers of experienced patients, 14 novice patients and 14 their primary family caregivers as dyads, and nine nurses organized in a core working group. Three concepts (successful living with a permanent colostomy, family-based care and empowerment) and the tendency of critical social theory to pursue emancipatory knowledge guided the development of this model.

In the reconnaissance phase, main problems in the situations of colostomy patients were identified. Before discharge at hospitalization, the major problems were: bodily and mental suffering before discharge, inadequate discharge preparedness of the patients and their family caregivers, and issues on communication between the patients and their family caregivers. After discharge at home, the focal problems involved: bodily and mental suffering after discharge, fewer social activities, insufficiency of continued nursing support for the patients and their family caregivers, and inappropriate family caregiving.

Moreover, the meanings of successful living with a permanent colostomy perceived by the patients were extracted into three aspects and eight components: (1) living with independence, including: performing the procedures of using ostomy appliances independently, and getting used to the new defecation pattern; (2) living without suffering, involving: being free from bodily discomfort, distancing from mental distress, being able to gain support from family, and surviving cancer; and

(3) living without self-inferiority, encompassing: keeping a normal body image in public, and being able to contribute to family.

Considering the above problems in the patients’ situations and their expectations of successful living with a permanent colostomy, the overall goals were identified before taking action. The nursing strategies were planed and implemented in the two distinct stages: (1) accepting the reality of colostomy formation and learning colostomy care (hospitalization); and (2) adapting to living with a colostomy and returning to a normal family life (discharge home). Most nursing interventions were jointly provided to the patients and their family caregivers by collaboration among the ET nurse, the nursing team leaders, the head nurse, and the researcher as a surgical nurse.

In the first stage (hospitalization), the overall goal was to help the patients to accept the reality of colostomy formation, and facilitating the dyads to learn colostomy care. The nursing strategies were planned and carried out, encompassing: (1) building rapport of relationships with the dyads; (2) facilitating mutual goal-setting and decision-making among the dyads and the nurses; (3) empowering the dyads to perform colostomy care by providing information and inspirational support; (4) encouraging the patients to accept the reality of colostomy formation and develop awareness and ability in colostomy self-care; (5) encouraging the family caregivers to provide the patients proper assistance and support; (6) providing preoperative ostomy site marking and education, and postoperative skill training and education; (7) providing bedside and group education to the dyads; (8) enhancing the nurses’ professional confidence and competency in colostomy care by group learning and interaction with the dyads. The main factors influencing successful living with a colostomy consisted of: (1) belief in self-care as the own responsibility; (2) physical and emotional status; (3) available family support; (4) information and encouragement provided by the nurses; (5) impacts of fellow patients; (6) family financial status.

In the second stage (discharge home), the overall goal was to empower the patients to adapt to living with a colostomy and return to a normal family life. The nursing strategies were set up and performed, including: (1) constantly facilitating mutual goal-setting and decision-making among the dyads and the nurses; (2) encouraging the patients to improve awareness and ability in colostomy self-care; (3)

encouraging the family caregivers to provide the patients proper assistance/support and gradually withdraw from colostomy care; (4) providing continued nursing support by telephone follow-up, counseling, ostomy clinic visit, and home visit; (5) improving communication and sharing among the dyads by the activity of an ostomate club; (6) applying supportive communication technique to provide informational and emotional support to the dyads; (7) constantly enhancing the nurses' professional confidence and competency in colostomy care by group learning and interaction with the dyads. The major factors influencing successful living with a colostomy involved: (1) independence in using ostomy appliances; (2) physical and emotional status; (3) available family support; (4) continued nursing support; (5) roles of the patients in their family.

During the action research spiral of planning, acting, observing and reflecting, the family-based care model was continuously refined. The components of this model were identified, encompassing: self-care with a proper degree of independence, proper family caregiving, active empowerment, and successful living with a permanent colostomy, in which self-care with a proper degree of independence was the core component.

Furthermore, this model's uniqueness and relationships among four components could be explained in relation to the specificity of the Chinese sociocultural context where this study was conducted. Firstly, the lifelong feature of a permanent colostomy requires long-term nursing support. However, due to lack of ostomy nursing care in community of China, hospital nurses played a key role to empower the dyads to perform independent colostomy care through preparing the dyads well before discharge, and providing continued nursing support after discharge. Secondly, proper family caregiving after discharge was important for the patients to adapting to changes in family life due to having a colostomy. However, the weakening of family caregiving function resulting from the nuclearization of Chinese family structure advocated that the patients should take more responsibility in colostomy care. Thirdly, thanks to Confucian philosophy about self-care as the basis of filial piety, Chinese patients commonly believed that taking good care of themselves is for the purpose of taking better care of others, especially their parents and family members. Therefore, the patients were willing to assume their self-care responsibility with a proper degree of independence in order to live well with their colostomies and maintain the harmony of their family. The meanings of successful living with a colostomy perceived by the patients were with respect to both personal positive outcomes (independence, no suffering, and no self-inferiority) and harmonious family relationships (being able to contribute to family and get support from family). Importantly, the same desire that the patients can achieve successful living with a permanent colostomy enabled three parties (patients, family caregivers and nurses) to work together.

Ultimately, the outcome of this model was mainly related to the patients who developed the ability of independent self-care to manage their colostomies and colostomy-related impacts, and thereby achieved successful living with a permanent colostomy. Synchronously, its outcome of this model was also in relation to the family caregivers who developed their ability of colostomy caregiving, and provided proper assistance and support to facilitate the patients' successful living with their colostomies. Moreover, both improved ability of self-care and acquired awareness about life situations enabled the patients to proactively overcome restrictions in living with a colostomy and return a normal family life. During the process of this study, an equal partnership was built up among nurses, patients and family caregivers with mutual understanding and collaboration. As a result, all 14 dyads felt satisfied with the provision of overall nursing service in this model. Also, the nurses expressed satisfied with this model, and commented that it was easily-understandable, applicable and sustainable to be used. They felt confident and competent to improve quality of care and communicate with patients and their family caregivers. Obviously, the ideological changes of participants about themselves and the situations where they live ensured the sustainability of behavioral changes.

## Implications for Nursing Profession

According to the findings of this study, there were three main implications for nursing professions: (1) information provision; (2) emotional support; (3) collaboration between ET nurses and ward nurses.

Firstly, the timely, adequate and precise provision of information is vital for the colostomy patients and their family caregivers to decide whether the patients accept the fecal diversion, learn and master usage of ostomy appliances, handle ostomy-related problems, and manage impacts of colostomy on family life. It has been suggested that teaching ostomy self-care should take place as early as possible in order to support the patients' recovery and cope with early discharge in the current environment of shortening hospital stays (Thorpe, McArthur, & Richardson, 2014). Meanwhile, the patients need a gradual process to reduce dependence on nurses and increase personal independence. Nurses should recognize the diversity of patients from various cultures, believe in their potential, encourage them to perform self-care actions, and guide their family caregivers to provide proper assistance and support.

Secondly, this study found that most patients felt free to express their emotions to the researcher during telephone follow-up and home visit on the basis of the trust relationships constructed before discharge. Previous studies claimed that Chinese patients rarely express their emotions to nurses, owing to the belief from the Doctrine of the Golden Mean of Confucianism that personal emotions should be controlled to proper degree (Lin, 2009), the distinction between insiders (e.g. family members) and outsiders (e.g. nurses) (Liu et al., 2005), or the perception that the nursing service excludes the content of psychological support (Zheng, Zhang, Qin, Fang, & Wu, 2013). However, nurses should take advantage and responsibility to initiate changes for better helping these vulnerable patients with a colostomy.

Thirdly, continued ostomy care requests reciprocal collaboration between ET nurses and ward nurses. ET nurses are equipped with specialist-level knowledge and skills on ostomy care, and they stand on an ideal position to provide professional care for colostomy patients, but a shortage of ET nurses may cause difficulty in meeting clinical and practical needs. For example, there was a comparison between 152 ET nurses until November 2008 (Xu, 2009) and about 100,000 new colostomy patients each year (Wan, 2007) in mainland China. ET nurses working with ward nurses as a team can promote ET nurses' working efficiency, improve knowledge sharing, enhance ward nurses' confidence and competency in ostomy care, and provide patients with more comprehensive nursing. Although some ward nurses working in ostomy unit are accustomed to relying on ET nurses, their better roles can be to perform routine ostomy care, deal with ostomy-related problems at night shift, and refer complicated cases to ET nurses. Apart from ET nurses, the experienced ward nurse whom the colostomy patient has been familiar with before discharge can be the proper candidate to conduct telephone follow-up. In this study, the researcher acted as a surgical nurse rather than an ET nurse, but she found herself acceptable and helpful to the patients.

## Recommendations for Further Research

Even though this study has found some impacts of Chinese traditional culture on individuals' self-care actions and family caregiving actions, ethnographic studies still need to be performed to deeply explore the culture of self-care and caregiving in which Chinese patients are living with their colostomies. Also, culturally-sensitive care models should be developed in particular cultural contexts. Moreover, the effectiveness of some nursing strategies/interventions applied in this study should be examined by the approach of quasi-experimental or randomized control trial, such as telephone follow-up performed by the nursing ream leaders. Besides, testing this family-based care model by the approach of quasi-experimental or randomized control trial will obtain stronger evidence about its effectiveness. Lastly, a well-evaluated self-care scale specific to Chinese colostomy patients should be developed as an operational instrument to guide and facilitate nurses to improve the individuals' self-care actions.

## Limitations of the Study

This study was conducted in southwestern China, the family-based care model produced in which, may not be directly generalized to other parts of China or other countries. As a situation-specific theory, this model needs necessary modification to be applied into other sociocultural contexts. Moreover, this study excluded the colostomy patients who live alone without any family caregiving. Nursing strategies/interventions for this group should be amended for specific needs. Besides, most patients and their family caregivers were Han people in this study. Self-care actions among the 55 other ethnicities may be different from Han people due to various family cultures, customs, lifestyles, and beliefs in self-care and family caregiving. In addition, an ostomy support group has not been built up during this study. There were two main reasons responsible for this: (1) shortage of nursing personnel; (2) difficulty in gathering colostomy patients due to decentrality of the patients' residential locations. However, with the declining of family caregiving function owing to one-child policy, nuclearization of family structure, ageing population and more career women, it will be necessary to expand the patients' social support system and network.

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# Appendices

# Appendix A

## Instruments

# Appendix A1

## Demographic Forms

### A1-1 For patient with a permanent colostomy

Code..........................

**Instruction:** Please fill in the blank and draw “ √ ” in the space ( ) that is true for you.

1. Date of filling in this form..........................................................................................
2. Age..........................................................................................................................
3. Gender ( ) Male ( ) Female
4. Ethnic......................................................................................................................
5. Religion....................................................................................................................
6. Education level..........................................................................................................
7. Occupational status.....................................................................................................
8. Marital status.............................................................................................................
9. Living with ( ) Spouse ( ) Children ( ) Parent ( ) Others....................
10. Who is your primary family caregiver?...........................................................................
11. Health insurance.........................................................................................................
12. Family average monthly income....................................................................................
13. Ostomy-related surgery
    Date..........................................................................................................................
    Surgical procedure.......................................................................................................
14. Medical diagnosis (staging)..........................................................................................
15. Type of ostomy ( ) Temporary ( ) Permanent; ( ) End ( ) Loop;
    ( ) Colostomy ( ) Ileolostomy ( ) Urostomy
16. Location of ostomy.....................................................................................................
17. Have you encountered radiotherapy or chemotherapy? When?...................................
18. Do you have any comorbidity?.....................................................................................
19. Have you heard the enterostomal therapy nurse?.........................................................
20. Your contact address...................................................................................................
21. Your telephone number...............................................................................................
22. Other.........................................................................................................................

### A1-2 For family caregiver

Code........................

**Instruction:** Please fill in the blank and draw “ √ ” in the space ( ) that is true for you.

1. Date of filling in this form........................................................................................
2. Relationship with the patient........................................................................................
3. Age........................................................................................
4. Gender ( ) Male ( ) Female
5. Ethnic........................................................................................
6. Religion........................................................................................
7. Education level........................................................................................
8. Occupational status........................................................................................
9. Marital status........................................................................................
10. Whether to live with the patient? ( ) Yes ( ) No
11. Whether to participate in caring the patient? ( ) Yes ( ) No
12. Other........................................................................................

### A1-3 For nurses

Code........................

**Instruction:** Please fill in the blank and draw “ √ ” in the space ( ) that is true for you.

1. Date of filling in this form........................................................................................
2. Age........................................................................................
3. Gender ( ) Male ( ) Female
4. Ethnic........................................................................................
5. Religion........................................................................................
6. Education level........................................................................................
7. Marital status........................................................................................
8. Present working position........................................................................................
9. Working experiences as a registered nurse..........................................................years
10. Experience of caring ostomy patients..........................................................years
11. Other........................................................................................

# Appendix A2

# Interview (Focus Group Discussion) Guideline

## A2-1 Guideline of interview with patient

**Goal:** To understand the person's experience of living with a permanent colostomy.

**Instruction:** Ask the participant the following questions after getting informed consent.

1. How do you feel about living with a permanent colostomy?
2. How do you think about colostomy and yourself with a colostomy?
3. What does successful living with a permanent colostomy mean to you?
4. How do you evaluate your current living?
5. What kinds of things do you do to manage your life after having a colostomy?
6. What can facilitate or inhibit you to manage your life with a colostomy?
7. Who is your primary family caregiver?
8. What kinds of things do you get from the family caregiver?
9. How do you think about care from the family caregiver?
10. What do you expect from the family caregiver?
11. What kinds of nursing care do you get from the nurses of this surgical unit?
12. How do you think about the nursing care from the nurses? Good aspects? Bad aspects?
13. What do you expect from the nurses?
14. What should be improved in the nursing care?

## A2-2 Guideline of interview with family caregiver

**Goal:** To understand the family caregiver's experience of caring the person with a permanent colostomy.

**Instruction:** Ask the participant the following questions after getting informed consent.

1. How do you feel about caring the person with a permanent colostomy?
2. How do you think about colostomy and a person with a colostomy?
3. How do you think about successful living with a permanent colostomy?

4. How do you evaluate the person’s current living?
5. What kinds of things do you do to care the person?
6. What can facilitate or inhibit the person to manage own life with a colostomy?
7. How do you think about the nursing care for the person from the nurses of this surgical unit? Good aspects? Bad aspects?
8. What do you expect from the nurses?
9. What should be improved in the nursing care?

### A2-3 Guideline of focus group discussion with nurses

**Goal:** To understand the nurses’ experiences of caring the persons with a permanent colostomy.

**Instruction:** Ask the participants the following questions after getting informed consent.

1. How do you feel about caring the person with a permanent colostomy?
2. How do you think about colostomy and a person with a colostomy?
3. How do you think about successful living with a permanent colostomy?
4. What kinds of things do you do to care the person?
5. What can facilitate or inhibit the person to manage his/her own life with a colostomy?
6. How do you evaluate the current nursing care which is provided to the person with a permanent colostomy?
7. What should be improved in the nursing care in your unit?

# Appendix A3

## Reflection Guideline

**Instruction:** The researcher should use the guideline for self-reflection and enlightening the participants' reflection during the process of this study.

1. What happened when you performed the action?
2. Who was involved in the plan and the action? How?
3. How do you feel?
4. What does it mean to you?
5. What is the difference between before and after the action?
6. Have you achieved your goal?
7. What has been changed in your life?
8. What have you learned?
9. How do you know that you have learned?
10. What do you need to study more?
11. How can we do better?

# Appendix A4

## Observation Record Form

**Instruction:** The researcher should use this form to make field note during the process of participant observation.

Observation record No.................................................................................Page...........

Date...........................................................................Time......................................................

Location.................................................................................................................................

Participants............................................................................................................................

| Observed data | Reflection |
|---|---|
| | |

# Appendix A5

## Record Form of Ostomy-related Complications

**Instruction:** The researcher should fill in this form to record the incidence, treatment and outcome of ostomy-related complications as necessary by the PIO (P-problem, I-intervention, O-outcome) format. Regularly, the researcher should observe and record ostomy-related complications at hospitalization, month 1 after discharge, and month 3 post-op.

Patient code........................................Gender....................Age......................

Date of surgery..................................................................................................

| Date | Ostomy-related complications |
|---|---|
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# Appendix A6

## Evaluation Form on the Skill of Ostomy Appliances

**Instruction:** The researcher should fill in this form to evaluate the skill of the patients and their family caregivers according to their different levels of mastery in using ostomy appliance at pre-op, at discharge, 1st and 3rd month after discharge.

Patient/caregiver code.................................Gender.......Age.......Date of patient's surgery.......................................................................

Level of mastery: 1 = Cannot do 2 = Can do with assistance 3 = Can do independently

| Code | Management skills | Pre-op | At discharge | 1st month after discharge | 3rd month after discharge |
|---|---|---|---|---|---|
| 1 | Look at colostomy picture (pre-op) or real colostomy (post-op) | | | | |
| 2 | Look at one-piece and two-piece ostomy appliances | | | | |
| 3 | Release gas in pouch | | | | |
| 4 | Empty and clean pouch (if one-piece), or change pouch (if two-piece) | | | | |
| 5 | Prepare equipment for changing ostomy appliance | | | | |
| 6 | Remove ostomy appliance | | | | |
| 7 | Clean colostomy and peristomal skin | | | | |
| 8 | Identify whether colostomy is normal | | | | |
| 9 | Identify whether peristomal skin is normal | | | | |
| 10 | Measure colostomy | | | | |
| 11 | Cut ostomy appliance | | | | |
| 12 | Check whether peristomal skin is dry | | | | |
| 13 | Adhere ostomy appliance on skin (if two-piece, and connect pouch to flange) | | | | |
| 14 | Close pouch with clip | | | | |
| 15 | Dispose used ostomy appliance | | | | |
| 16 | Identify different ostomy accessories, e.g. belt, hernia belt, skin protection powder, adhesive remover etc. | | | | |

# Appendix A7

# Satisfaction Evaluation Forms

## A7-1 Patient/caregiver's satisfaction with nursing service

Code..................

**Instruction:** The form is to understand your evaluation on nursing service provided by the nurses of the surgical unit. Please draw " √ " in the box which represents the degree of your satisfaction/dissatisfaction. Please fill in all of the boxes as possible as you can. Thank you very much for your participation and collaboration.

| Code | Item | Strongly satisfaction 5 | Satisfaction 4 | Unsure 3 | Dis-satisfaction 2 | Strongly dissatisfaction 1 |
|---|---|---|---|---|---|---|
| | Nursing service: | | | | | |
| 1 | Received nursing service at pre-operation | | | | | |
| 2 | Received nursing service at post-operation | | | | | |
| 3 | Received nursing service after discharge | | | | | |
| | Education and guidance: | | | | | |
| 4 | Nurses teaching me to use ostomy appliance and accessory | | | | | |
| 5 | Nurses teaching me how to obverse colostomy and peristomal skin | | | | | |
| 6 | Nurses teaching me knowledge on ostomy-related complications | | | | | |
| 7 | Nurses teaching me how to train regular defecation habit of colostomy patients | | | | | |
| 8 | Nurses guide diet of colostomy patients | | | | | |
| 9 | Nurses guide activities of colostomy patients | | | | | |
| 10 | Nurses guide sexual life of colostomy patients | | | | | |
| | Emotional support: | | | | | |
| 11 | Nurses provide opportunity of expressing my feelings | | | | | |
| 12 | Nurses give me encouragement and consolation | | | | | |

Other evaluation and suggestion:

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## A7-2 Nurse’s satisfaction with the family-based care model

Code......................

**Instruction:** The form is to understand your evaluation on the family-based care model. Please draw “ √ ” in the box which represents the degree of your satisfaction/dissatisfaction. Fill in all of the boxes as possible as you can. Thank you very much for your participation and collaboration.

| Code | Item | Strongly satisfaction 5 | Satisfaction 4 | Unsure 3 | Dis-satisfaction 2 | Strongly dissatisfaction 1 |
|---|---|---|---|---|---|---|
| 1 | The model is easily understood. | | | | | |
| 2 | The model is applicable. | | | | | |
| 3 | The model is sustainable to use. | | | | | |
| 4 | The quality of nursing has been improved. | | | | | |
| 5 | My competence on ostomy care has been improved. | | | | | |
| 6 | I feel more confident to provide ostomy care. | | | | | |
| 7 | I feel confident to communicate with patients and family caregivers. | | | | | |

Other evaluation and suggestion:

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## Appendix A8

## Content Validity Evaluation Form for Expert

**Instructions:** The content validity evaluation form will be used by the experts assessing the quality of several instruments in this study. The relevancy of objective and content, clarity and conciseness in each item should be appraised. It will be appreciated that you draw " √ " in the box which represents your opinion, and give advice/comment for improvement. The criterion of opinion is described as follow:

**Relevancy:** 1= not relevant, 2 = somewhat relevant, 3 = quite relevant,
4 = very relevant
**Clarity:** yes = clear, no = unclear
**Conciseness:** yes = concise, no = redundant

Name of form........................................................................................................................

Signature of expert......................................................Date...............................................................

| Code of item | Relevancy | | | | Clarity | | Conciseness | | Other comments |
|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | Yes | No | Yes | No | |
| 1 | | | | | | | | | |
| 2 | | | | | | | | | |
| 3 | | | | | | | | | |
| 4 | | | | | | | | | |
| 5 | | | | | | | | | |
| 6 | | | | | | | | | |
| 7 | | | | | | | | | |
| 8 | | | | | | | | | |
| 9 | | | | | | | | | |
| 10 | | | | | | | | | |
| 11 | | | | | | | | | |
| 12 | | | | | | | | | |
| 13 | | | | | | | | | |
| 14 | | | | | | | | | |
| 15 | | | | | | | | | |
| 16 | | | | | | | | | |

## Appendix A9
## List of Experts

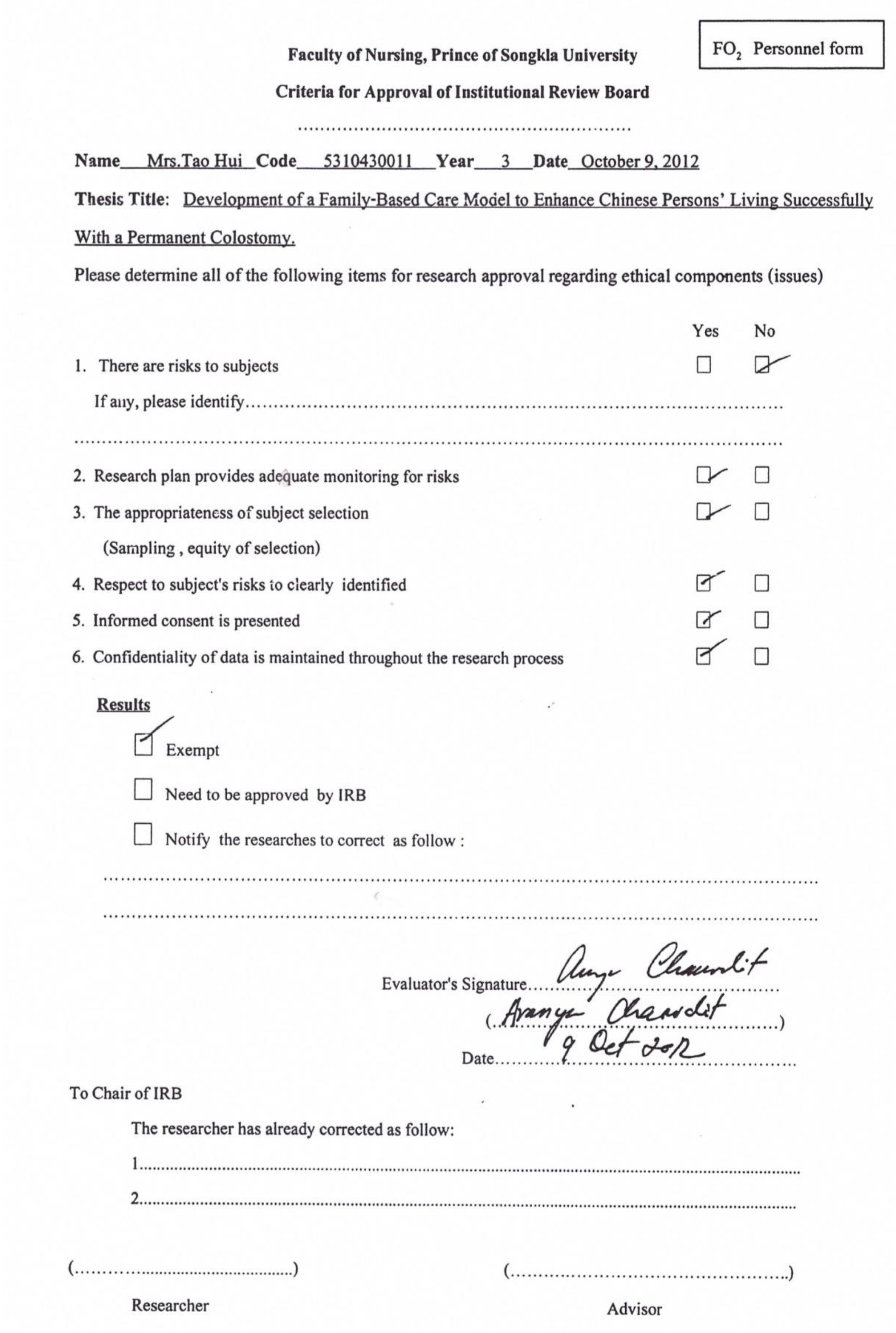
| | |
|---|---|
| 1. Junchai Saetung | Bachelor of Science in Nursing<br>Master of Public Administration<br>Enterostomal Therapist Nurse, RN<br>Supervisor of Operation Room<br>Songklanagarind Hospital<br>Prince of Songkla University, Thailand |
| 2.Umaporn Boonyasopun | Doctor of Philosophy in Nursing<br>Assistant Professor, RN<br>Faculty of Nursing<br>Prince of Songkla University, Thailand |
| 3. Qingxi Wang | Bachelor of Science in Nursing<br>Enterostomal Therapist Nurse, RN<br>Department of Colorectal Cancer<br>Third Affiliated Hospital<br>Kunming Medical University, China |
| 4. Ping Fan | Bachelor of Science in Nursing<br>Associate Professor, RN<br>School of Nursing<br>Kunming Medical University, China |
| 5. Hongtao Zhang | Master Degree of Health Science<br>Postgraduate diploma of Surgery<br>Associate Chief Surgeon<br>Department of Colorectal Cancer<br>Third Affiliated Hospital<br>Kunming Medical University, China |

# Appendix B

## Ethnical Consideration

# Appendix B1

# IRB Approval Document
of the Institutional Ethics Research Committee,
Faculty of Nursing, Prince of Songkla University



FO$_2$ Personnel form

**Faculty of Nursing, Prince of Songkla University**

**Criteria for Approval of Institutional Review Board**

……………………………………………………

**Name** Mrs.Tao Hui **Code** 5310430011 **Year** 3 **Date** October 9, 2012

**Thesis Title:** Development of a Family-Based Care Model to Enhance Chinese Persons' Living Successfully With a Permanent Colostomy.

Please determine all of the following items for research approval regarding ethical components (issues)

| | Yes | No |
|---|---|---|
| 1. There are risks to subjects | ☐ | ☑ |
| If any, please identify…………………………………………………………………………………… | | |
| 2. Research plan provides adequate monitoring for risks | ☑ | ☐ |
| 3. The appropriateness of subject selection<br>(Sampling , equity of selection) | ☑ | ☐ |
| 4. Respect to subject's risks to clearly identified | ☑ | ☐ |
| 5. Informed consent is presented | ☑ | ☐ |
| 6. Confidentiality of data is maintained throughout the research process | ☑ | ☐ |

**Results**

☑ Exempt

☐ Need to be approved by IRB

☐ Notify the researches to correct as follow :

…………………………………………………………………………………………………………

…………………………………………………………………………………………………………

Evaluator's Signature………………………………………

(Aranya Chaowalit)

Date 9 Oct 2012

To Chair of IRB

The researcher has already corrected as follow:

1………………………………………………………………………………………………

2………………………………………………………………………………………………

(…………………………………) (…………………………………)

Researcher Advisor

# Appendix B2

# Permission Letter for Collecting Data of the Medical Ethical Committee, the Third Affiliated Hospital, Kunming Medical University

## Permission Letter for Collecting Data

21 December, 2012

To the chairman
The medical ethical committee, the third affiliated hospital of Kunming Medical University, Kunming, China

Subject: Asking permission for collecting data

Dear Sir,

With due respect, I beg to state that I am Hui Tao, a lecturer of School of Nursing of Kunming Medical University. Now I am studying PhD program in nursing at Prince of Songkla University (PSU), Thailand. To fulfill the partial requirement of my doctoral degree, I will conduct a research entitled “Development of a family-based care model to enhance Chinese persons’ living successfully with a permanent colostomy”. This study has been reviewed and approved by the Institutional Review Board (IRB), Faculty of Nursing, PSU. I would like to collect data from the patients admitted in the center of excellence in large bowel cancer treatment and their family caregivers, and the nurses working in this center in order to develop a family-based care model appropriate for Chinese context. The estimated duration of data collection is about 8-10 months. So, I am applying for your kind permission to collect data in this center to complete my doctoral study.

I am looking forward to your kindness to give me permission to collect data.

Yours sincerely,

Hui Tao
(Hui Tao)
Lecturer
School of Nursing, Kunming Medical University
Kunming, Yunnan, China, and

Student of PhD in nursing
Faculty of Nursing, Prince of Songkla University
Hat Yai, Songkhla, Thailand

主任委员：

这项目符合我院伦理委员会采用快速审查方式进行伦理审查的有关要求，采用快速审查方式进行审查。

秘书：
2012.12.24.

2012.12.24.

# Appendix B3

# Informed Consent Forms

## B3-1 For Patient with a permanent colostomy

Dear participant,

I am Hui Tao, a lecturer of School of Nursing of KMU (Kunming Medical University). Now, I am also a PhD. student in Faculty of Nursing, PSU (Prince of Songkla University), Thailand. Currently I am undertaking a research project entitled "development of a family-based care model to enhance Chinese persons' successful living with a permanent colostomy". You are an important participant who has the experience of living with a permanent colostomy. The study will develop appropriate care to serve the needs of the persons and their family caregivers in order to enhance the persons' successful living with a permanent colostomy.

I would like to ask you to complete the relevant forms, participate in the interviews with the researcher, and collaborate with the nurses. The aim of the interviews is to understand (1) your experience at pro-op, post-op and post-discharge; (2) your needs and expectations about nursing care and family caregiving at pro-op, post-op and post-discharge; (3) your opinion about this developed care model. Several interviews will be performed in hospital or at home according to your priority and it will take about 30-60 minutes for each interview. I would like to get your permission to tape the interviews by audio-recorder and take photos for important occasions. All information provided will be treated in a confidential manner and no name will appear in the transcripts of the interviews. Moreover, I would like you to collaborate with the nurses and contribute your views. We will work together for decision-making and problem-solving in care activities.

If you have any question about this study, I will be glad to answer at anytime. You have the rights to make decision whether you would like to participate in this study or not. Moreover, you may withdraw at any time without penalty even though you have participated in this study.

Thank you for your collaboration

.........................................................................

(Mrs. Hui Tao)

**Agreement to participate in this study**

I am invited to participate in this study. I have understood the objective of this study and the procedures that I have to involve.

( ) I am willing to participate in this study.

( ) I am not willing to participate in this study.

Participant's signature.................................................Date.......................................................

If you have any questions regarding this study, please do not hesitate to contact me.

**Contact Address:**

Tao Hui, a PhD student, Faculty of Nursing, Prince of Songkla University. Hat Yai, Songkhla, Thailand, 90112. Mobile: 66-084-2563486. Or, a lecturer, School of Nursing, Kunming Medical University, Kunming, Yunnan, China, 650031. Mobile: 86-13888327822.

**B3-2 For family caregiver**

Dear participant,

I am Hui Tao, a lecturer of School of Nursing of KMU (Kunming Medical University). Now, I am also a PhD. student in Faculty of Nursing, PSU (Prince of Songkla University),Thailand. Currently I am undertaking a research project entitled "development of a family-based care model to enhance Chinese persons' successful living with a permanent colostomy". You are an important participant who has the experience of caring the person with a permanent colostomy. The study will develop appropriate care to serve the needs of the persons and their family caregivers in order to enhance the persons' successful living with a permanent colostomy.

I would like to ask you to complete the relevant forms, participate in the interviews with the researcher, and collaborate with the nurses. The aim of the interviews is to understand (1) your experience of caring the person with and a permanent colostomy at pro-op, post-op and post-discharge; (2) your needs and expectations about nursing care at pro-op, post-op and post-discharge; (3) your opinion about this developed care model. Several interviews will be performed in hospital or at home and it will take about 30-60 minutes for each interview. I would like to get your permission to tape the interviews by audio-recorder and take photos for important occasions. All information provided will be treated in a confidential manner and no name will appear in the transcripts of interviews. Moreover, I would like you to collaborate with the nurses and contribute your view. We will work together for decision-making and problem-solving in care activities.

If you have any question about this study, I will be glad to answer at anytime. You have the rights to make decision whether you would like to participate in this study or not. Moreover, you may withdraw at any time without penalty even though you have participated in this study.

Thank you for your collaboration

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(Mrs. Hui Tao)

**Agreement to participate in this study**

I am invited to participate in this study. I have understood the objective of this study and the procedures that I have to involve.

( ) I am willing to participate in this study.

( ) I am not willing to participate in this study.

Participant's signature..................................................Date......................................................

If you have any questions regarding this study, please do not hesitate to contact me.

**Contact Address:**

Tao Hui, a PhD student, Faculty of Nursing, Prince of Songkla University. Hat Yai, Songkhla, Thailand, 90112. Mobile: 66-084-2563486. Or, a lecturer, School of Nursing, Kunming Medical University, Kunming, Yunnan, China, 650031. Mobile: 86-13888327822.

### B3-3 For nurses

Dear participant,

I am Hui Tao, a lecturer of School of Nursing of KMU (Kunming Medical University). Now, I am also a PhD. student in Faculty of Nursing, PSU (Prince of Songkla University), Thailand. Currently I am undertaking a research project entitled “development of a family-based care model to enhance Chinese persons’ successful living with a permanent colostomy”. You are an important participant who will have the experience of caring the persons with a permanent colostomy. The study will develop appropriate care to serve the needs of the persons and their family caregivers in order to enhance the persons’ successful living with a permanent colostomy.

I would like to ask you to complete the relevant forms, participate in focus group discussion and group meetings, and collaborate with the persons with a permanent colostomy and their family caregivers. The aim of focus group discussion is to understand (1) your experience of caring the persons with an ostomy; (2) your self-evaluation about the current ostomy care; (3) your suggestions about colostomy care. Several group meetings will be conducted to (1) discuss a tentative care model proposed by the researcher before application; (2) implement, evaluate and revise the tentative care model; (3) implement and evaluate the actual care model. I would like to get your permission to tape the focus group discussion and group meetings by audio-recorder and take photos for important occasions. All information provided will be treated in a confidential manner and no name will appear in the transcripts of interviews. Moreover, I would like you to collaborate with the persons and their family caregivers. We will work together for decision-making and problem-solving in care activities.

If you have any question about this study, I will be glad to answer at anytime. You have the rights to make decision whether you would like to participate in this study or not. Moreover, you may withdraw at any time without penalty even though you have participated in this study.

Thank you for your collaboration

..............................................................

(Mrs. Hui Tao)

**Agreement to participate in this study**

I am invited to participate in this study. I have understood the objective of this study and the procedures that I have to involve.

( ) I am willing to participate in this study.
( ) I am not willing to participate in this study.

Participant’s signature.......................................Date...........................................

If you have any questions regarding this study, please do not hesitate to contact me.

**Contact Address:**

Tao Hui, a PhD student, Faculty of Nursing, Prince of Songkla University. Hat Yai, Songkhla, Thailand, 90112. Mobile: 66-084-2563486. Or, a lecturer, School of Nursing, Kunming Medical University, Kunming, Yunnan, China, 650031. Mobile: 86-13888327822.

# Appendix C

## Characteristics of Each Participant

## Appendix C1

*Demographic Characteristics of Each Experienced Patient (n = 7)*

| Code | Gender | Age (years) | Ethnic | Educational level | Occupational status | Marital Status | Type of family | Primary family caregiver | Monthly family income (Yuan) | Medical insurance* |
|---|---|---|---|---|---|---|---|---|---|---|
| PE1 | Male | 68 | Han | Primary school | Retired | Married | Nuclear family | Spouse | ≥ 5000 | UE |
| PE2 | Male | 47 | Han | High school | Unemployed | Married | Nuclear family | Spouse | 1000 – 2999 | UE |
| PE3 | Female | 39 | Han | Primary school | Peasant | Married | Extended family | Spouse | 1000 – 2999 | NR |
| PE4 | Female | 57 | Han | Illiteracy | Peasant | Married | Nuclear family | Spouse | ≥ 5000 | NR |
| PE5 | Male | 52 | Han | Primary school | Peasant | Married | Nuclear family | Spouse | < 1000 | NR |
| PE6 | Male | 53 | Han | Middle school | Retired | Married | Nuclear family | Sister | 1000 – 2999 | UE |
| PE7 | Female | 62 | Han | Illiteracy | Peasant | Married | Extended family | Daughter | < 1000 | NR |

*Note.* *NR: the new rural cooperative medical insurance; UE: the basic medical insurance for urban employees.

Appendix C2

*Medical Characteristics of Each Experienced Patient (n = 7)*

| Code | Diagnosis | Surgical procedure | Period of having a colostomy (months) | Preoperative chemo/radio-therapy | Postoperative chemo/radio-therapy | Comorbidity | Ostomy-related complications | Other health-related problems |
|---|---|---|---|---|---|---|---|---|
| PE1 | Rectal cancer | Hartmann | 2 | Yes | Yes | Prostatitis | Itching of peristomal skin | Perineal wound pain<br>Loss of appetite during chemotherapy |
| PE2 | Rectal cancer | Miles | 6.5 | Yes | Yes | None | None | Nausea and dizziness during chemotherapy |
| PE3 | Rectal cancer | Miles | 11 | No | Yes | Uterine fibroids<br>Anemia | Itching of peristomal skin<br>Ostomy bleeding | None |
| PE4 | Rectal cancer | Hartmann | 3 | Yes | Yes | None | None | Loss of appetite, and vomiting during chemotherapy |
| PE5 | Rectal cancer | Laparoscopic radical rectectomy | 5 | No | Yes | Chronic hepatitis B | Itching of peristomal skin | Vomiting during chemotherapy |
| PE6 | Rectal cancer | Miles | 3 | Yes | Yes | None | Itching of peristomal skin | Perineal wound pain |
| PE7 | Rectal cancer | Miles | 3.5 | No | Yes | Hypertension | Itching and redness of peristomal skin | Loss of appetite, nausea, and vomiting during chemotherapy |

Appendix C3

*Demographic Characteristics of Each Novice Patient (n = 14)*

| Code | Gender | Age (years) | Ethnic | Religion | Educational level | Occupational status | Marital Status | Type of family | Primary family caregiver | Monthly family income (Yuan) | Medical insurance* |
|---|---|---|---|---|---|---|---|---|---|---|---|
| PN1 | Female | 45 | Han | None | Illiteracy | Peasant | Married | Nuclear family | Spouse | < 1000 | NR |
| PN2 | Male | 50 | Hani | None | Middle school | Peasant | Married | Extended family | Son | < 1000 | NR |
| PN3 | Female | 32 | Han | None | Primary school | Peasant | Married | Nuclear family | Spouse | 1000 – 2999 | NR |
| PN4 | Female | 47 | Han | None | Primary school | Unemployed | Married | Nuclear family | Spouse | 1000 – 2999 | UN |
| PN5 | Female | 35 | Han | None | Primary school | Peasant | Married | Nuclear family | Spouse | 1000 – 2999 | NR |
| PN6 | Male | 30 | Han | None | Middle school | Peasant | Married | Nuclear family | Spouse | < 1000 | NR |
| PN7 | Male | 63 | Han | None | Primary school | Peasant | Married | Extended family | Son | < 1000 | NR |
| PN8 | Male | 58 | Han | Buddhism | Primary school | Peasant | Married | Nuclear family | Spouse | < 1000 | NR |
| PN9 | Female | 49 | Han | Buddhism | Middle school | Worker | Married | Nuclear family | Spouse | 3000 – 4999 | UE |
| PN10 | Female | 42 | Han | None | High school | Businessman | Married | Nuclear family | Spouse | ≥ 5000 | UN |
| PN11 | Male | 56 | Han | None | High school | Unemployed | Married | Extended family | Son | 1000 – 2999 | UN |
| PN12 | Male | 66 | Han | None | Middle school | Retired | Married | Nuclear family | Spouse | 3000 – 4999 | UE |
| PN13 | Male | 40 | Yi | Buddhism | Middle school | Businessman | Married | Nuclear family | Spouse | Unknown | UN |
| PN14 | Male | 51 | Miao | None | Middle school | Businessman | Married | Extended family | Brother | Unknown | NR |

*Note*. *NR: new rural cooperative medical insurance; UE: basic medical insurance for urban employees; UN: basic medical insurance for urban nonemployees.

## Appendix C4

*Medical Characteristics of Each Novice Patient (n = 14)*
8

| Code | Preoperative diagnosis | Surgical procedure | Postoperative pathological diagnosis | Preoperative chemo/radio-therapy | Postoperative chemo/radio-therapy | Comorbidity |
|---|---|---|---|---|---|---|
| PN1 | Rectal cancer | Miles | Rectal cancer pT2N0M0 | No | No | None |
| PN2 | Rectal cancer | Hartmann | Rectal cancer pT3N1bM1a | Yes | Yes | None |
| PN3 | Rectal cancer | Hartmann | Rectal cancer pT3N2bM0 | Yes | Yes | None |
| PN4 | Rectal cancer | Sigmoid colostomy | Rectal cancer pT3N1M0 | No | Yes | None |
| PN5 | Rectal cancer | Hartmann | Rectal cancer pT4aN2aM0 | No | Yes | None |
| PN6 | Rectal cancer | Miles | Rectal cancer PT4aN0M0 | No | Yes | Mild fatty liver |
| PN7 | Rectal stromal tumor | Miles | Rectal stromal tumor | No | No | None |
| PN8 | Rectal cancer | Miles | Rectal cancer pT2N0M0 | Yes | No | None |
| PN9 | Rectal cancer | Miles | Colorectal cancer pT2N0M0 | No | Yes | Hypertension |
| PN10 | Rectal cancer | Miles | Rectal cancer pT2N0M0 | No | No | None |
| PN11 | Rectal cancer | Hartmann | Rectal cancer pT4N0M0 | No | Yes | Cataract |
| PN12 | Rectal cancer | Miles | Rectal cancer pT3N1M0 | Yes | Yes | Hypertension |
| PN13 | Rectal cancer recurrence | Miles | Rectal cancer ypT3N1M0 | Yes | Yes | None |
| PN14 | Rectal cancer | Laparoscopic radical rectectomy | Rectal cancer pT1N0M0 | No | No | None |

## Appendix C5

*Demographic Characteristics of Each Family Caregivers of Experienced Patient (n = 4)*

| Code | Relationship with the patient | Gender | Age (years) | Ethnic | Marital Status | Occupational status | Educational level | Living with the patient in the same house |
|---|---|---|---|---|---|---|---|---|
| CE1 | Spouse | Female | 66 | Han | Married | Retired | Illiteracy | Yes |
| CE5 | Spouse | Female | 53 | Han | Married | Peasant | Middle school | Yes |
| CE6 | Sister | Female | 55 | Han | Married | Retired | High school | No (but live nearby) |
| CE7 | Daughter | Female | 37 | Han | Married | Peasant | Middle school | No (but live nearby) |

## Appendix C6

*Demographic Characteristics of Each Family Caregivers of Novice Patient (n = 14)*

| Code | Relationship with the patient | Gender | Age (years) | Ethnic | Marital Status | Occupational status | Educational level | Living with the patient in the same home |
|---|---|---|---|---|---|---|---|---|
| CN1 | Spouse | Male | 44 | Han | Married | Peasant | Primary school | Yes |
| CN2 | Son | Male | 27 | Hani | Married | Peasant | Middle school | Yes |
| CN3 | Spouse | Male | 39 | Han | Married | Peasant | Primary school | Yes |
| CN4 | Spouse | Male | 46 | Han | Married | Unemployed | Middle school | Yes |
| CN5 | Spouse | Male | 38 | Han | Married | Peasant | Primary school | Yes |
| CN6 | Spouse | Female | 29 | Han | Married | Peasant | Primary school | Yes |
| CN7 | Son | Male | 33 | Han | Single | Peasant | Primary school | Yes |
| CN8 | Spouse | Female | 57 | Han | Married | Peasant | Illiteracy | Yes |
| CN9 | Spouse | Male | 60 | Han | Married | Worker | Primary school | Yes |
| CN10 | Spouse | Male | 47 | Han | Married | Businessman | Middle school | Yes |
| CN11 | Son | Male | 30 | Han | Married | Soldier | University | Yes |
| CN12 | Spouse | Female | 59 | Han | Married | Retired | Middle school | Yes |
| CN13 | Spouse | Female | 41 | Yi | Married | Businessman | Middle school | Yes |
| CN14 | Brother | Male | 42 | Miao | Married | Physician | Technical secondary school | No (but live nearby) |

Appendix C7

*Demographic Characteristics of Each Nurse in the Core Working Group (n = 9)*

| Code | Gender | Age (years) | Ethnic | Religion | Educational level | Marital Status | Current work position | Professional title | Work experience as a registered nurse (years) | Work experience of engaging in ostomy care (years) |
|---|---|---|---|---|---|---|---|---|---|---|
| SX | Female | 40 | Han | None | Bachelor degree | Married | Head nurse | Middle level | 22 | 0.33 |
| WQ | Female | 44 | Han | None | Bachelor degree | Married | ET nurse | Middle level | 26 | 9 |
| CS | Female | 38 | Han | None | Bachelor degree | Married | Senior nurse | Middle level | 20 | 6 |
| SY | Female | 35 | Han | None | Bachelor degree | Married | Senior nurse | Middle level | 16 | 9 |
| TH | Female | 41 | Han | None | Bachelor degree | Married | Senior nurse | Primary level | 22 | 21 |
| XD | Female | 33 | Han | None | Bachelor degree | Married | Team leader | Primary level | 14 | 14 |
| LL | Female | 38 | Han | None | Bachelor degree | Married | Team leader | Middle level | 19 | 19 |
| LX | Female | 34 | Bai | None | Bachelor degree | Married | Team leader | Primary level | 9 | 8 |
| LS | Female | 32 | Han | None | Bachelor degree | Married | Team leader | Primary level | 12 | 10 |

# VITAE

| | |
|---|---|
| **Name** | Mrs. Hui Tao |
| **Student ID** | 5310430011 |

**Educational Attainment**

| **Degree** | **Name of Institution** | **Year of Graduation** |
|---|---|---|
| Bachelor of Science (Nursing) | West China University of Medical Science | 2000 |
| Master of Science (Public Health) | Kunming Medical University | 2008 |

**Scholarship Awards during Enrolment**

Scholarship Award for Doctor of Philosophy in Nursing (international Program) provided by Faculty of Nursing, Prince of Songkla University

**Work – Position and Address**

Lecturer, School of Nursing, Kunming Medical University, China 650500
Email: taohui216@hotmail.com

**List of Publication and Proceeding**

**Publication**

Tao, H., Songwathana, P., Isaramalai, S. A., & Zhang, Y. (2014). Personal awareness and behavioural choices on having a stoma: A qualitative metasynthesis. *Journal of Clinical Nursing, 23*(9-10), 1186-1200. doi: 10.1111/jocn.12309

**Proceeding**

Tao, H., Songwathana, P., & Isaramalai, S. A. What does having an ostomy mean?: A qualitative meta-synthesis. Poster presentation at the 2012 Kunming International Nursing Conference, Kunming, China, 18-20 October, 2012.

Tao, H., Songwathana, P., & Isaramalai, S. A. Self-care experiences of Chinese persons with a permanent colostomy. Oral presentation at the 2013 International Nursing Conference on Health, Healing, & Harmony: Nursing Values, Phuket, Thailand, 1-3 May, 2013.

Tao, H., Songwathana, P., & Isaramalai, S. A. Supportive communication for Chinese patients with a permanent colostomy: A case study approach. Oral presentation at the 17th East Asian Forum of Nursing Scholars, Manila, Philippines, 20-21 February, 2014.