COLOSTOMY PATIENTS' IDENTIFICATION OF LEARNING NEEDS
IN THE EARLY REHABILITATION PERIOD

By

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ABSTRACT

The creation of a permanent colostomy has implications for the physical and psychosocial wellbeing of the individual. Studies reviewed have suggested that effective patient teaching is a way of assisting individuals to develop coping strategies to manage the physical changes in the body and patterns of social and emotional interaction.

This descriptive study is based on the theory that the adult is able to self-diagnose learning needs and actively participate in the planning of learning to meet these needs.

Data were collected and analyzed to identify the learning needs and resource utilization of patients with a newly created permanent colostomy from their perspective. Patient interviews were conducted with eight participants ten to twenty-one days postdischarge from hospital, using a semistructured interview guide developed by the researcher.

Findings of the study suggested that participants were able to self-define the knowledge and skills that allowed them to develop positive coping behaviors to manage their newly created permanent colostomy.
Themes which emerged from the data collected were the need to get on with life, the person's need to tell "their story" to reinforce their individuality, and the need to develop mastery over the physical aspects of stoma care.
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Jeter (1979) has described the creation of an ostomy in Freudian terms: "To deprive a person of fecal . . . control is, perhaps, the most brutal rape of the ego" (p. 73). Quality of life for the person with a permanent colostomy is much more than having a stoma that is well placed and pouchable, it is successful rehabilitation that gives both physical and mental comfort. Nursing's role in the rehabilitation process is to assist the person with a colostomy to revise preexisting attitudes, to develop coping strategies, and to strengthen existing support systems so that rehabilitation is facilitated.

Those individuals with a permanent colostomy are required to make lifestyle changes and develop coping strategies that will maintain them for the remainder of their lives. Effective patient teaching is a way of assisting individuals to develop coping strategies to manage the emotional response to diagnosis, physical changes in the body, an alteration of normal elimination patterns, and patterns of social interaction (Dobkin & Broadwell, 1986).
Shipes (1987) identified societal norms for the body -- that it be young, healthy, fully-functioning, continent, and odor free. In studying the psychosocial issues of the person with a colostomy, Shipes categorized the issues as body image alteration, reactions to the diagnosis and ostomy, and losses. According to Shipes, body image relates to how we see ourselves, how we look, and how we function. The interpersonal self refers to our relationship with others, the achieving self to productivity, and the identification self to spiritual and ethical beliefs, values and behaviors.

The usual shortness of time between diagnosis, surgery to create a stoma, and its inherent problems does not allow for a gradual change in body image such as one finds in the normal aging process. Reactions to the altered body image incorporate loss of body integrity and control. Emotional reactions are similar to the grief process associated with death (Shipes, 1987).

An individual's past experience, including patterns for dealing with life's problems, will impact on how the problems of life with a colostomy will be managed. Personality characteristics such as ego strength, positive self-concept, positive coping
skills, high motivation and ability to learn new skills easily, and an internal locus of control, combined with healthy relationships and a stable economic status, will likely lead to good psychological adjustment. These characteristics are considered as positive forces in the person's life. Those individuals who exhibit the opposite characteristics, and have unhealthy relationships, an unstable economic status, and who reject counselling, have negative forces which will impact on their ability to learn new coping strategies (Shipes, 1987).

Other implications which should be considered are the physical and psychological components of growth and development. The majority of permanent colostomies are created in males over the age of 50 (Jackson & Broadwell, 1986). It is essential to identify which changes are due to aging, and which to disease. As individuals age, there already exists a fear of change from independence and productivity to dependence and curtailment of activity. This fear is increased by an unplanned event which may increase dependency, if only temporarily, on others (Motta, 1987).
A permanent colostomy is defined as the permanent formation of an artificial anus by bringing the colon through the abdominal wall to the exterior. The continuity of the bowel cannot be restored in the future.

Surgery to create this permanent stoma is performed primarily for low rectal carcinoma located within five centimetres of the anus (Ellis, 1987). The surgical procedure of choice was, until just recently, the abdominal perineal resection. This extensive procedure, first performed in 1908 by a British surgeon by the name of Miles (Coogan-Bland & Tolins, 1979), creates a permanent colostomy, removes not only the tumor, but other tissue as well to accommodate possible lateral and vertical spread of the tumor and removes the anal sphincter. The purpose of the operation is to remove the rectum, the site of the tumor, the anus, the distal colon, the perineum and perirectal tissues, and the mesentery of the sigmoid colon. This includes three areas of regional lymphatic spread. The surgery is often palliative, since the rectum is a vascular area, and cancer of
the rectum spreads by blood vessel invasion. Secondary tumors may present at distal sites (Ellis, 1987).

More recently, surgeons are attempting to preserve the sphincter without jeopardizing chances of prolongation of life (Gordon & Dalrymple, 1987). Anal preservation has been assisted by surgical techniques which facilitate lower anastomosis without compromising care.

Conservative surgeons have been concerned that restorative resection (preservation of the anal sphincter without the requirement of a permanent stoma) was promoted by the patients' rejection of the procedure and the underlying feeling of the surgeon that a colostomy is distasteful. "The surgeon holds that colostomy is such an unpleasant affliction that is is justifiable to accept some lessening of the chances of complete eradication of the tumor in order to avoid it" (Ellis, 1987, p. 1471).

Recent studies by Ellis (1987), Gordon and Dalrymple (1987), and Heald and Chir (1987), on survival rates for both anterior resection (no requirement for stoma, and preservation of the anal sphincter) and abdominal perineal resection (permanent colostomy with no sphincter preservation) are
comparable. Ellis does caution the reader that the more favorable tumors, as classified by Dukes (Appendix I), were treated by anterior resection, and this may account for the lack of difference in five-year survival rates (Ellis, 1987).

Present criteria for abdominal perineal resection include actual invasion of the anorectal ring by the tumor or the inability of the surgeon at operation to apply a clamp distal to the tumor after mobilization (Heald & Chir, 1987). A major drawback to surgical anastomosis is anastomotic leakage requiring a second surgery and creating the potential for peritonitis.

In summary, the majority of cancers requiring a permanent colostomy are found in the distal rectum or up to five centimetres above the rectum. Additional considerations include the requirement for a wide resection for removal of the cancer, causing interference with rectal sphincter control; invasive, poorly differentiated midrectal cancer in obese patients; or patients with a narrow pelvis, making tumor resection with end-to-end anastomosis difficult or undesirable (Dobkin & Broadwell, 1986).

Although the primary medical intervention for rectal tumors is surgical, both radiation therapy and chemotherapy are included as adjunctive therapies for
resectable tumors (O'Connell, Gunderson & Fleming 1988). These therapies are used to reduce the risk of local recurrent tumors and the distant spread of malignancy either due to lymphatic involvement or to malignant cell migration from handling the primary tumor during surgery. Treatment may occur either pre- or postoperatively, and entails significant physical and psychological discomfort, thus adding to the existing problems related to surgery.

Problem and Purpose of Study

Problem

The creation of a stoma for fecal diversion causes changes in body image and/or lifestyle which may necessitate changes in coping strategies, those characteristic patterns developed by individuals to meet their needs.

Nurses, if they were aware of the patients' perceived knowledge deficits, could institute teaching programs that would assist clients to develop positive coping behaviors.
Purpose

The purpose of this study was to explore the learning needs and resource utilization of patients with a newly created permanent colostomy, from their perspective.

This study used a semistructured interview conducted by the researcher two weeks after the patient's discharge. The objectives of this study were to:

1. Determine what patients found were the new knowledge and skills needed to cope with their new colostomy.

2. Identify the resources they used to provide this information.

3. Discern whether the information provided was adequate in kind and amount.

4. Discern whether the information provided was given at an appropriate time.

5. Identify areas where learning needs were not met, and the patients' perception of what would have helped.
The UBC Model for Nursing views the individual as a behavioral system made up of nine subsystems. Each subsystem is responsible for the satisfaction of one basic human need (Campbell, 1987). These nine human needs formed the framework for categorizing the learning needs identified by study participants.

The Model identifies that each subsystem has an inner personal region representing the basic human need and the ability, cognitive and executive, to meet the need. There is also a psychological environment which represents the need-related goals and forces which influence goal attainment.

Forces influencing goal attainment are of three types, personal, sociocultural, and impersonal, and may influence coping behaviors in a negative or positive way. It is important to note that a positive force in one subsystem may become a negative force in another subsystem (Campbell, 1987, p. 9).

The role of nursing as identified by the Model is to nurture individuals who are experiencing critical periods so that they may develop and use a range of coping behaviors that will permit them to satisfy
their basic human needs, to achieve stability and reach optimal health (Campbell, 1987, p. 10).

This study will focus on the teaching aspect of the nurturing role and its importance in promoting or monitoring positive coping behavior for individuals.

Definitions

1. Basic Human Need: "A fundamental requirement for survival and growth of the behavioral system" (Campbell, 1987, p. 35).

2. Critical Period: "A maturational event or an unpredictable event in the life cycle that requires the development and use of suitable coping behaviors to satisfy basic human needs, achieve stability, and reach optimal health" (Campbell, 1987, p. 35). The creation of a permanent colostomy may be considered an unpredictable event, coincident with which there may be maturational events, e.g. retirement, which require new, different, or alternative coping behaviors.

3. Suitable Coping Behaviors: Are defined as purposeful actions, thoughts, feelings, and psychological responses which reduce tension and promote satisfaction of basic needs.

4. Ineffective coping behaviors are
inappropriate, and do not relieve tension or satisfy basic human needs.

5. Nurturing (the role of nursing): Is accomplished through fostering, protecting, sustaining and teaching (Campbell, 1987).

6. Enterostomal therapist: The enterostomal therapist is a registered nurse with a post-graduate diploma in care of the stoma patient. Diploma programs are hospital or community college based.

Assumptions

1: Creation of a colostomy is an unpredictable life event which necessitates the learning of new coping behaviors in relation to physical, psychological, and social needs.

2: Knowledge is a way of assisting individuals to develop suitable coping behaviors to respond to changes resulting from the creation of the colostomy.

3: Adult learners will self-diagnose learning needs.
Limitations

Patients self-defined their learning needs and may have chosen to disregard components of stoma care that are psychologically or esthetically unacceptable to them (Jackson, 1976).

Patients who received a formal education program may have perceived all information presented as important, rather than focussing on their own unique needs and ability to cope with changes in body image and lifestyle resulting from the colostomy.

The sample population was small (8) and was recruited from two hospitals. Idiosyncrasies of care delivery in those institutions may have had an impact on the response of the participants.

The patients' perception of adequacy of information regarding stoma care given while in hospital may have been impacted by their ability to learn. Problems such as stress related to altered body image, low pain tolerance, or complications of surgery may have rendered the subjects incapable of identifying learning needs or learning suitable coping behaviors.

Subjects were interviewed eleven to twenty-one
days post discharge from the hospital. This time period may, or may not, have provided them with sufficient time to identify their learning needs in relation to their evolving self-concept and lifestyle.

Summary

This chapter introduced the framework which will be used to interpret the learning needs of colostomy patients.

In Chapter 2 the literature on existing patient education programs, specific education programs for colostomy patients, a framework for adult learning, and the relationship of the literature to a nursing model which identifies the behavioral needs of adult patients is reviewed.

Chapter 3 includes a description of the methodology used to implement the study.

Chapter 4 presents the data from study participants.

Conclusions from the data are presented in Chapter 5. Implications for nursing practice are drawn from these conclusions, as are further research questions.
Chapter Two

Review of Related Literature

The purpose of the literature review is to provide a framework within which to review the learning needs of colostomy patients. The identified areas for literature review included:

1. Existing patient education programs and perceptions of patients' learning needs.
3. Theories of adult learning.

Patient Education Programs

The objectives of health teaching relate to reinforcement of positive behaviors, changes in negative behaviors, or learning of new behaviors. The motivation for learning may be related to a change, or a perceived change, in the health status of the patient or an awareness of the impact of lifestyle. (Redman, 1984)

Redman identified that the general goal of health
teaching is "to assist individuals to develop their optimal health potential" (Redman, 1984, p. 60), and related learning objectives to behaviors:

1. Cognitive behaviors, which deal with intellectual abilities;
2. Affective behaviors, which deal with feelings, attitudes and values; and
3. Psychomotor behaviors, which deal with motor skills.

Although there is general agreement that patients should be involved in the setting of behavioral objectives based on learning needs, a review of the literature has identified that there is inconsistent application of this philosophy in patient teaching. (Areneth & Mamon, 1985; Casey & O'Connell, 1984; Clarke, 1982; Fox, 1986; Hopp & Hills, 1985; Lauer, Murphy & Powers, 1982; McHatton, 1985; and Redman, 1984).

Areneth and Mamon (1985), in a study of 56 oncology patients, documented disagreement between nurses' and patients' perceptions of discharge requirements. They concluded that nursing's contribution to discharge planning is hampered by the nurse's perspective. Patients' needs are identified as they relate to hospitalization, rather than to home
McHatton (1985) and Jackson (1976) identified that the timing of information presentation is critical. To provide information when a patient is not ready is distressing to the patient and wasteful of nursing time. McHatton described the stages of emotional adjustment to trauma based on stages proposed by Lee (1970).

The four stages described by Lee are as follows:

1. The Impact Stage, which is characterized by feelings of lack of control, despair, and mortality. At this point the individual lacks insight, therefore little or no learning can occur. A support role is appropriate for the nurse. The patient's fear is greater than the need to know.

2. The Retreat Stage, which may follow physiological stability, is where denial of the occurrence is a familiar patient response. Mourning of a loss of body image may occur. Anger towards, and rejection of, care given and family are common behaviors. Conflict may occur between the goals of nursing, which are to make the person independent, and denial of the occurrence by both the patient and the family, followed by their rejection of treatment goals. Lee reinforces the need to keep communication
open by accepting behavior, but not reinforcing it.

3. The Acknowledgment Stage, in which there is a lack of self-esteem and self-confidence, and fear of abandonment by friends, family, and society in general. It is the stage where the patient starts to perceive a need to know information. There is a need to move toward mastery, and to progress. The role of the nurse is to become aware of the individual's interests and future plans, in order to assist realistically with the attainment of these goals.

4. The Reconstruction Stage, during which the patient starts to look to the future, but is vulnerable and sensitive to failure. Lee identifies three areas where mastery needs to occur to integrate fully the reconstruction stage: "(a) reintegration of the person's altered body image, (b) reorganization of social values, (c) adjustment to technical devices or procedures" (p. 586). Lee suggests that in this stage, regressive tendencies to return to any or all of the preceding phases may occur as a result of failure to master. Information needs to be presented in a nonthreatening way, and opportunities for success must be identified and reinforced.

Fox (1986) integrated requirements for timing identified by McHatton with an andragogical approach
to patient-identified needs for learning, and stated that by finding out what the patient wants to know, the credibility of a teacher increases, as does the value placed on the information provided.

Discrepancies between patient- and nurse-identified learning needs are described in studies by Clarke (1982) of nonurgent emergency department patients, Casey and O'Connell (1984) and Karlik and Yarcheski (1987) of patients with myocardial infarctions, and Lauer et al (1982) of cancer patients. Patients in these studies identified that their greatest learning needs related to diagnosis, self-preservation, knowledge about risk factors, situational control, and relief of pain, whereas nurses identified medication and dealing with feelings as the most important areas for patient education.

In the study of emergency patients, nurses identified prevention strategies as highest, whereas patients identified concerns over recovery rate, explanation of signs and symptoms, and possible complications.

Patients in studies done by Karlik and Yarcheski (1987), Clarke (1982), and Casey and O'Connell (1984), identified physicians as the preferred source of
information to satisfy learning needs related to prognosis and prevention of disease. This has major implications for nursing, since patient education is considered an important role of the professional nurse (Megenity, 1982; Redman, 1984; Roberts, 1978). Karlik and Yarcheski (1987) identified a further research question regarding "Who, the physician or nurse, is more effective in patient teaching, and whose teaching the patient is more apt to comply with" (p. 550). An extension of that research question could identify if the effectiveness of teaching is driven by the information content as well as the professional doing the teaching.

A multidisciplinary task force from the National Veterans' Administration was assigned the task of developing an assessment format which would facilitate identification of patients' learning needs (Kisner Berg, Eckhoff-Biafi, Hebert, Rodell, and Sprafkin, 1987). Issues that were considered by the task force were prior exclusion of the patient as an active participant in determining education needs, goals and priorities, and health care staff's unawareness of the need and/or unwillingness to assess multi-causal factors which motivate patients to comply with the medical regimen.
The general guide developed by the task force consisted of two sections, a common content area, which included signs, symptoms, medications, and self-management skills, and a section based on Becker's Health Belief Model, identifying five components which impact on how people will behave in relation to their health. These are susceptibility to illness, the perceived severity of illness, perceived benefits of taking action, barriers to action, and cues to action. The implication is that assessment of the person's perceptions of their condition is necessary prior to effective planning for education (Kisner Berg et al, 1987, p. 201). The guide construct is not identical to, but does incorporate, the stages of emotional adjustment to trauma as identified by Lee and Fox.

Hopp and Hills (1985) also referred to Becker's Health Belief Model, and extended the model to include theories of "Locus of control". Those who are externals believe that they are controlled by outside forces, e.g. fate, or powerful others, whereas internals believe that they personally are in control of their own lives, and are responsible for what happens to them. The concept, used in relation to patient-identified learning needs, adds another
dimension to assessment and impacts on how information is given, and by whom.

**Studies Specifically Identifying the Learning Needs of Colostomy Patients**

Few research studies were found which dealt with the learning needs of ostomy patients. None dealt specifically with the learning needs of patients with permanent colostomies during their initial rehabilitation phase. Studies found used a questionnaire to solicit patient input, and were conducted on average 5 to 10 years post surgery. A review of these studies and articles written by physicians and nurses, based on their personal practice, is presented.

Articles, based on their personal practice, by Doering (1984) and Thielman (1983) presented a task-oriented approach to patient teaching including stoma and skin care, diet, control of constipation, diarrhea, gas and odors, and where to purchase stoma supplies.

Other authors (Bailey, 1977; Cole & Perreault, 1985; Dietz, 1980; Druss, O'Connor & Stern, 1968 & 1969; Follick, Smith & Turk, 1984; Jackson, 1976;
Jeter, 1979; Keltikangas-Jarvinen, Loven & Moller, 1984; Mitchell, 1980; Watson, 1983 & 1985) identified the importance of dealing with psychosocial concerns as well as the physical care associated with creation of the colostomy. Documentation by Druss et al, Follick et al, Jackson, Keltikangas-Jarvinen et al, Mitchell, and Watson was research-based, and that of Bailey, Cole and Perreault, Dietz, and Jeter was experience-based. These studies and articles did emphasize the importance of consultation with the patient. Druss et al, Follick et al, Jackson, and Keltikangas-Jarvinen et al, used input obtained from patient questionnaires as well as their personal practice to identify needs of the ostomy patient.

Bailey (1977) reviewed patient education information available at that time. Major content areas found were selection of appropriate appliances, dealing with skin irritation, irrigation of the colostomy, and selection of foods. Although Bailey identified the potential for psychological and social problems, and identified that nursing shared in the responsibility of assisting the patient to adjust to change, the major focus was on physiological changes.

Druss et al (1968) and Prudden (1971) indicated that for the majority of patients undergoing colostomy
surgery for cancer of the bowel, knowledge of their diagnosis and prognosis was the primary need and, in their experience, care related to the colostomy was secondary. They recommended ongoing support from the surgeon.

The study conducted by Druss et al consisted of 36 patients who had undergone abdominoperineal resection for cancer of the large intestine. Patients included in the study were three to ten years postoperative. They addressed the period of rehabilitation, and believed it may take the first year for patients to learn new coping strategies to deal with social, emotional and physical changes relating to their colostomy. Patients in the study viewed this first year as a period of adjustment and experimentation.

Cole and Perreault (1985) documented issues identified by colostomy patients six months postdischarge. These patients were seen in the outpatient department of a Veterans' Administration Medical Center. Issues unresolved at this time included social, emotional and vocational concerns. Patients reported that social and emotional concerns were so overwhelming that the postoperative learning of technical skills was difficult.

P. G. Watson (1983), in a study of 31 subjects
who underwent ostomy surgery for colorectal or bladder cancer, identified a positive response to counselling intervention in the postoperative period during hospitalization. The focus of the study was the impact of the ostomy surgery on the person's self-concept. The results of the study supported the notion that those who receive counselling were able to integrate organization of the cancer/ostomy experience into the self-concept in a positive way. Issues that were addressed were mastery over the ostomy, early in the postoperative period so that it did not become a controlling factor in everyday life, abdominal disfigurement, probable sexual dysfunction, and cancer.

P. G. Watson (1985) proposed a model whereby the needs of ostomy patients (informational needs, technical ostomy-management needs, and emotional support needs) were superimposed on fundamental psychosociological needs. Watson's paper supported the use of research to confirm the patient information needs identified by the model.

Mitchell (1980), using data from questionnaires completed by 317 ostomates (ileostomy, colostomy, and urostomy) five years postsurgery, identified that ostomates believed that there was insufficient
information given in hospital relating to living with an ostomy, and insufficient assistance provided to them once they were discharged home. The major source of assistance provided postdischarge was from the patients' general practitioners or the appliance maker's representative.

Jackson (1976) studied a group of six patients having colostomy surgery, and suggested that since the period between diagnosis and surgery is limited -- approximately one month between the individual becoming ill and having surgery -- it is an extreme test of coping resources. Jackson identified this period, between diagnosis and discharge from hospital following surgery, as a crisis situation where there is a threat to physical or family integrity, radical change to the social role and to life goals, and the utilization of customary methods of problem solving may be inadequate or inappropriate.

Research by Follick et al (1984) identified problems in psychosocial adjustment of 131 ostomates (ileostomy, colostomy and urostomy) reported through patient questionnaires, and examined their interrelationship with biological and social components. The results of this study suggest that adequacy of preparatory information, and its effect on
postsurgical adjustment, is an important component in interventions to enhance patient coping. It is suggested by Hopp and Hills (1985) that externals respond better to information given by a powerful other, e.g. a physician, whereas for internals information offered by any health care professional is evaluated in the light of its meaning for their life situation.

Jeter (1979) proposed a rehabilitation model in which the health care team acts in the role of friend, rather than as strictly professionals. The emphasis in the relationship is to establish a plan of self care. Jeter cited a high correlation between what patients are able to do for themselves and their emotional recovery, and recommended that the patients meet with a recovered ostomate as a motivator to promote autonomy and involvement of the patients in their care and their return to a normal lifestyle.

**Adult Learning**

Studies in the area of health care conducted by Anderson, (1986); Casey and O'Connell, (1984); Clarke (1982); Fox (1986); Hopp and Hills, (1985); McHatton (1985); and Waters, (1987), have identified the
requirements for patients to be involved in the identification of their learning needs. These findings are consistent with the significant change in thinking concerning adult learning which occurred in the mid-60's. Teaching theories began directing a change from a pedagogical method (teacher directed) to an andragogical method (learner directed) (Knowles, 1973).

The pedagogical model is characterized by the following assumptions (Knowles, 1984):

1. The learner is a dependent personality, and the teacher takes full responsibility for making all decisions about what and how information should be learned.

2. The previous experience of the learner is of little value as a resource for learning.

3. Readiness to learn is a function of age. Students are told what is important for them to learn.

4. Subject content drives the curriculum, and students learn progressively more complex material, based on placement of the subject, not the students' interest in the subject.

5. Motivation to learn is from external pressures which may include consequence of failure, peer pressure, or competition to succeed.
The Andragogical Model proposed by Knowles was based on the psychological definition of man: "We become adult psychologically when we arrive at a self concept of being responsible for our own lives, of being self-directed" (Knowles, 1984, p.55). Knowles was influenced by the work of Carl Rogers. Rogers (1951) began to look at principles that he applied to counselling clients, and to assign these same principles to adult education. Principles applied by Rogers to the education field are as follows:

1. The teacher facilitates the learning of the student by finding out what the student hopes to learn from the course.

2. Real learning is enhanced when the person sees relevance in the information for attaining personal goals.

3. Learning, particularly if it is significant, is often a threatening thing, and may relate to a value with which self has become identified. The effective teacher provides a situation where the threat to the learner is reduced to the minimum. When reality provides the threat, the learning of behaviors that maintain the self is enhanced (Rogers, 1951). The basic assumption is that the individual is able to handle his own life situation in constructive ways.
This includes identifying problems, having a realistic view of self, and adapting to new situations and information.

Knowles acknowledged the contributions to adult learning theory made by Rogers, and recognized the special role that safety, as identified by Maslow, plays in the process of personal growth that follows learning (Knowles, 1984).

Knowles accommodated in his concept of teaching the nurturing elements of both Rogers' and Maslow's theories, which include the teacher as facilitator, the creation of a nonthreatening environment, and the recognition that the individual has the ability to develop himself on his own terms.

The assumptions inherent in Knowles' Andragogical Model are as follows:

1. The adult learner is self-directed, and takes responsibility for self.

2. The learner's experience is valued, and becomes the source of the adult's self-identity.

3. Adults become ready to learn when they experience a need to know or do something which may be related to a developmental task or an unanticipated change in some aspect of their lives.

4. Adults are motivated to learn after they
experience or identify a need in their life situation. A connection is made between the information and its relevance to their identified need.

5. Adults are motivated by internal (self-esteem, recognition, self-actualization), rather than external forces (Knowles, 1984).

Brundage (1980) utilized similar principles of adult learning to develop a comprehensive program planning guide for the Ministry of Education in Ontario. An issue identified by Brundage, and not identified in other literature is that although adults' attendance at learning programs is voluntary, individuals may feel that external conditions over which they have no control are forcing them to attend a learning program against their wishes. In this instance, adults act like involuntary learners, and may exhibit behaviors such as lack of motivation or disruptive behavior.

This issue of lack of control has implications for teaching programs in health care. As identified earlier, patients who are external in their locus of control believe that the "illness event" is outside of their control, and may have little motivation to learn information that will allow them to assume control over the illness or to cope with changing life
circumstances resulting from the illness (Hopp & Hills, 1985).

Brundage described motivation for learning as either the drive for reducing of unmet needs or the drive for positive growth. Approaches to the adult learner may differ, depending on the motivation. Those motivated by unmet needs may require more emphasis on meeting safety needs and reduction of threat, prior to active learning.

Adult learning theory is particularly applicable to health care situations since patients are frequently faced with situations where the need to have information, and to use that information in the immediate future, is germane to their survival.

Fox (1986), in a comparison of the pedagogical and andragogical teaching styles (Appendix II), identified problems in the approach which nursing has utilized towards patient education, and suggested that the nurse's own learning experience may impact on the way in which the nurse views the individual, and the value placed by the nurse on information presented.

Ammon-Gaberson (1987) used principles of adult learning to teach nurses in an operating room setting, and reinforced that the most enduring role models likely come from childhood school experiences, and the
pedagogical model throws up barriers to learning in the adult.

Ammon-Gaberson recommended that the following principles be reinforced to minimize the effect of earlier learning experiences of the health care professional. The teacher should facilitate learning through reducing obstacles to learning by:

1. Providing an environment that doesn't threaten the learner's self-concept and self-esteem.

2. Allowing adults to think of themselves as achievers and building on experience. The adult learner should be encouraged to be responsible for planning, implementing, and evaluating the learning that is occurring.

3. Allowing for the practice of new skills, and ensuring that feedback is immediate, descriptive, and nonjudgemental.

4. Reinforcing successful learning.

Thus by providing a more positive learning experience for nurses, they may be influenced in their own teaching style.

A Theoretical Framework for Patient Needs Assessment

Literature reviewed to this point has identified
theory relating to adult learning, and has identified inconsistencies present in existing patient education programs as they relate to patients' perceptions of learning needs and nurses' perceptions of learning needs.

Nursing identifies patient/client teaching as an independent function of nursing, although several studies (Karlik & Yarcheski, 1987; Clarke, 1982; Casey & O'Connell, 1984) indicate a preference by patients to have information given by physicians.

The nurturing aspect of teaching was addressed by Ammon-Gaberson, 1987; Brundage, 1980; Knowles, 1973 and 1984; and Rogers, 1951. There is a general agreement amongst authors that the facilitative role of the teacher in health education requires knowledge of the patient's past experience, perceived threats to safety, and areas of strength and weakness in order to assist with the development of coping strategies.

Only one article was found which identified a specific nursing model as giving direction for nursing practice in the area of health education. Bromley (1980, p. 246) utilized Orem's self-care model and identified that the major goal of nursing is to assist patients in learning what they need to know in order to do self-care as dictated by the anatomical
modification (creation of a stoma).

A number of authors (Cole & Perreault, 1985; Dietz, 1980; Follick et al, 1984; Jeter, 1979; and Roberts, 1978) identified coping strategies and use of adaptive behaviors, but did not present them in the context of a nursing model.

The UBC Nursing Model (Campbell, 1987) was chosen as the framework to assess study patients. In the UBC Nursing Model the individual is identified as a behavioral system, and nursing's role is to nurture the behavioral system. This behavioral system is made up of nine subsystems, each of which is responsible for the satisfaction of a basic human need (Appendix III). The UBC model accommodates the nurturing aspects of the teaching role.

Nursing's unique function is to nurture individuals experiencing critical periods in the life cycle so they may develop and use coping behaviors which permit them to satisfy their basic human needs (Campbell, 1987, p.6). The nurturing role of nursing is enacted by fostering, protecting, sustaining, and teaching. It is the function of teaching that will receive the major attention in this study.

Interventions used by nursing to enhance the patient's coping behaviors include reducing negative
forces, maintaining and strengthening positive forces, and fostering the development of cognitive and executive abilities.

To review how the UBC Nursing Model will be utilized in relation to the study patients, outcome standards prepared by the International Association of Enterostomal Therapists (IAET) are presented and related to the basic human needs of the behavioral systems identified in the UBC Nursing Model.

The IAET standards are:

1. Clients understand the diagnosis, prognosis and planned interventions, and possess knowledge related to therapies and stoma functioning to enable them to participate fully in the plan of care.

2. The client achieves optimal physical status appropriate for the immediate postoperative period, and exhibits adaptive coping behavior.

3. The client possesses sufficient knowledge to assume self-care and for the prevention, detection and management of potential problems related to altered body function or image.

4. The client achieves optimal physical status based on acquired knowledge and practical application of learned skills, enabling a resumption of prior activities.
5. The client understands the anatomy and physiology of the digestive system, recognizes the dietary restrictions specific to the ostomy, and possesses knowledge to maintain optimal nutritional and physical status.

6. The client understands and manages medications in a knowledgeable and responsible manner.

7. The client attains an acceptable body image following ostomy surgery.

8. The client understands the relationship between the physiological and psychological aspects of sexuality, and possesses knowledge to be able to participate in sexual activities commensurate with pre-operative or desired levels (Bordon et al, 1983).

The outcome standards of the IAET provide a frame of reference for patient learning needs, and the UBC Nursing Model provides a framework of behavioral needs common to all patients. Based on the assumption that adults will identify what they need to know and will arrange that learning around life's problems (Knowles, 1973), this study examined what patients with a permanent colostomy perceived they needed to know and when, and further, how that information was obtained, if at all.
Table I shows the correlation between the UBC Nursing Model and the IAET Standards (Bordon et al, 1983).

Table I
Correlation between the UBC Nursing Model and the IAET Standards

<table>
<thead>
<tr>
<th>UBC NURSING MODEL</th>
<th>RELATED IAET STANDARD</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 Basic Human Needs</td>
<td></td>
</tr>
<tr>
<td>Achieving: The need for mastery.</td>
<td>All</td>
</tr>
<tr>
<td>Affective: The need for love, belongingness, and dependence.</td>
<td>4, 7, 8</td>
</tr>
<tr>
<td>Ego-valuative: The need for respect of self by self and others.</td>
<td>4, 7</td>
</tr>
<tr>
<td>Excretory: The need for collection and removal of accumulated wastes.</td>
<td>5</td>
</tr>
<tr>
<td>Ingestive: The need for intake of food and fluid; for nourishment.</td>
<td>5</td>
</tr>
<tr>
<td>Protective: The need for safety and security.</td>
<td>2, 3, 4, 5, 6</td>
</tr>
<tr>
<td>Reparative: The need for balance between production and utilization of energy.</td>
<td>2, 4, 5</td>
</tr>
<tr>
<td>Respiratory: The need for intake of oxygen.</td>
<td>None</td>
</tr>
<tr>
<td>Satiative: The need for stimulation of the system's senses.</td>
<td>3, 7, 8</td>
</tr>
</tbody>
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Chapter Three

Methodology

Research Design

A descriptive research design that involved one interview two weeks after discharge with a convenience sample of patients with a newly created permanent colostomy was used to obtain perceptions of their learning needs and to determine resource utilization.

Selection of Participants

Initially, information was to be gathered during a four-month period using patients discharged from one hospital. Unfortunately, due to the illness of the surgeon who did the specific procedure, an additional source of patients had to be found. A delay of several months occurred while permission to conduct research in another hospital was sought. A further complication, which reduced the number of patients available to the researcher, was the development of an improved surgical procedure in 1986-87, and its introduction to use in late 1987, which reduced the
number of permanent colostomies required for resection of malignant rectal tumors. Surgical techniques to minimize the requirement for a permanent colostomy have evolved with the introduction of surgical staples in North America by Ravitch and Steichen. The use of a circular stapler has extended the limits of low anterior resection further than was technically possible with the hand-sutured anastomosis (Gordon & Dalrymple, 1987). Not only has the stapler minimized the requirement for a permanent colostomy by allowing resection of lower rectal carcinomas, but it has also minimized the surgical skill required for surgical bowel anastomosis, allowing the surgeon to concentrate more fully on resection of the tumor (Heald & Chir, 1987). The procedure, which uses the EEA (end-to-end anastomosis) surgical stapling device, allows for an anastomosis that is as secure as a hand-sewn anastomosis, but at a much lower level in the rectal area than was technically possible with a hand-sewn anastomosis. This procedure has just recently been introduced in the Vancouver area (personal communication with the primary surgeon).

Colorectal cancer remains a leading cause of death in both Canada and the United States: 140,000 new cases were diagnosed in the United States in 1986, and
there were 60,000 deaths (Doughty, 1986). Surgical excision of the malignant tumor remains the treatment of choice, and a significant number of individuals will be left with a permanent colostomy. Of those patients undergoing a resection, the five-year survival rate is 45% (Doughty, 1986).

When the study proposal was initially developed in early 1987, the projected number of patients per year requiring permanent colostomy, based on the previous year's statistics from the initial hospital, was 50, making a study of 8 not unrealistic.

Study patients were selected from those meeting the following criteria:

1. Between the ages of 25 to 70
2. Having a newly created permanent colostomy.
3. Having no physical or mental handicap which would prevent them from carrying out stoma care.
4. Living in the Lower Mainland of British Columbia.
5. Able to speak and understand English.

Patient criteria were selected to give as much scope to the findings as possible. Epidemiological data from the 1986 National Cancer Institute Surveillance, Epidemiology and End Results Program (Jackson & Broadwell, 1986) described the person at
risk for colon cancer as between the ages of 35 and 74, with 94% occurring after the age of 50. Since an interview format was being used to collect data, it was necessary for the participants to understand and speak English. Although no greater weight was given to learning needs related to performance of physical tasks associated with stoma care, the study participants' ability to do these tasks was felt to be important. The majority of literature on teaching programs for ostomy patients highlights tasks associated with care of the stoma, and the researcher felt it would be important to validate the need.

Permission to conduct the study was obtained from the University of British Columbia Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects (UBC Ethics Committee). Permission to conduct the research at Shaughnessy Hospital (now University Hospital, Shaughnessy Site) and at Vancouver General Hospital was obtained from the hospitals' research committees. Approval to conduct the study included initial contact with patients in hospital and approval to review the patients' records to obtain demographic data.

Surgeons in one hospital whose patient populations met criteria for inclusion in the study were given an
information letter (Appendix IV) about the study. The letter was followed up personally by the researcher, and all surgeons gave verbal consent for their patients to be approached to be involved in the study.

At the second hospital the Vice-president of Medicine gave consent on behalf of the surgeons. Permission was documented in a letter to the researcher.

Procedure

The enterostomal therapists (three) at both hospitals were introduced to the study through review of the research proposal and were included in the approval process. All three reviewed the interview format (Appendix VI) and confirmed potential areas of learning needs based on their personal experience with patients having permanent colostomies. The experience of the enterostomal therapists included both inpatients and outpatients. The head nurses of hospital units having the majority of stoma patients were also introduced to the study. In the first hospital chosen, nursing staff were invited to an education session to review the purpose of the study, and to introduce them to a nursing study, as this was
the first study done on a surgical nursing unit. This was not done in the second hospital, as the Director of Nursing Research reported that nursing staff were familiar with nursing research protocols.

Subjects were approached in hospital primarily by the enterostomal therapist, but on occasion by the head nurse, and were given a "Letter of Information" (Appendix IV). Those patients (n = 8) who agreed to meet with the researcher were visited while in hospital, had their questions regarding the study answered, and signed a consent form agreeing to participate in the study.

The researcher recognized that creation of a stoma has a major impact on a person's self-image, making the patient particularly vulnerable. Therefore, the researcher tried to visit patients the day prior to discharge, to minimize the association between care given in the hospital and involvement in the study. In two instances patients were discharged early, and the first contact was made by telephone, and a verbal consent to participate in the study was given. Each patient (n = 8) was contacted by telephone approximately ten days postdischarge, and the time and date for an interview agreed upon. Interviews were conducted in the patient's homes, and lasted from
one-to-one-and-a-half hours. Prior to beginning each interview, the purpose of the study was reviewed, and any outstanding questions were answered.

**Sample**

The study sample was a convenience one (n = 8), from two hospitals in the Greater Vancouver area. The investigator is aware of only two possible candidates who did not wish to be part of the study sample. All those who agreed to be part of the study indicated that their motivation was to assist others having this type of surgery.

**Data Collection**

The interview guide (Appendix VI) was used to provide direction for data collection. Broad, open-ended questions were used at the beginning of the interview. The questions were designed to be nonthreatening, and to allow study participants to talk about their experience prior to surgery, during hospitalization, and at home. Study participants were encouraged to describe their learning needs based on prior experience, their unique lifestyle, and their
perceived strengths.

Prior to each home interview, patient demographic data were collected from the patient record in the hospital. This was done to minimize the length of the interview. Discussion with the enterostomal therapists had suggested that individuals who undergo permanent colostomies complain of significant fatigue for weeks after discharge from hospital.

The interview guide (Appendix VI) outlined areas of potentially needed information required by colostomy patients. These areas of need were selected based on a compilation of Patient Outcome Standards developed by the International Association of Enterostomal Therapists and review of literature on stoma patient education programs. The content of the interview guide was reviewed and validated by the enterostomal therapists from the two major teaching hospitals.

Interviews with study participants were tape recorded and transcribed. Data were reviewed, and themes relating to information needs emerged. Initially, some study patients were concerned about having the interview recorded. They were reassured that, if they wished, portions of the tape could be erased, or certain pieces on information not used. Study participants were assured that all information
would be treated in confidence and names would not be used in any reports of the study, data would be coded, and all tapes erased at the end of the data collection period.

During interviews where questions relating to health care arose, the researcher identified the appropriate resources and recommended that participants follow up with their concerns.

Where the researcher felt qualified to answer questions or provide supporting information, she did. She reinforced, however, that her purpose was to gather information from the study participant.

Data Analysis

Transcribed data from the taped interviews were analysed to identify frequency of patient-identified learning needs, resource utilization, patients' perception of adequacy of information, appropriate timing of information, and information deficits.

Assessment of patients' perceived learning needs and the interpretation of data collected have been directed by use of the UBC Nursing Model (Campbell, 1987). Patients' perceived learning needs were examined in relation to the needs of the behavioral subsystems.
No attempt was made to evaluate coping behaviors that already existed or that were developed as a result of information given during the hospitalization. For each study patient, emerging themes were examined in relation to impact on any, or all, of the nine subsystems. This was followed by a search for commonalities across the study group. During the interview process, the researcher attempted to validate perceived themes as they were identified by the study participant, and confirm the relevance to the individual being interviewed.

Findings are presented in the following chapter.
Chapter Four

Findings of the study

The first section describes the study sample, and is followed by study findings. Major themes of study patients are described in relation to the objectives of the study, and categorized according to basic human needs (Campbell, 1987). Major themes identified through the interviews were: coping with a diagnosis of cancer; coping with pain; the impact of fatigue and lack of activity on sleep patterns; the need to have a positive interaction with recovered persons with a stoma; and the need for a supportive and loving significant other.

The sample (n = 8) was composed of three females, age 37 - 60 years, and five males, age 51 - 70 years. The range of ages was 37 - 70, the average age was 55. This age related data is consistent with the 1986 epidemiological data from the National Cancer Institute, which described the person at risk for colon cancer as between the ages of 35 and 74. All sample patients had abdominal perineal resections as a result of cancer of the lower bowel and rectum.

Seven surgeries were done on an elective basis,
one on an emergency basis. Five of the eight had adjunctive therapy: One had chemotherapy, three had radiation therapy, one had both. Four had postoperative complications: One had an abscess in her perineal wound postdischarge, and was being treated for it at home; one had a bowel obstruction postdischarge and returned to hospital; two had complications while in hospital, one related to alcohol withdrawal and aspiration pneumonia, and the other to a dehiscence of his abdominal wound.

Of the eight, five had a positive prognosis: according to their account the tumor was removed, and they were looking forward to recovery. Of the remaining three, one patient was terminal, and the remaining two were uncertain of their prognosis.

Five of the participants worked prior to surgery. Four planned to return to work, and the fifth was nearing retirement age and believed that she would not be returning to work.

Five of the participants lived with a spouse, one was separated and lived with a teenaged son, one was widowed and lived with her daughter and grandchildren, and one was single and lived alone.

The open-ended questions used at the beginning of the interviews gave participants the opportunity to
describe what it was like for them to have a colostomy. All participants (n = 8) used this as an opportunity to "tell their story". The following descriptions are samples of the stories related by four participants. The other four participants also had stories to tell. One participant described the experience of being told by the oncologist that she was going to die. She described her anger with him, his perceived insensitivity and lack of support, and her feelings of despair:

He spent most of his time telling me how he wasn't looking forward to this visit and how personally difficult it was for him to tell me the diagnosis. He didn't see me as an individual, but as just another statistic. He added up all the points against me and decided I was going to die.

It was only after she described her reaction to the physician and how she dealt with the information that she went on to describe what changes had occurred in her life as a result of the colostomy.

Another participant described his visit to the emergency department the day after discharge from hospital, for a problem unrelated to the colostomy. He described feelings of anger, lack of control, a perceived lack of credibility with the emergency physician when dealing with the problem. He summed up the experience in the following way: "Well, I guess I'm going to have to be in absolute, writhing agony to
Descriptions of a spouse's medical problems were the focus of two participants. They related their responsibilities for their spouses' health, and their role as provider of emotional and physical support.

One participant, whose wife had a colostomy twenty years ago, spent considerable time describing her treatment, her reaction to the colostomy, and her present state of mind in relation to his surgery.

She was in shock when the diagnosis came through on my biopsy. As a matter of fact, she was pretty well in shock when I came out of the hospital, still in trauma about the situation.

It appeared that all participants were setting the stage prior to describing the impact that their colostomies had on their lives.

Identification of New Knowledge and Skills Needed to Cope with the Colostomy

Care of the Colostomy

All participants acknowledged the need to be provided with information relating to physical care of their stoma while they were in the hospital. Information given to the participants, and identified...
as useful to them, included information about choosing an appropriate ostomy appliance, cleansing of the stoma, care of the skin around the stoma, changing the appliance, cleansing the appliance between changes, and use of deodorants for the appliance.

Although participants acknowledged that they were given information about care of the colostomy, not all were prepared to cope with stoma care once they were home from the hospital.

One participant said:

The reason I couldn't handle it, I figured I had too much on my hands to start with, without worrying about the bag, the colostomy. I was a little bit depressed when I came home . . . I thought I'd just had enough.

Negative forces such as pain, depression, lack of energy, appeared to be stronger than the need for mastery over the care of the stoma. This participant described his wife as supportive. She assisted with stoma and incision care. The spousal support was a positive force for his need for dependence, but a negative force in terms of motivating the participant to involve himself in the care of his stoma.

One participant, who initially was able to manage stoma care on discharge from hospital, developed an abscess in her perineal wound. She described this as
a "setback". She relied increasingly on analgesics to control her pain. The analgesics caused her to feel weak, and less in control. She described that feeling as "woozy". A home care nurse monitored the infection daily, and took over the care of her colostomy. She described this period the following way:

I had a setback. I just felt I couldn't do it. For a while, I wasn't confident. I was afraid, I guess due to my health, really, because I was shaking from being sick. I think that was it.

Negative forces such as pain, reaction to pain medication, malaise from the illness and effect of the medication, decreased this person's ability to cope with stoma care, even though she initially had the knowledge and skills necessary to carry out the care.

Those participants (n = 4) who were confident about colostomy care described the following:

The stoma part hasn't created a difficulty.
The colostomy was secondary, it was the least of my problems.

I'm a private person. I don't want anyone else. It would be like asking, on a normal day, asking someone to come in and wipe your behind. You just don't do that, as far as I'm concerned.

The colostomy is secondary to the other problem. I'm feeling comfortable with doing it on my own.

Two of the participants had other significant health care problems: One was a diabetic, and one had
urinary problems. The significance to them of the other problems minimized concerns they may have had over stoma care. The other health problems appeared to give these participants a different perspective. They were more matter-of-fact about stoma care, and how they went about incorporating it into their lives. The other health care problems were positive forces in relation to self-care of the stoma, but negative forces in that they created increased demands of energy for healing.

Diet and Control of Bowel Movements

Information needs related to diet and bowel movements were considered together by participants.

Six participants described limited modifications to diet as a result of the colostomy. One said: "The things I'm not supposed to eat, I don't like to begin with."

Another patient, who had shared his wife's diet for twenty years (she also has a colostomy) said:

My one love in vegetables was creamed corn, and I can't have creamed corn. I've been eating about everything, staying away from fatty foods, and you can't eat too much fruit. I don't worry about diet. If I notice the stool is hard, I'll drink some prune juice.
Information provided to several participants proved to be problematic for them. One said:

I was told "eat anything you want". So of course I ate. I ate everything -- sausage, potatoes, and all those things. Mom was with us at the time, and she cooked a real good meal. The next day I ate licorice and a chocolate bar with nuts, plus regular eating. That night I got cramps, and had to go back in [to hospital].

One participant, who admitted to a drinking problem, and who worked an evening shift, described the following:

I had to change my living habits and my eating habits. I used to eat before I went to work and when I got home. A . . . . [his wife] is trying to talk me into taking a lunch with me.

About his alcohol intake, he said:

If I did drink, she [the enterostomal therapist] told me how sloppy my stool will be. And if you're going to come home at two o'clock in the morning and try to clean out your colostomy, if you're drunk you're going to make a terrible mess.

One of the reasons I have no qualms saying that the drinking is over with is that I never want to go through what I went through again [this participant had delirium tremens while in hospital]. It was more than enough, thank you.

The alcohol abuse and eating pattern described acted as a negative force by limiting his energy available for activity, and producing loose, unpredictably timed bowel movements.

This participant acknowledged that the weakness and fatigue he was feeling would likely still be a
consideration when he returned to work. He recognized that he would need to change his eating patterns to provide for increased energy demands while he was at work.

He was aware that a high alcohol intake, combined with low food intake, would make the bowel movement loose and would complicate control over bowel movements, and that emptying or changing the bag while intoxicated could result in spills.

Another participant, who described himself as "a big beer drinker", described his diet in the following way:

Everything that's bad for you, I like -- fish and chips, french fries, beer. You're not supposed to eat bacon, you'll get cancer . . . you listen to everyone about these things, you wouldn't be eating enough to keep yourself alive.

This participant's food preferences were likely to influence his capacity to control the type and timing of his bowel movements. He did modify his beer drinking, although he hadn't been told to do so. No one had discussed alcohol with him. When questioned whether he had asked specifically about alcohol, he stated: "No, I'm stubborn. I'm gonna go for quite a while, I'll go for 100 days anyway, on the wagon."

One participant made a major decision about change to diet, and was investigating a macrobiotic diet,
which she described as relying primarily on grains, beans, and rice. She was aware that such a diet could be deficient in protein. She had done a significant amount of investigation, including reading and attending macrobiotic cooking classes. She was, at the time of the interview, undergoing chemotherapy, so she had decided to continue to use poultry and fish in her diet, because of her concerns about protein intake for tissue repair. She did indicate that, once the chemotherapy was finished, she would eat a totally macrobiotic diet. This participant identified learning needs in areas considered to be nontraditional by health care workers, or which were not introduced by other participants. These information needs were related primarily to her diagnosis of cancer and her terminal prognosis.

Discussions of information needs relating to bowel movements were frequently related to the production of gas. Issues that were addressed related to noise, and what to do if there was unexpected noise or smell while they were with others (family or friends). Three participants described their concerns in the following way:

The colostomy, I know it's there. I think a lot about that, because you can't help but know it. I'm always feeling it to make sure there's not too much gas in it.
I'm wondering, if I go, let's say, to a funeral, everything is quiet, and my colostomy acts up, with wind and gas, people won't know I've got a bag, it's liable to be embarrassing. I don't know what to do about that.

I think I smell . . . I warned someone that I was smelling, and asked if he wanted me to go outside, and he said he didn't smell a thing. Chances are I smell it, and nobody else.

These comments indicate the participants' perception that they are somehow less attractive, less socially acceptable, if they have gas from their colostomy. The production of gas is a negative force on their need for respect, acceptance, and inclusion by others.

One participant described his coping strategy, in relation to gas, this way:

Well, it's something you've got to get used to, you have no control if you pass gas. The noise is there! You can only say 'pardon me', so it's embarrassing, but it's just something you have to get along with, and I just hope they understand.

Frequency of bowel movements was a concern for a number of participants. Comparisons were made between the frequency of bowel movements before and after the colostomy. One participant recited the dates and times of his bowel movements. Another participant described feelings of anxiety when she hadn't had a bowel movement for three days after discharge from hospital. She called the stoma therapist, her surgeon
and her general practitioner about her concerns. She feared bowel obstruction, since that was what brought her to hospital initially. Her concerns motivated her to return to the stoma clinic to obtain more information about diet and activity as they related to the frequency of bowel movements.

One of the participants who was coping with changes in elimination patterns stated:

I'm very irregular now, and I used to be quite regular before I had my stoma, but it's a matter of using the right laxative, and time to get yourself acquainted to it.

Bowel movements were an indication to some (n = 5) that the surgery was a success and their stoma was functioning properly. Constipation, as identified by the participants, posed a threat, and was a negative force for their feeling of security.

**Activity in and Outside the Home**

Six participants actively sought information about expectations of activity after discharge from hospital. Activity was identified in relation to their presurgery state. All participants identified differences between their expected energy level and what they actually felt. Pain was a major limiting
factor for all participants. Identified pain was primarily in relation to the perineal incision. Fatigue associated with previously unstressful social interaction was also identified as a factor which limited activity.

Visits by friends and relatives were tiring. Sitting, because of the perineal incision, was uncomfortable. One man summarized his concerns:

When I came out of hospital, I had lots of company, some stayed too long, and it's hard on a person . . . it got out of hand a little bit. Anyway, I just got up and went and lay down in the bedroom . . . pass on that it's okay to have company, but keep it short, 'cause you can't hold a person's interest that long, just 'Nice to see ya', talk for a while, then 'See ya later when you're feeling better', then leave. That's my rule for company.

Travel was identified as important to five participants. Information about when they could travel, and restrictions because of adjunctive therapy (radiation and chemotherapy) were important to study participants, three of whom described their expectations for travel as follows:

I told my doctor I wanted to get away as soon as possible for holidays, he figured in eight to ten weeks I should be able to travel. I'll see him on Wednesday, and that will be high on my 'Questions & Answers'.

The long and the short of it is, I have to come back for treatment, radiation, however I'm going away for Christmas.
We [participant and wife] intend to give up apartment managing fairly soon, then we'll probably do a lot of travelling ... to the East Coast. We know the East Coast fairly well, and Prince Edward Island is one of our favorite spots.

Pain

Participants were not prepared for the amount of pain they had after discharge from hospital. Not all participants described the sensation as pain: Discomfort, aches, soreness were words used to describe what they were feeling. All described an impact on energy level, the ability to get back to normal and resume activities of daily living.

Three participants described their pain in the following ways:

I've been in the house, and I've just started getting out. I'm still sore, and I can't sit properly, and . . . you know, it's aches and pains . . . I was sore all over.

I still have a fair amount of pain and discomfort with this.

It's painful at times to walk. This is about the longest I've sat still.

One participant, when discussing the use of pain medication and lack of activity, said: "It's due to not handling the pain."

Another participant's recommendation was to:
"Prepare the patients for more pain. I had no idea it was going to be as painful as it was."

Activities which were limited because of the pain described included helping with household chores, such as vacuuming and shopping; child care and home care; getting back to work, if only part time; and socializing with friends.

Pain acted as a negative force on the participants' ability to carry out former roles. This limitation on former roles acted as a negative force on their self-respect, and their need for inclusion and intimacy.

Closely associated with pain and limited activity were changes to former sleep patterns. All participants described changes in sleep and rest requirements since being home. Sleep and rest patterns took the form of naps during the day to cope with the fatigue, but resulted in inability to fall asleep at night or, alternatively, waking up at night and not being able to get to sleep again.

Coping strategies described by participants when they were unable to sleep included:

1: having a sitz bath or changing the colostomy bag
2: taking sleeping pills
3: taking pain medication
4: listening to the radio
5: reducing time spent napping during the day
6: increasing activity during the day, such as going for a walk.

Concerns over sleep were not always linked with the colostomy, but were associated with patterns established while hospitalized.

One participant described the hospital/home sleep pattern as follows:

I couldn't sleep, of all the times it was least enjoyable. I walked around, and walked around, and I became a fixture on the [ward] floor.

**Family and Social Relationships**

Participants indicated a need to talk to others who had a colostomy. Four participants actively sought out friends and family who had a colostomy, or members of the Ostomy Association. Information needs were described in the following ways:

I happen to have a good friend who talked with me before I went into the hospital. He's 69 now, and has had a colostomy for four years. He golfs, he fishes, he hunts . . . he does everything, and I thought that if at his age he can do it, at my age I can do it too. I felt really good about that part of it.
Concerns about leisure time activity were of particular importance to this person. He had retired recently, and had an image of what life was going to be like:

I was really looking forward to getting out and going fishing. Then I found out that I had the tumor, and it kind of knocked the legs out from under me for awhile. Now I'm going to have to change my lifestyle from what it was before. My life, I just kind of liked it, there was nothing to worry about.

The value of information gained from talking to others who had a colostomy was described by three participants:

I have a friend who's had a bag for twenty years, and he leads a normal life. This helped, it really did.

I met with KR from the Ostomy Association. She gave me a bunch of literature . . . and a lot of information about what they were going to be doing with me. Thanks to her, I went to the enterostomal therapist at [hospital] before the surgery.

This participant was particularly concerned about where the stoma was to be located. He had concerns about his appearance and what he could wear to work.

One participant, where there was a family history of colon cancer, described memories of her grandfather's situation:

I remember my grandfather, and he had a colostomy bag . . . when he had his operation, then he moved to the garage, made himself a bedroom in the garage, because Grandma couldn't stand the smell.
It was then that this woman decided to talk to an uncle who also had a colostomy:

I talked to my uncle, we'd come a long way since Grandfather's day. He said he and his wife had no problems at all.

Her uncle explained his stoma care. After that discussion, she decided her care could be even more streamlined, and began to actively seek information about her stoma from the enterostomal therapist.

Although study participants were not able to identify explicitly why they believed talking to or meeting with someone who had a colostomy was important, it was a theme which ran through all interviews. There was a sense that this person was living proof that there was life after a colostomy. Three participants knew people who had a colostomy, and who shared information about living with a colostomy, as well as providing emotional and social support. One participant, whose wife had a colostomy twenty years earlier, described how he and his wife had counselled and supported a business associate when he required a colostomy. From descriptions given by participants, people they knew with colostomies were willing to share life experiences in an attempt to decrease the participants' anxiety.
Sexual Relationships

Two of the participants actively sought information about sexual activity, as well as having discussions with the stoma therapist. Both were referred to other stoma patients of the same age and sex. One participant described her feelings this way:

Right now, the shape I'm in, it's going to be an awful long time before I even think of doing anything. But you like to know that down the road, right now I don't have the desire, but down the road I might. It's nice to know whether to tell yourself to forget it, it's impossible, or whether you can, 'cause that's how relationships usually end up.

One other participant described sexual relations as being important to her. She linked her sexuality closely with her self-image, and described her need to feel loved and close to her husband:

My husband thinks I'm beautiful, and I feel beautiful. The stoma hasn't changed that.

Female participants were more comfortable discussing sexual information needs than the male participants. No male participant volunteered information, and when asked if information on sexual relations was either discussed initially or was sought, responses were vague, i.e. "Yes, the doctor brought the subject up". (This participant then
stated that he was comfortable with his relationship with his wife.)

Another participant responded:

No, no discussion. I was warned about that when I had the prostate. The doctor pointed out the limitations, which I accepted. I never considered myself sexual, I had friendships. No, we take this like everything else -- be grateful for the good times, but don't make a big thing of it.

Information Related to Diagnosis or Prognosis

All study participants identified the need to have information about the surgery, the reason for it, an explanation of adjunctive therapy and what to expect as a result of that therapy, and their prognosis. Information about prognosis was particularly important to participants.

One participant described how he believes the need may be met:

I think the booklet that they provide in the hospital for colostomy patients is an excellent one, and I think anybody with normal intelligence can read that, and there's diagrams in there where the stoma is placed on the body, and the reason for it, and those that can be hooked up again. I think that's a benefit that should be looked at, and also the different treatments, people that may have to have chemotherapy or radiation treatment, I think they should be fully advised, nothing held back, fully advised about what may happen to them.

Another participant summed up her information needs in this area as follows:
My questions to him [her doctor] were "How long for recovery, before I'm back to work?", and then I talked to him about the cancer treatments too, because that kind of thing worried me, the radiation and chemotherapy, because I had not heard anything good about that, and even the radiation therapy I wasn't sure about. So basically, just those things -- how is it going to affect me, and how much time before I'm back to being where I was before, as far as getting around and getting back to work?

A number of participants wanted details of the surgery, wanted to know why the stoma was placed where it was.

One person described it this way:

I've made a point of asking Dr. ___ just what did they do down there, how they got the stoma up where they do, how they get it, this kind of thing.

An attempt was made to understand what the diagnosis meant in terms of how the body functioned -- how it was taken apart and how it was put back together. The tumor, a negative force, posed a threat to survival. Participants sought information on diagnosis and prognosis to satisfy their needs for safety and security.

When news of a positive prognosis was given to participants (n = 5), typical reactions were: "When I woke up [from surgery], I had already made up my mind that I could live with that without any problems"; "The main concern was the cancer. That [the positive prognosis] more than relaxed my mind"; and "I was more
concerned about getting the cancer, and the colostomy came second". One participant stated:

When you're faced with something that's normally a terminal situation, and you wake up to find the pathology report was Grade A, that they'd recovered everything, though you're faced with a certain amount of dismemberment, it's a very small price to pay for being alive.

One woman recalled sharing the news with her son:

He said "Oh, is that all, but you'll be rid of the cancer." I said yes, and he said "Well, Mom, that's okay". That was the best answer I got from anybody . . . I said well, it's okay.

Identification of Resources Used by Participants

The participants saw major sources of information as coming from the enterostomal therapist, the surgeon, and others who had a colostomy. Although home care nurses were involved with the care of all participants, they were not perceived as being a significant information source. Participants indicated that the role of the home care nurse was supportive, reinforcing information and learning that had occurred during hospitalization.

The enterostomal therapist was considered to be the technical expert regarding care of the stoma, including the type of appliance, hygiene associated with care of the stoma, ensuring security of the
appliance, and care of the skin under it. Typical comments made about the enterostomal therapists included: "I trust ___ implicitly"; "Where would we be without ___?"; and "I couldn't ask for anything better, for help and trying to give me confidence".

Most of the information about diet also came from the enterostomal therapists. Only two participants had been referred to a dietitian.

Female participants discussed sexual concerns with the enterostomal therapists. When asked if the physician had also provided information in this area, the reply was:

No, I didn't feel I'd get a straight answer from him, I didn't feel he'd be comfortable talking about it . . . I thought he'd probably tell me to "Ask ___", so I didn't even bring it up with him.

The participant whose wife had a colostomy felt that he was a resource to the nurses. His contact with the stoma therapist was limited to two occasions when she assisted with his appliance. He was critical of the home care nurses, and felt that although they had general knowledge, it was not adequate. He said:

You wonder where they got their knowledge from, a lot of it is in conflict. But they're very helpful, for the most part.

The role of the home care nurse was not so much information giving, but to provide support, either physical (assistance with appliance change and
dressings) or to reinforce previous learning.

They watch me. I wait until they come . . . hoping they'll change the whole thing . . . but then they say no, it's not necessary. Most of the time I do it on my own and she's guiding me, telling me what to do.

Two participants indicated that the nurses caring for them in hospital gave information, one in the form of a pamphlet on care. In another instance, the unit nurse introduced the person to another stoma patient who also had a young family and shared similar concerns.

One subject commented on the general knowledge of the nurses on the unit:

Not too many people know about it, like when __ was cleaning me up, the first time she was about to clean it up and put the two pieces on, there was two or three nurses, we had the curtains drawn, but "Oh, can I watch? I've never seen this done before." And my doctor, Dr. __, doesn't seem to know a heck of a lot about it.

When asked how he felt about having an audience, he replied:

I didn't feel bad at all -- come one, come all -- I don't care. If you want to watch, watch. If it's helping you, it's helping me.

The role of the surgeon or surgical resident, from the respondents' perspective, was to provide information on the surgical procedure, to discuss the requirement for surgery, results of diagnostic tests and, for those who hadn't had their prognosis
confirmed while in hospital, to discuss this. Two participants, who asked their surgeons questions about stoma care were referred back to the enterostomal therapist by the physician.

Five of the participants sought, or were given, information from others who had a colostomy. Participants were not able to state what specific learning needs were satisfied, but used general descriptive phrases such as: "It helped, knowing someone survived for twenty years", and "I got a lot of information on what they were going to do with me".

One person, who had two friends with colostomies, said: "They offered me any help, any advice, [answered] any questions, they were very good that way, so I can't say that I didn't know about it."

This participant found that the sharing of information was important, although at the time of the interview, he remembered little of the content.

Knowledge that others with a colostomy survived, were accepted by spouses and family, socialized, returned to work, and were active in sports, provided reassurance for these five participants that they too would survive and resume their former roles.
Adequacy and Timing of Information

Evaluation of the adequacy of information given to the participants was subjective, and based on their perceptions of whether it met their needs or not. Three participants identified that they had inadequate information about the surgery.

These three participants did have difficulty coping with their colostomy when they were discharged home, but none of the three attributed it to the lack of information given about their surgery.

As an example, one participant said:

He [the surgeon] talked to me, and kind of brushed it off as 'just an operation' . . . I still don't understand how they did my operation . . . I can't comprehend how one can start above and the other below, and when they meet the operation's over. I kind of laughed about it at the time, but I really don't understand what they did down there.

When asked whether the surgeon had told him what to expect of the surgery, this man answered: "Well, no, the ET's helped me, they came in and gave me a booklet, they were really very helpful".

One woman explained that she knew she would have an opening in her abdomen: "I knew I was going to have that, of course, but I was still surprised. I was very surprised at the abdominal surgery that I have."
She was not aware that she would have a perineal incision: "No, these things are really more than a surprise, I guess". She then went on to describe her feelings about the lack of information regarding her surgery: "At that time I wasn't angry, I got angry later. But I'm just very sad". When discussing her sadness, she said: "Why me? I think that's what it is". And when talking about her anger: "Because you're so helpless, you're sick and you can't help yourself, you have to rely on somebody".

Seven of the participants believed they had adequate information about management of their colostomy prior to discharge from hospital. One respondent, a woman, recognized that she did not have adequate information, but felt that part of the responsibility was hers. After what she described as a "disastrous" session with her oncologist, who told her she was going to die, she demanded an early discharge. Since she had had a temporary colostomy in the past (for a period of two weeks, as a result of a bowel obstruction) she believed that the nurses assumed her to have skills that she did not, in fact, possess. She had never fully demonstrated the appliance changing procedure to the enterostomal therapist. She stated: "I am the kind of person who
always seems in control", and because of this she believed she didn't demonstrate a need for assistance, nor did she ask for assistance. She stated that this appearance of control is her way of coping with new experiences. She wanted those around her to see that she was handling the situation. As a result of that, she was sent home with, from her perception, inadequate skills and information, and no referral to the home care nurses.

Of the seven who believed they had adequate information about colostomy care, all required some assistance from the home care nurses. They perceived that they were given adequate information, but due to circumstances, not all of the information could be retained.

One woman explained:

. . . the information I got, I probably didn't absorb it all because of the way I felt, so I think it all came back to me, sort of, but it took a while.

Another woman stated:

If I wanted to know something, I could look in the book, but everything seemed to come natural, like I say, it was the least of my problems at the time, the incision at the front and the bottom weren't bad, even when I went home, I didn't worry about diet . . . .

Two participants referred to information in terms of what had meaning for them, for example:
"Everything that I learned I tried to absorb, and run around in my mind as to how it was going to affect me . . . .", and "I'm still experimenting, but I've been thinking ahead, I'm anxious to get going".

Participants also looked forward to sharing information. When asked if he minded people asking questions about his colostomy, one man replied:

- It doesn't bother me at all, no. In fact, I look forward to them asking me questions, that way I can tell them, and they'll be more informed, and they can maybe pass it on too.

The sharing of information and providing assistance for others, was discussed with four of the participants. It appeared that they were coping with the experience of having a colostomy by wanting to share their experience.

The sharing of their knowledge could be described as a positive force for their need for respect. They were attempting to balance the loss of normal bowel function with the gain of the stoma, and the skills and knowledge to live with the stoma. Sharing the knowledge assisted with the process of validating the experience.

Three of the participants found that the postdischarge visits to their surgeons gave them the opportunity to obtain information on outstanding concerns or physical problems, and to ask questions
about the surgery. One man explained:

I went to see him [the surgeon] yesterday, and asked him a bunch of questions that were bothering me, like the muscle in my buttock, it's sore, and the rectal area, where they sewed up my anus . . . he [the surgeon] said "It's going to take a couple of months until everything gets straightened around", and then he asks me "Is there anything else you want to know?". Time was nothing to him.

Typical questions were "How am I doing now?", "What is my prognosis?", and "What's it going to be like for the rest of my life?".

This man's response was typical:

. . . I don't think I was worried about the rest [care of the colostomy], but it's how I was doing, and how the cancer was, whether I had to go for treatment, for radiation treatment, or not.

Timing of the information was not perceived to be an issue for participants, with the exception of information regarding the extent of the surgery. As described earlier, one woman was saddened and angry over the lack of information about the extent of her surgery. Of the two others who identified inadequate information regarding their surgery, one had obtained information from another source, and the other received more information during the follow-up visit with his surgeon.
Unmet Learning Needs

The preceding information on adequacy of information assists in identifying areas where participants believed needs were not met.

Surgical procedure

Information needs about the surgical procedure, how the procedure was done, the extent of the surgery, number of incisions, location of incisions, and the location of the stoma, were unmet for three participants.

Diet

Two participants were told to eat anything they liked. One woman believed that as a result of the information she ate food that caused a blockage of her colostomy and resulted in readmission to hospital. The other woman believed that she did overeat as a result of the information. She believed that the constipation and cramps which occurred for three days postdischarge were a result of the information. During those three days she described herself as anxious and unable to cope.

The participants' perception that their learning needs regarding diet went unmet was a negative force
on their ability to manage their diet and regulate their bowel movements.

**Use of alcohol**

Four participants had a history of significant alcohol intake. Two of the participants acknowledged that their drinking had become a problem for them. Only one participant had alcohol intake discussed with him. Two were limiting their intake, but had not been told to do so, and one had wine with his meals, but stated that he had lost his taste for it.

**Impact of lifestyle**

One woman believed that the individual's lifestyle should direct the information provided. She described information needs in relation to her roles as mother and wife, as well as her expectations of resuming sports activities. She described the following information needs. Prior to surgery she was used to having a bath with her three-year-old daughter about three times a week. She wasn't concerned about her daughter seeing the stoma, but because her daughter was being toilet trained, didn't want to confuse her about where bowel movements came from.

She sought out information about child care, and was put in touch with another young mother. She learned not to pick up her daughter, since the
potential for herniating her stoma was high. She discussed sex with the other young mother. She wanted to know what she and her husband could and couldn't do. She learned about making love with a bag on and the availability of "lovemaking pouches".

She described herself as physically active, and asked her doctor when she could ski, hike and swim. Since she had already had the experience of chemotherapy, she wanted to know specifically what drugs would be used and what side effects to expect.

Of the eight study participants, this was the only person who had definitive information of a terminal prognosis. The medical treatment plans were palliative only. This could have influenced her perceptions of the usefulness of the following identified information needs:

1: The need for more information on nontraditional therapy for cancer patients, such as diet therapy (macrobiotics).

2: Group therapy, such as "HOPE", and the services of psychologists associated with the group.

3: Laugh therapy and positive imaging.

This woman identified a need to control situations, and identified that others believed she needed to be "in control". She described her feelings
when she was given her prognosis -- this took everything away from her, and that her life no longer belonged to her. She stated that a way of coping was to obtain as much information as she could about alternate methods of "cure", and that she wanted to put herself in the best physical and mental condition possible for this "cure" to occur. She stated that she had not given up hope.

The Importance of Support Systems

A significant factor identified by seven of the eight participants related to the importance of having a significant other available at the time of discharge from hospital. This may have been significant for the eighth person as well, although he didn't express this as a specific need. He was making plans to travel to visit a close friend in Europe. He described himself as "not really a misogynist", but admitted to having few close friends in this country, either female or male. His trip to Europe was being fitted in between discharge from hospital and the beginning of his radiation treatments.

Descriptions of the loving and helping relationships indicated that they were a positive
force which contributed to coping with life with a colostomy.

One participant said "My wife is one hundred percent behind me, so there is no problem that way", and, later in the interview, when discussing the support given by his wife, added "I can't say enough about that, I probably take it for granted".

Another participant, in discussing his relationship with his wife, said "It's good, no stress, comfortable, supportive. I hope it stays this way. We're good together".

One woman, who lives with her daughter and grandchildren, said that "Things have been so much better than I thought they would be, so it's really nice for me. My family's been excellent, just excellent, and that makes all the difference in the world".

Another woman stated that the love and acceptance of her family was the most important thing for her.

These statements suggest that love, caring, and support from significant others are positive forces which promote coping strategies for this group. These attitudes promote feelings of belonging and assist in getting back to normal roles of wife, husband, worker, travel companion, mother, and lover.
In summary, in this chapter the researcher has identified knowledge and skills that colostomy patients believe are important in order to cope with their new colostomy. Common concerns of these colostomy patients, such as pain, fatigue, problems with sleep, and the diagnosis of cancer were reported. The support of family and friends, and the importance of talking with those who live successfully with a colostomy, were themes identified by participants.
Chapter Five

Summary, Conclusions, Implications, and Recommendations

Summary

The creation of a permanent colostomy has implications for the physical and psychosocial wellbeing of the individual. Studies reviewed have suggested that effective patient teaching is a way of assisting individuals to develop coping strategies to manage the physical changes in the body and patterns of social and emotional interaction (Bailey, 1987; Cole & Perreault, 1985; Dobkin & Broadwell, 1986; Follick, Smith & Turk, 1984; Jackson, 1976; Mitchell, 1980; Watson, 1985).

Data were collected and analyzed to identify the learning needs and resource utilization of patients with a newly created permanent colostomy from their perspective. Patient interviews were conducted with eight participants ten to twenty-one days postdischarge from hospital, using a semistructured interview guide developed by the researcher.

Findings of the study suggested that participants were able to self-define the knowledge and skills that
allowed them to develop positive coping behaviors to manage their newly created permanent colostomy. Themes which emerged from the data collected were the need to get on with life, the persons' need to tell "their story" to reinforce their individuality, and the need to develop mastery over the physical aspects of stoma care.

Need to get on with life.

Although the findings suggested that diagnosis, prognosis, and mastery over physical care were important learning needs of these subjects, there was an identified need to know information that would allow them to continue to be the person they were before surgery. Role identification, and learning needs in relation to that role, were described by all participants. Irrespective of prognosis, the resumption of their life role had value for the participants. Life expectations were identified in relation to their roles, and included: the role of wife, mother, lover, and friend; the role of husband, son, and wage earner; the role of mother, grandmother, and amateur artist. Five participants identified learning needs in relation to travel for recreation.
and to allow them to be near good friends.

All participants found that pain and fatigue were major inhibitors in relation to resumption of role, and identified the need to be better informed about the impact of pain and fatigue on their lifestyle.

The significance of supportive family and friends was described by all participants. Support was provided through physical comfort such as assistance with dressing changes and colostomy care \( (n = 2) \), emotional support \( (n = 7) \), and provision of information on living with a colostomy \( (n = 5) \).

**Need to tell their story.**

Participants described their lifestyle and the impact of that lifestyle on their learning needs. This description occurred near, or at, the beginning of the interview, in response to the question "Will you share with me what it has been like for you to have a colostomy?" All participants described what was going on in their lives prior to surgery. In that description, they included other health problems \( (n = 2) \), the health problems of a spouse \( (n = 2) \), the kind of people they were, and their social and recreational expectations \( (n = 4) \). Of the four who
discussed their alcohol intake, only one received any counselling for the problem while in hospital. Three participants described problems related to excessive use of alcohol in the past, and how they were planning to deal with this perceived problem.

This need of the participants to identify to the researcher who they were and what their life was about, suggested that each was trying to identify the uniqueness of their situation, their lifestyle, and their support systems, and therefore what they were going to need to know to get back "to normal".

Need for mastery over physical care of the stoma.

All participants identified the need to have information relating to the physical care of the stoma. Information needs included care of the stoma, care of the perineal wound, diet, elimination patterns and the use of laxatives, and hygiene. Seven of the participants were caring for their stomas at the time of interview. The eighth participant stated that he knew how to do the care, but psychologically was unable to carry out the physical care of his stoma at that point.

All eight participants who had care provided by
home care nurses at some time during the period between discharge from hospital and the interview, perceived that the home care nurse provided support, but not expertise in the care of the colostomy. Seven of the participants had either called or gone to see the enterostomal therapist since discharge from hospital for concerns about stoma care, diet, and elimination problems. The enterostomal therapist was perceived to be the expert.

Methodological issues.

Two issues should be considered in relation to the study. First, the approach to the surgical intervention for low bowel tumors has changed radically during the last two years. The surgical intervention described by Gordon and Dalrymple (1987) results in fewer permanent colostomies, which is clearly advantageous to persons with lower bowel tumors. The survival rate has not been reduced (Gordon & Dalrymple, 1987, Heald & Chir, 1987). It did, however, limit the availability of study participants.

Of those who met the criteria for the study, over the six-month period of data collection, only two were
not interested in participating in the study. Those who agreed to participate were eager to share experiences with a view to helping others who require permanent colostomies.

The second issue related to the participants' need to tell their story. Although the semistructured interview format and initial open-ended questions allowed this disclosure to occur, it was not anticipated by the interviewer. Since all participants felt the need to share this type of information, the format for future studies should accommodate this.

In view of the fatigue described by participants, consideration could be given to conducting two separate interviews, the first exploratory, the second more specific to the research question(s).

Conclusions

Technical skills.

Consistent with the findings of a study done by Watson (1983), early postoperative counselling allowed for mastery over the technical aspects of ostomy care for all but one participant in the present
study. This finding is contrary to the results of a study by Cole and Perreault (1985), who identified that postoperative learning of technical skills was problematic as a result of social and emotional concerns. Seven of the present study participants were coping effectively with care of the colostomy. The eighth person was struggling with resolving feelings related to his surgery, prognosis and information about adjunctive therapy, and had not yet assumed care of the stoma. This person indicated that he knew how (had the cognitive ability) but could not cope with the tasks involved in the care.

Skills that were most readily identified and learned were those related to actual care of the stoma. Knowles (1984) identified that adults become ready to learn when they experience a need to know or do something, and that this may be related to an unanticipated change in some aspect of their lives. Recognizing that the interviews were done ten to twenty days postdischarge, the physical acts of caring for the stoma may have been the participants' way of demonstrating mastery or control over one aspect of the change in their lives. The results of the study suggest technical skills are an important component of postoperative counselling, and should be
included in predischarge teaching.

**Role of the enterostomal therapist.**

The rehabilitation model proposed by Jeter (1979) suggested that the health care team act in the role of friend, rather than a strictly professional role. The concept of a friendship described by Jeter included cogent and careful interviews tailored to the patient's needs, and spending time with patients who may be feeling unloving and unloved. Those interviewed spoke with warmth and praise of the support given by the enterostomal therapists. The continuity of care provided by the enterostomal therapists was reassuring; all participants felt reassured that they could contact the enterostomal therapists at any time for advice or support. At the time of interview, seven of the participants had been in touch with the enterostomal therapists by telephone, or had gone to see them, and the eighth was planning to make contact the following week. The caring, technical expertise, and teaching aspects of the role of the enterostomal therapist was supported in the interviews.
Role of the physician.

Results of this study indicate that the participants regard the surgeon as the one who provides information on diagnosis, surgical intervention, and prognosis. This is consistent with the surgeon's role as described by Dietz (1980), Dlin, Perlman, and Ringold (1969), and Druss et al (1969). Additionally, the males in this study either obtained or requested information from the surgeon about sexual functioning postsurgery. The one male who neither requested nor obtained information, indicated that he had information from a previous surgery, "a warning" was how he described it, and that limitations had been pointed out. Female subjects did not seek information about sexual functioning from the male physicians, but from the female enterostomal therapists.

Body image.

Druss et al (1969), Gloeckner (1984) and Shipes (1987), described depression, fear of social rejection, sleep disturbance, and severe weakness as symptoms indicative of disturbance of body image.
These symptoms were consistent with those described by this study's participants. Seven participants in the study described changed sleep patterns, or problems with sleep. Only one related the problem to concerns about his stoma (checking to see whether the pouch was in place, and that there wasn't too much gas in the bag). Depression was openly referred to by two participants, and all were concerned about fatigue.

**Implications**

Although the small size of the study population gives rise to problems of generalization, study findings identified patients' perceptions of their learning needs, and how these needs were met by the enterostomal therapist and the physician.

**Nursing practice.**

Findings of this study suggest that there be ongoing consultation with the enterostomal therapist. A supportive relationship had been established, as evidenced by the way participants spoke of the enterostomal therapists, and by the way their advice was sought postdischarge. Participants were
impressed by the knowledge of the enterostomal therapists concerning stoma care, and the support and continuity of care provided to them by the enterostomal therapists while in hospital.

Questions about stoma care posed to the surgeons were deflected back to the stoma therapists, as they were considered the experts in stoma care.

Hospital nurses who provided ongoing care to participants during hospitalization were perceived to have limited knowledge and expertise about stoma care. The home care nurses were perceived to be supportive, reinforcing learning that had occurred during hospitalization, but not particularly knowledgeable about care requirements. Participants acknowledged that the physician (surgeon) is the preferred source of information about diagnosis, surgical intervention, and prognosis.

In light of the information needs and sources of information identified by this study, it seems reasonable to suggest that the enterostomal therapist be the coordinator of care for the patient undergoing surgery for permanent colostomy, to ensure coordination of preoperative counselling by the surgeon, postoperative teaching, and ongoing rehabilitation relating to physical and psychosocial
needs. A detailed patient history, that would allow patients to tell their story, would provide information about past and present coping behaviors and available support systems. This knowledge, if used by the hospital nurses providing ongoing care, would give direction to interventions to support the individual through this life crisis.

The role of the enterostomal therapist, as coordinator of care, should not stop at discharge from hospital, but should include direction to the home care nurse, as well as referrals to the home care visitors from the Ostomy Association.

Nursing education.

The coordinator role suggested for the enterostomal therapist requires a nurse with specialist preparation. The role envisaged for the enterostomal therapist is similar to that of the clinical nurse specialist (CNS). The role of the CNS includes patient and nurse education, consultation and collaboration with nurses and physicians (both within and outside of the hospital), and research in the area of clinical specialization. Educational preparation for the CNS role is at the Masters level, with
clinical specialization in the area of interest.

This preparation provides needed knowledge in the areas of required rehabilitation for the colostomy patient, such as mastery of physical care and issues relating to self-concept, body image, and quality of life. Issues raised by study participants related to the knowledge level of staff nurses and home care nurses could be alleviated through nurse education and collaboration with the clinical specialist.

Recommendations for Further Research

Based on the findings of this study, the following further research is suggested:

1: A longitudinal study interviewing participants at one month, six months, and after one year, in order to identify ongoing perceptions of learning needs and how they were met.

2: Reinterview this study group in one year's time to assess the quality of spousal/family support. In this study, participants perceived support and relationships to be positive. Druss et al (1968) identified that there was a significant deterioration in social and family relationships during the first year after
surgery. Are the perceptions of the study group valid, or could the brief period between discharge from hospital and interview be considered a "honeymoon period"?

3: Identify the perception of physicians, staff nurses, and home care nurses, of the role of the enterostomal therapist in the care and teaching of patients with stomas.
References


Dukes' Classification of Large Bowel Cancers was done according to the spread of the tumor in the surgically resected specimen:

1: A Cases -- those in which the carcinoma is limited to the wall of the rectum, no extension into the extra-rectal tissues, and no metastases in the lymph nodes.

2: B Cases -- those in which the carcinoma has spread by direct continuity to the extra-rectal tissues, but has not yet invaded the regional lymph nodes.

3: C Cases -- those in which metastases are present in regional lymph nodes.

The classification is based on the proved depth of malignant spread requiring microscopic confirmation.

## APPENDIX II

### Comparison of Pedagogical and Andragogical Teaching Styles

<table>
<thead>
<tr>
<th>Assumptions</th>
<th><strong>Pedagogical Teacher-directed</strong></th>
<th><strong>Andragogical Self-directed</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Concept of the learner</strong></td>
<td>dependent personality</td>
<td>self-directed person</td>
</tr>
<tr>
<td><strong>Role of learner's experience</strong></td>
<td>to be built on more than used</td>
<td>a rich learning resource</td>
</tr>
<tr>
<td><strong>Readiness to learn</strong></td>
<td>dictated by curriculum</td>
<td>develops from life tasks and problems</td>
</tr>
<tr>
<td><strong>Orientation to learning</strong></td>
<td>subject centred</td>
<td>task or problem centred</td>
</tr>
<tr>
<td><strong>Motivation</strong></td>
<td>external rewards and punishments</td>
<td>internal incentives and curiosity</td>
</tr>
<tr>
<td><strong>Climate</strong></td>
<td>formal, authoritarian, competitive, judgemental</td>
<td>informal, mutually respectful, consensual, collaborative, supportive</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Processes</th>
<th><strong>Planning, identifying needs, setting goals, and evaluating learning</strong></th>
<th><strong>Designing a learning plan</strong></th>
<th><strong>Learning activities</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>primarily by nurse</td>
<td>content units, course syllabus arranged logically</td>
<td>transmittal techniques, assigned readings</td>
</tr>
<tr>
<td></td>
<td>by mutual agreement</td>
<td>learning projects, content arranged in terms of readiness</td>
<td>inquiry projects, independent study, experiential techniques</td>
</tr>
</tbody>
</table>

Fox, V. (1986). p. 236
### APPENDIX III

The UBC Nursing Model

#### Need and Goal of Each Subsystem

<table>
<thead>
<tr>
<th>Subsystem</th>
<th>Need</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Achieving</td>
<td>For mastery</td>
<td>Feelings of accomplishment; satisfaction with accomplishments</td>
</tr>
<tr>
<td>Affective</td>
<td>For love, belongingness and dependence</td>
<td>Feelings of love, belongingness and dependence</td>
</tr>
<tr>
<td>Ego-valuative</td>
<td>For respect of self by self and others</td>
<td>Self-esteem</td>
</tr>
<tr>
<td>Excretory</td>
<td>For collection and removal of accumulated wastes</td>
<td>Absence of accumulated wastes</td>
</tr>
<tr>
<td>Ingestive</td>
<td>For intake of food and fluid; nourishment</td>
<td>Nourishment; satisfaction of hunger and thirst</td>
</tr>
<tr>
<td>Protective</td>
<td>For safety and security</td>
<td>Integrity of the system</td>
</tr>
<tr>
<td>Reparative</td>
<td>For balance between production and utilization of energy</td>
<td>Capacity for activity</td>
</tr>
<tr>
<td>Respiratory</td>
<td>For intake of oxygen</td>
<td>Oxygenation; easy respiration</td>
</tr>
<tr>
<td>Satiative</td>
<td>For stimulation of the system's senses (i.e., hearing, vision, smell, touch, and taste)</td>
<td>Sensory satisfaction</td>
</tr>
</tbody>
</table>

Campbell, M., (1987), p. 38
APPENDIX IV

Information Letter to Participants

Patients who have recently had surgery to create a colostomy are being asked to participate in a research study. Would you be willing to help us find out what patients with new colostomies need to learn?

Mrs. Gail Keirstead, a registered nurse at Shaughnessy Hospital and a student in the Masters Program at U.B.C. is conducting the study.

If you are willing to participate, this is what you can expect:

-- An interview conducted in your home by Mrs. Keirstead at a time convenient to you.
-- The interview would last one hour and take place two weeks after your discharge.
-- You will be telephoned for a convenient time.
-- A tape recorder will be used.
-- At any point in the interview you may indicate you want the tape turned off or a portion of the tape erased.
-- Complete confidentiality will be observed. Your name will not be used on the tape or the interview notes.
All these materials will be destroyed at the end of the project.

You will have the opportunity to ask Mrs. Keirstead questions at the end of the interview and she will assist you with your concerns.

You have the right to refuse to participate or withdraw from the study. Your decision will in no way affect your present or future medical or nursing care.

If you are willing to participate please let the nurse know and Mrs. Keirstead will contact you prior to discharge to provide any additional information, answer your questions and obtain your consent.

Thank you for your interest in this project.
APPENDIX V

Consent Form for Research Study

Stoma Patients' Identification of Learning Needs in the Early Rehabilitation Period

I agree to take part in a study whose purpose is to identify the learning needs and resource utilization of stoma patients.

The nature, demands and benefits of the study have been explained to me. I understand that I may ask questions and that I am free to withdraw from the study at any time without it affecting my future medical or nursing care.

I agree that Gail Keirstead may visit my home to interview me. I understand that the interview will be tape recorded and the tapes will be erased when the study is completed.

I also give permission to Gail Keirstead to read my hospital chart to obtain background information for the study. All my questions about the study have been answered by Gail Keirstead. I have received a copy of the letter of information and the consent form.

_________________________ Date ________________
Subject's signature

_________________________ Date ________________
Witness' signature
APPENDIX VI
Chart Review and Interview Guide

Demographics:
Collected from patient record.

1: Telephone number
2: Address
3: Chart number
4: Doctor (Name)
5: Age in years ___ 6: Sex M ____ F ____
7: Ethnic origin
8: Living arrangements
9: Date of surgery
10: Medical reason for surgery

11: Elective ___ 12: Emergency ___
13: Type and location of colostomy

14: Complications:
Infection Yes ____ No ____ Other ____

15: Other Health Problems:
List ____________________________ ____________________________
______________________________ ______________________________
______________________________ ______________________________
INTERVIEW GUIDE

Home Visit:

People who have had surgery similar to yours have many different feelings. Will you share with me what it has been like for you to have a colostomy?

In the two weeks since you've been home from hospital have you needed to make changes in you daily activities as a result of your stoma?

After the general response specific areas of potential problems will be explored.

21.A On a scale of 1 to 10, where 10 = very confident, and 1 = not very confident, how would you rate your present feelings of confidence regarding the care of your stoma?

1 _________ 10    # ______

What factors influenced you to select # ______

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________
Subjects will then be asked to describe how they manage:

22.A  The stoma:

Problems encountered:  
   _____ fear of touching stoma
   _____ sensitivity of skin around stoma
   _____ skin breakdown

Other  __________________________________________________________

23.A  The number and type of bowel movements:

Problems encountered:  
   _____ diarrhea
   _____ constipation
   _____ frequency

Other  __________________________________________________________

24.A  Their diet:

Problems encountered:  
   _____ food preparation
   _____ appetite
   _____ effect of food on bowel movements
   _____ production of gas
   _____ blockage of stoma as a result of diet

Other  __________________________________________________________
25.A Activities of daily living:
Problems encountered:  
   ____ lack of energy
   ____ discomfort
   ____ interest in ADL

Other ________________________________

26.A Sleep and rest:
Problems encountered:  
   ____ sleep habits changed
   ____ fear of bag coming off
   ____ sleeps in different
   ____ location than spouse

Other ________________________________

27.A Relationships with family:
Problems encountered:  
   feeling of alienation
   ____ related to stoma
   ____ emotional
   ____ physical
   ____ reluctance to leave home

Other ________________________________
28.A  Outside the home:

Problems encountered:  have not gone outside home since discharge from

_____ hospital

_____ fear of embarrassing

_____ accidents

_____ too uncomfortable

_____ too weak

Other ____________________________________________
When patients have your type of surgery, they often receive lots of information. I would like to get an idea of what information you received, who gave it and when, and how it helped or didn't help.

Coding as follows

21.B Care of stoma:

Information given: yes __  no __
Adequate: yes __  no __
Given by: ET __  nurse __
          DR __  other __

Timing of information: during hospitalization __
                        after discharge 1 - 3 days __
                        1 week __
                        2 weeks __
                        other ________________________

22.B Skin Care:

<table>
<thead>
<tr>
<th>Information given</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Given by</td>
<td>ET</td>
<td>nurse</td>
</tr>
<tr>
<td></td>
<td>DR</td>
<td>other</td>
</tr>
</tbody>
</table>

Timing of information:
- during hospitalization
- after discharge 1 - 3 days
- 1 week
- 2 weeks
- other

23.B Bowel Movements:

<table>
<thead>
<tr>
<th>Information given</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Given by</td>
<td>ET</td>
<td>nurse</td>
</tr>
<tr>
<td></td>
<td>DR</td>
<td>other</td>
</tr>
</tbody>
</table>

Timing of information:
- during hospitalization
- after discharge 1 - 3 days
- 1 week
- 2 weeks
- other
### 24.B Diet:

<table>
<thead>
<tr>
<th>Information given</th>
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<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Given by</td>
<td>ET</td>
<td>nurse</td>
</tr>
<tr>
<td></td>
<td>DR</td>
<td>other</td>
</tr>
</tbody>
</table>

**Timing of information:**
- during hospitalization
- after discharge 1 - 3 days
  - 1 week
  - 2 weeks
- other

### 25.B Activities of daily living:

<table>
<thead>
<tr>
<th>Information given</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Given by</td>
<td>ET</td>
<td>nurse</td>
</tr>
<tr>
<td></td>
<td>DR</td>
<td>other</td>
</tr>
</tbody>
</table>

**Timing of information:**
- during hospitalization
- after discharge 1 - 3 days
  - 1 week
  - 2 weeks
- other
### 26.B  Sleep & rest:

<table>
<thead>
<tr>
<th>Information given</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
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<td>ET</td>
<td>nurse</td>
</tr>
<tr>
<td></td>
<td>DR</td>
<td>other</td>
</tr>
</tbody>
</table>

**Timing of information:**
- during hospitalization
- after discharge 1 - 3 days
- 1 week
- 2 weeks
- other

### 27.B  Family relationships:

<table>
<thead>
<tr>
<th>Information given</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adequate</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Given by</td>
<td>ET</td>
<td>nurse</td>
</tr>
<tr>
<td></td>
<td>DR</td>
<td>other</td>
</tr>
</tbody>
</table>

**Timing of information:**
- during hospitalization
- after discharge 1 - 3 days
- 1 week
- 2 weeks
- other
28.B Outside home:

Information given: yes __ no ___

Adequate: yes __ no ___

Given by:
- ET ____ nurse ____
- DR ____ other ____

Timing of information:
- during hospitalization ___
- after discharge 1 - 3 days ___
- 1 week ___
- 2 weeks ___
- other ___

29. Are there other areas in which you have found you needed information or reassurance?

_________________________________________

_________________________________________

_________________________________________

30. Assistance at home provided by:

- Spouse _____
- Family member _____
- Non-family member _____
- Health care worker _____
31. Type of assistance provided:

Health: Care of stoma or related care

Hygiene:

Dietary:

Home care & maintenance:

Social:

32. Worked prior to surgery? Yes ___ No ___

33. Occupation: Physical ___ Office ___

34. Returning to work? Yes ___ No ___

If no, is the reason

Related to stoma? Yes ___ No ___