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EXPLORATION OF CHANGES IN TRUST, AUTONOMY AND
PSYCHOSOCIAL DISCOMFORT EXPERIENCED BY THE POST-OPERATIVE
CANCER PATIENT WITH A COLOSTOMY

by

Lois Ramer

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF NURSING SCIENCE

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of the

UNIVERSITY OF CALIFORNIA

San Francisco



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Lastly, I wish to thank the patients, who were willing to share of themselves and their time during a very stressful experience. Without them, there would have been no study.

**The University of California, San Francisco
School of Nursing**

ABSTRACT

**EXPLORATION OF CHANGES IN TRUST,
AUTONOMY AND PSYCHO-SOCIAL
DISCOMFORT EXPERIENCED BY THE
POST-OPERATIVE CANCER PATIENT WITH
A COLOSTOMY**

by

Lois Ramer

People who undergo colostomy surgery experience both body mutilation and loss of body function which in turn causes their concepts of self to change. Although nurses use both physical and behavioral indicators as bases for assessment and for the planning and evaluation of nursing intervention, there is only minimal empirical data on the behavioral indices of self-concept (e.g., depression, anxiety, fear of social rejection, etc.) among these patients.

The purpose of this study is:

1) To build a descriptive behavioral assessment data base of the post-operative responses of colostomy cancer patients using Erikson's (1956) theoretical framework of trust and autonomy.

2) To describe the trust and autonomy (Erikson, 1956) changes experienced by the cancer colostomy patient at four weeks and twelve weeks post-operative.

3) To measure several indices of psycho-social discomfort as anticipated by cancer patients before colostomy operations and compare those measurements with similar measurements of psycho-social discomfort made at four weeks and twelve weeks post-operative.

4) To determine the appropriateness of using the phases of trust and autonomy of Erikson's developmental framework as a theoretical explanation for the post-operative experience of the colostomy patient.

5) To determine the appropriateness of utilizing the phases of trust and autonomy according to Erikson's developmental framework as a theoretical explanation for the post-operative experience of the colostomy patient.

The study design incorporated three serial assessments in which each consenting subject was interviewed once before the operation, and twice after, at four and twelve weeks post-operative. The study sample consisted of twelve subjects who had colostomy surgery for cancer. Their ages ranged from 41 to 74 years with a mean age of 59.4.

Results show an increase in trust from a mean of 203.6 at four weeks post-operative to a mean of 221.7 at twelve weeks post-operative. Autonomy scores decreased from a mean of 146.2 at four weeks post-operative to a mean of 143.9 at twelve weeks post-operative. All categories of autonomy decreased in both males and females, with but one exception: Females reported an increase in the "learning" category at the twelve-week interview.

Psycho-social discomfort decreased from a mean of 25.7 before surgery to a mean of 22.1 four weeks after surgery and a mean of 8.0 twelve weeks after surgery. Females consistently reported higher psycho-social discomfort than males, although these scores were not statistically significant.

The implications for clinical practice are that trust, autonomy and the

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indices of psycho-social discomfort are true variables, and do change as a function of time but further research is needed to establish and verify the numerical functional relationship of these independent variables. Further, the study indicates that gender may be a significant factor in the all of the trust/autonomy/psycho-social relationships as functions of time and must be taken into account in all nursing situations.

A replication of this study with a larger sample would further clarify these results. All three concepts (trust, autonomy, and psychosocial discomfort) need further exploratory description in this population at 6 month, 1 year, 18 month, and 2 year intervals following surgery. The data from these measurements over longer intervals would assist in describing how the stages change or stabilize over time, delineating the relationship between trust and autonomy, and clarifying the role of psycho-social discomfort.

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CHAPTER I

STATEMENT OF THE PROBLEM

Introduction

People who undergo colostomy surgery for colon cancer experience both body mutilation and loss of body function which usually results in self-concept changes (Hurny and Holland, 1985; Donovan and Girton, 1984). Acceptance and positive adjustment to such changes may be influential in preserving and maintaining a positive self-concept (Roberts, 1987) and patient self-care facilitates self-acceptance (Smith, 1985). Nurses have been limited in making clinical judgments about colostomy patients' progress in accepting changes regarding self-concept by a lack of empirical data describing the process of self-concept adjustment in colostomy patients. Although most nurses are aware of the fact that mutilation of the physical body can influence the patient's overall concept of self, defining the problem theoretically and quantifying it have been difficult for nurse researchers.

The Erikson framework has been used to describe the process of adaptation to a new self-concept (Rubin, 1968; S. Roberts, 1978; and McCarty, 1980), and has been selected by the author for application to a sample of colostomy patients because trust and autonomy (the first two stages of Erikson's developmental theory) are relevant to the self-care tasks that colostomy patients need to relearn. The psycho-social crises encountered in these two stages are significant factors in the post-operative experience of colostomy patients. Such patients must redevelop trust in their physical bodies and must re-establish autonomy after their colostomies.

Nurses use behavioral indicators (i.e. patient participation in care, anxiety and compliance to medical regime) as bases for assessment and evaluation of intervention techniques (Riehl & Roy, 1980), but empirical data on the behavioral indices of self-concept changes experienced by the colostomy patient is minimal. In addition, behavioral indicators of progress in adjustment to self-concept changes are neither described nor quantified. Consequently, there is no normative data base to set criteria for clinical assessment. The analysis of available empirical data suggests that colostomy patients experience depression, anxiety, fear of social rejection, fear of rejection by significant others and fear of sexual rejection, but these reactions have not been thoroughly studied (Hurny & Holland, 1985; and Wassner, 1982). Depression, anxiety, fear of social rejection, fear of rejection by significant others and fear of sexual rejection can be perceived as the antithesis of the state of psycho-social well-being referred to by Erikson. The characteristics of this antithetical state will be referred to as "psycho-social discomfort" in this study of colostomy patients. The psychological progress a patient makes is reflected in the patient's ability to manage care of the colostomy. Clinical data suggest that acceptance and adjustment to the colostomy procedure is a phenomenon that can take up to two years (Hurny & Holland, 1985).

Clinical description of problem

A permanent colostomy is the surgical treatment for cancer of the colon, usually the lower colon, and the rectum. The decision to do a colostomy (as opposed to anastomosis) depends on the stage of the cancer and whether the tumor can be resected (Givens & Simmons, 1984; Weakley, 1983; and Fazio, 1982). Usually the sigmoid or descending colon is brought out on to the surface of the lower left quadrant of the abdomen. When the cancer is in the lower third of the rectum and does not meet the criteria for local treatment surgery is required. Surgery, including removal of the entire rectum, the perirectal fat and lymphovascular tissue, the perineal muscle and the perianal skin, is required for the adequate removal of the tissue likely to be tumor-bearing (Weakley, 1983). This procedure is often part of an abdomino-perineal resection, which is a two-step surgical procedure. A colostomy is formed through an abdominal

incision and the involved colon is freed. The abdominal incision is made and the freed bowel, anus and rectum are removed. The perineal incision may be closed or may be left to heal without suturing (Givens & Simmons, 1984).

Perineal wound management is dependent on whether the incision is closed, partially closed, or left an open wound and the healing process may take from six to eight months. During healing, care must be taken to prevent infection, to notice unusual bleeding and to manage drainage. The perineal wound causes discomfort particularly during movement and sitting. When packing is present, the patient feels a sensation suggesting the need to evacuate.

The location of the colostomy in the large intestines is important to the management of the colostomy, since this determines the consistency of the fecal material that is expelled. If the colostomy is located in the descending colon, the consistency of the stool is solid and the colon has holding ability for storing fecal material so a patient may need only a small dressing to cover the opening and develops control through a colostomy irrigation schedule consistent with his or her preoperative bowel habits. The patient with a colostomy from the ascending colon will have fecal material more directly from the ileum and consequently will need to wear a bag continuously due to the more liquid consistency of the drainage.

If the patient needs to wear an appliance continuously, skin care becomes a crucial component of post-operative care. The patient is taught to use some type of skin barrier such as Karaya gum. The type of skin barrier and appliance to be used is determined by the location of the stoma and the personal characteristics of the patient, such as age, health and bowel habits (Jackson and Broadwell, 1986).

Other side effects of externalization of the bowel and loss of rectal control include problems of controlling odor and flatus. Nursing management includes teaching the patient to mitigate these side effects using dietary control and deodorant in the colostomy bag (Donovan & Girton, 1984). Flatus-producing foods which must be avoided vary from one individual to another, but some consistently problematic foods are legumes, carbonated mineral water (and

other carbonated beverages), onions and cabbage (Rebuffat, Negri, Maruotti, Zannini, Rosati, Voci & Petrojustri, 1983). Milk, vegetables, soup, meat broth and cabbage are foods that frequently cause diarrhea (Rebuffat, et al, 1983).

Impotence in males is a major side effect of the abdomina-perineal resection procedure and is dependent on the degree of damage sustained to the pelvic portion of the sympathetic and parasympathetic nervous systems at the time of surgery (Bauer, 1983). The sympathetic chain that innervates the pelvis is part of the hypogastric plexus and extends into the pelvic plexus. Ejaculation is mediated by the inferior hypogastric plexus and injury to this plexus causes loss of ejaculatory function (Bauer, Glernt, Salky & Kreel, 1983). The main pelvic parasympathetic supply to the pelvis is the *nervi erigentes* which comes off the lumbosacral plexus and injury to this nerve causes impotence (Bauer, 1983). In men over age 50, the rate of impotence is generally higher than in men under age 50 (Bauer, 1983).

The female pelvic structures are innervated by the inferior hypogastric plexus fibers which connect to the *nervi erigentes* and the sacral sympathetic chain to form the pelvic plexus. In the control of female sexual function, cerebral control and peripheral sensory *nervi* stimulation in the perineum play a more significant role than do the autonomic nerves (Bauer, et al, 1983). Peripheral stimuli are brought to the area by the pudendal nerve which connects the pelvic area to sexual centers in the cerebrum. The pudendal nerve is well protected in the pelvic area by thick layers of endopelvic fascia (Bauer, et al, 1983). This protection from the endopelvic fascia may be the reason for the lower rate of sexual dysfunction in females after proctocolectomy. Other factors that may give the lower dysfunction rates in females are the strong cerebral control plus the fact that the pudendal nerve is completely independent of the more accessible *nervi erigentes*. Bauer, et al (1983) report only 2 of the 152 females with colostomies experienced temporary dyspareunia. Clinical and research data describe the physical changes experienced by patients with colostomies and the psychological manifestations in their daily lives. These changes are theorized to affect the most central part of the person, the self, and are described as

self-concept or self-esteem changes (Sutherland, et al, 1952; and Orbach & Tallent, 1965), but these changes have not been substantiated.

Statement of the Problem

The nurse who is planning post-operative care for the colostomy patient assesses the patient's progress of psycho-social well-being by evaluating the patient's responses to physical care and the patient's acknowledgement of psycho-social discomfort. Assessments by the nurse include evaluating the patient's psychological responses which reflect his ability and willingness to manage his own care. Trust, autonomy and psycho-social discomfort provide a conceptual frame of reference for the assessment process. For purposes of this study, trust is defined as, "the motivation which generates a person's willingness to be involved in self-care," and autonomy is defined as, "the demonstration of the individual's ability to perform tasks related to self-care." Behavioral indices of psycho-social discomfort may offer insight into an individual's lack of progress in self-care.

This study will address three specific questions:

- 1) What changes in trust (Erikson, 1956) are experienced by the cancer patient with a colostomy at four and twelve weeks post-operative? .
- 2) What changes in autonomy (Erikson, 1956) are experienced by the cancer patient with a colostomy at four and twelve weeks post-operative?
- 3) What are the changes in psycho-social discomfort experienced by the cancer patient with a colostomy both pre-operative and at four and twelve weeks post-operative?

Purpose of the Study

The purpose of this study is:

1) To build a descriptive behavioral assessment data base of the post-operative responses of colostomy cancer patients using Erikson's (1956) theoretical framework of trust and autonomy.

2) To describe the trust and autonomy (Erikson, 1956) changes experienced by the cancer colostomy patient at four weeks and twelve weeks post-operative.

3) To measure several indices of psycho-social discomfort as anticipated by cancer patients before colostomy operations and compare those measurements with similar measurements of psycho-social discomfort made at four weeks and twelve weeks post-operative.

4) To determine the appropriateness of using the phases of trust and autonomy of Erikson's developmental framework as a theoretical explanation for the post-operative experience of the colostomy patient.

Significance of the Study

For the Patient.

The effects of disfiguring surgeries are increasingly important in modern society because of the increasing survival rate due to modern medical technology (Henkler, 1979). Many patients are surviving injuries and diseases that were fatal in the past. Because of the technological advances in surgery and medicine, the number of patients salvaged who require complex personal adjustment has greatly increased. There are approximately 150,000 ostomates in North America today (United Ostomy Association, Irvine, CA 1988). The American Cancer Society estimates that there were 105,000 new cases of colon cancer and 42,000 of rectal cancer in 1988 of which 15% require a colostomy (American Cancer Society, 1988). Adsett (1963) considers fear of mutilation to be a major personal issue for the cancer patient, along with subsequent feelings of rejection and

isolation. These fears and multiple losses lower the individual's self-esteem and generate feelings of worthlessness.

Cohen and Lazarus (1977) identified six categories in the experience of physical illness that patients perceive as threats, two of which involve self-concept: 1) a threat to body integrity, which includes bodily injury or disability, permanent physical changes or incapacitation; 2) a threat to one's concept of self and future plans that include the necessity to alter one's self-image or belief system and subsequent loss of autonomy or control.

The threat of loss of body integrity can be so frightening as to precipitate suicidal ideation. Devlin, Plant and Griffin (1971) interviewed 124 colostomy patients and reported two anecdotes of homosexual males who committed suicide after colostomy surgery. Druss, O'Connor and Stern (1972) described a colostomy patient's suicidal ideation. Wirsching, Druner and Herrmann (1975) reported 10% of 114 subjects in their sample of colostomy patients had suicidal ideation. This investigator has also been the recipient of suicidal ideation description during patient interaction with patients anticipating colostomy surgery. It was not unusual to hear patients state, "I would rather die than have this surgery."

For Nursing Practice.

Nursing has a major role in the pre- and post-operative care of the colostomy patient. A long-term nursing goal for patients with colostomies is self-care of the colostomy and self-acceptance (Jackson and Broadwell, 1986). In caring for patients, nurses rely on the belief that psychological responses reflect the patient's ability to perform self-care and resume normal activities of daily living (Roberts, 1978). Nurses are responsible for teaching patients self-care and how to reintegrate self-care into their lifestyles. Although the quality of life for these patients has improved due to technical improvements in ostomy appliances, the teaching and education of these patients has largely been done without theoretical rationale. Frequently, clinical care is based on intuition which leads to difficulties in evaluating the results of intervention. Erikson's framework of self-concept development has been proposed as the basis for the

evaluation of the psycho-social crisis experienced by colostomy patients because the behavioral responses complement the process of developmental crisis (McCarty, 1980 and Orbach et al 1965).

Descriptive data targeted for investigation in this study can establish the optimal time periods for nursing intervention. For example, if anxiety is shown to be high four weeks post-operative, then studies could be undertaken to examine the effects of intervention to diffuse anxiety at that particular time. Findings from such studies would provide an empirical base for nursing practice to enhance patient progress and facilitate the identification of patients who are at risk of post-operative psycho-social discomfort.

For Theory Development

Although the effect of body image changes on self-concept development has been described in Erikson's psycho-social developmental framework (Rubin, 1968; Roberts, 1978; and McCarty, 1980), this framework has not been tested empirically in an acute medical sample. This study is the result of an investigation into the appropriateness of Erikson's theoretical model for clinical application to the post-operative experience of the cancer patient with a colostomy. Findings from this new study will provide both pre- and post-operative empirical data to describe trust, autonomy, and psycho-social discomfort as perceived and experienced by the cancer patient with a colostomy. Results of this study can guide nurses in building trust and autonomy, and easing the psycho-social discomfort of cancer patients who have undergone colostomy procedures.

<p style="text-align: center;">CHAPTER II</p> <p style="text-align: center;">LITERATURE REVIEW</p>
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Historical Research

In 1908, abdomina-perineal resection became the preferred treatment for cancer of the bowel. Along with the new procedure were born new sets of problems for both patients and nurses. The patient was required to adapt to a body with an artificial anus. At that time, such individuals managed without any of the modern appliances and with minimal training. Duke (1947) recorded the first responses of patients to this procedure through 100 home visits that were designed to examine colostomy irrigation habits. He focused on the work habits of the subjects and the type of belts and dressings used. Duke (1947) did not use a standardized instrument nor did he describe how his subjects were selected. In spite of this, his study is important because it was the first such study to provide descriptive data on the patient's perception of living with a colostomy.

Sutherland, Orbach, Dyk and Bard (1952) conducted a classic descriptive study of the physical adjustment to a colostomy and patient's adjustments with integration of the irrigation procedure into one's lifestyle (see Table 2.1). These researchers conducted 273 unstructured interviews with 57 subjects, of which 20 subjects willingly participated in the Rorschach test. The exact sequence of these interviews was not described nor was the method of sample selection discussed. Subjects' ages ranged from 28 to 69 at the time of surgery. The interviews were conducted at least five years after surgery. Areas of the subjects' lives that were found to be affected were work, social, sexual and emotional status (Sutherland et al, 1952). Of the 29 males in the study, 24 returned to pre-operative employment and five returned to pre-operative activities with a

Table 2.1
Studies of Subjects with Ostomies, Cancer and/or Self-Concept Changes

Author, Source and Purpose	Variables	Instruments	Subject and Time Period	Pertinent Findings
<p>Sutherland, A.M., Orbach, C., Dyk, R.B. and Bard, M., 1952, September</p> <p>The psychological impact of cancer and cancer surgery <i>Cancer</i>, 5, 857-872</p> <p>What are the work, emotional, social, and sexual problems experienced by the person with a colostomy?</p>	<ul style="list-style-type: none"> - Colostomy - Social patterns - Emotional response - Working habits - Sexual Activity 	<ul style="list-style-type: none"> - Unstructured interview - Validity and reliability not discussed - Rorschach given to 20 subjects 	<ul style="list-style-type: none"> - 57 subjects 273 interviews - 5 years or more past surgery 	<ul style="list-style-type: none"> - Detailed descriptive data about each variable - Difficult to summarize since no statistical compression of data was done but all areas were affected
<p>Dyk, R.B. and Sutherland, A.M., 1974</p> <p><u>Psychological Impact of Cancer</u> American Cancer Society, pp. 72-88</p> <p>What is the family's adaptation to having member with cancer?</p>	<ul style="list-style-type: none"> - Adaptation to work; sex and social life 	<ul style="list-style-type: none"> - Unstructured interview - Validity and reliability not discussed 	<ul style="list-style-type: none"> - 38 patients 9 Spouses - 5 to 14 years after surgery 	<ul style="list-style-type: none"> - Person with a colostomy may hide it from spouse - Families reaction to the colostomy were considered important to the person with the colostomy - Husband seem to be the more accepting spouse in reacting to a colostomy
<p>Wirsching, M., Druner, H.J. and Herman, G., 1975</p> <p><u>Psychother. Psychosom.</u> 26, 245-256</p> <p>What are the differences in social adjustment in subjects with a colostomy compared to those with colon surgery?</p>	<ul style="list-style-type: none"> - Social activities - Colostomy 	<ul style="list-style-type: none"> - Heidelberg Colostomy Questionnaire - Giessen Test validity and reliability not discussed 	<ul style="list-style-type: none"> - n = 114 with colostomy - Time since surgery - (x = 9.7 years) - 110 in control group 	<ul style="list-style-type: none"> - 34% decrease in social activities - 44% increased sensitivity about appearance - 28% fearful of others reactions - 31% fear leakage and odor - 10% suicidal ideation - 27% loneliness due to social isolation

Table 2.1 (Continued)

Studies of Subjects with Ostomies, Cancer and/or Self-Concept Changes

Author, Source and Purpose	Variables	Instruments	Subject and Time Period	Pertinent Findings
Follick, M.J., Smith, T.W., and Turk, D.C. 1984 <i>Health Psychology</i> 3 (6), 505-517 What are the concerns of the ostomy patient according to a psycho-social model?	<ul style="list-style-type: none"> - Technical difficulties - Emotional difficulties - Psychological and social difficulties 	<ul style="list-style-type: none"> - Questionnaire 	<ul style="list-style-type: none"> - 131 with all types of ostomies - Time since surgery 1-10 years 	<ul style="list-style-type: none"> - 53% skin problems - 38% irrigation difficulties - 38% leakage occurrences - 37% appliance problems - 34% complained about noise from the stoma - 16% altered diet - 16% had clothing difficulties - 34% depression - 24% felt increased anger and irritability
Morris, C., 1985 <i>Nursing Clinics of North America</i> 20 (4), 611-630 What are the behavioral and emotional defining characteristics of the psychological construct self-concept as it is altered by the diagnosis of cancer?	<ul style="list-style-type: none"> - Cancer - Self concept 	<ul style="list-style-type: none"> - Verbal questions - Check list - Content validity - Test retest $r = .97$ 	<ul style="list-style-type: none"> - 60 subjects, 2 groups: A) Cancer diagnosis at least 3 months B) 6 to 8 weeks after diagnosis 	<ul style="list-style-type: none"> - 20 of the 30 subjects felt hopeful rather than hopeless - 15 of the 30 subjects felt strongly worthwhile - 14 of 30 subjects felt in control - 17% felt acceptance
Oberst, M.R. and James, R.T., 1985 <i>Topics in Clinical Nursing</i> , 1 (7), 46-57 What is the adjustment process the cancer patient experiences after discharge from hospital?	<ul style="list-style-type: none"> - Cancer - Length of time discharged from hospital - Physical and psychological symptoms 	<ul style="list-style-type: none"> - State-Trait Anxiety Inventory - Brief Symptom Inventory - COPE - Established reliability on each instrument 	<ul style="list-style-type: none"> - 40 subjects 50% had colostomies - Time since discharge equal to 10 days, 30 days, 60 days, 90 days, and 180 days 	<ul style="list-style-type: none"> - Ostomy patients reports shock and disbelief - For 2 months physical care was priority, then concerns about dying become priority - Symptoms of distress include wound discomfort, bowel problems, feeling weak and shaky

Table 2.1 (Continued)
Studies of Subjects with Ostomies, Cancer and/or Self-Concept Changes

Author, Source and Purpose	Variables	Instruments	Subject and Time Period	Pertinent Findings
Thomas, C.; Madden, F.; and Derek, J., 1987 <i>Journal of Psychosomatic Research</i> , 3 (31), 311-316 What are the psychiatric and social results of having a colostomy?	- Psychiatric and social outcome	- Unstructured interview where subjects were rated by points - Validity and reliability not addressed	- 3 and 12 months post-operative ; - 66 subjects: 38 with bowel cancer; 15 with colitis or diverticular disease	- 6% moderate anxiety - 13% severe anxiety - 7% moderate depression - 12% severe depression
Thomas, C.; Madden, F.; and Derek, J., 1987 <i>Journal of Psychosomatic Research</i> , 3 (31), 311-316 What are the factors associated with psychiatric morbidity in patients with colostomies?	- factors influencing psychiatric outcome	- Unstructured interview where subjects were rated by points - Eysenck Personality Questionnaire - Crownl Experiential Index	- 3 and 12 months post-operative - 66 subjects; 38 with bowel cancer; 15 with colitis or diverticular disease	- age, sex, marital status or occupational status were not significantly related, but previous psychiatric illness was ($p < 0.02$) relating to developing psychiatric morbidity

reduction in activities. Most women reduced amount of housework done; only five reported returning to their pre-operative level of housework.

Sutherland et al (1952) investigated several psychosocial variables that affected the subjects' lifestyle. One variable examined could be defined as "social acceptance." Fifty-three of the fifty-seven subjects decreased their social activities and 33% stopped participating in community events. The only three females who reported that there was no change in their social activity after surgery were not socially active prior to surgery.

Another variable was defined as "sexual activity." Of the 29 males in the sample, 14 were "wholly impotent," 5 had "marked impairment," and 7

experienced "slight or no change." Of those who reported "slight or no change," 6 maintained their same levels of pre-surgical sexual relations. The 7th subject's wife discontinued sexual relations. Of the females, 11 were unwilling to share sexual information. Of the remaining female subjects 3 terminated sexual relations prior to surgery, 4 terminated sexual activity after surgery, 2 engaged in sexual activity only on insistence by their husbands, and 2 continued sexual activity at their pre-operative levels. Sexual activity in this study was investigated solely as a physical function. The psychological component of the sexual experience was not considered.

A third variable defined and studied by Sutherland et al (1952) was "family relationships." Support from family members was found to be important, but in some cases the colostomy is kept a secret and spouses may never see the colostomy. Children, and especially children of the opposite sex, never viewed the colostomy. Of 57 subjects, 25 never let the spouse see the colostomy. The authors concluded that the status of the marital relationship prior to the surgery was the strongest indicator of likely status of the marriage after surgery.

Sutherland et al, (1952) identified depression as a major emotional response to the colostomy procedure. Of 57 subjects, 20 were found to be depressed with some suicidal ideation, generally reporting feelings that life was not worth living. The Rorschach test, which was taken by 12 men and 8 women, revealed general depression in all of the subjects which was attributed to body mutilation and disfigurement.

The Sutherland et al, (1952) study contained specific recommendations for pre- and post-operative care. The studies' limitations are: 1) No structured interviews of the entire sample were reported (except for the Rorschach test which was given to 20 subjects). 2) The number of interviews per subject was not reported. 3) The data obtained was retrospective because all patients were at least five years post-operative. 4) Content analysis of the data is not provided. 5) Sample selection criteria was vaguely identified as being a minimum of at least five years after surgery, but the mean time after surgery was not reported.

Dyk and Sutherland (1956) investigated family adaptation to having a member with a colostomy (see Table 2.1). Of the original 52 subjects in the Sutherland et al, 1952 study, 38 participated in unstructured interviews. This sample included 22 men and 16 women. The subjects were chosen because they had "maintained marital relationships post-operative." The subjects were five to 14 years post-operative. Data were reported in narrative form according to pre-operative phase, hospitalization, convalescent time and post-convalescent phase. Findings indicate subjects with colostomies may hide their stoma from their spouses even if there was no physical sexual involvement. Children, especially children of sex opposite to that of the subject, were generally not involved in the care of the colostomy (Dyk and Sutherland, 1956). Women tended to perform their own care. When help was required and permitted, it was generally provided by a female child or other female relative. Dyk and Sutherland (1956) interpreted the reluctance of patients with colostomies to allow their spouses to see the stoma as a manifestation of lowered self-esteem.

The wives of men with colostomies tended to feel lowered self-esteem if their husbands' income was reduced because the husbands were unable to be employed in their previous capacities, and they often expressed dissatisfaction by sexual withdrawal. Husbands tended to be more accepting of their wives with colostomies and did not feel it lowered their self-esteem, (Dyk & Sutherland, 1956). Both studies (Sutherland et al, 1952; and Dyk & Sutherland, 1956) indicate that a stable pre-operative marriage would withstand this additional strain, but if there was hostility between the partners pre-operatively, it intensified post-operatively.

The Sutherland et al (1952) study was the impetus for the Orbach, Bard, and Sutherland, 1957 work which described the meaning of loss of anal control. Orbach et al (1957) retrospectively used a psychoanalytical perspective in which symbolic meanings were attached to the losses experienced by the colostomy patients, and to the requirements of post-colostomy care such as irrigation, and they interpreted the behavior of the patients in the light of the symbolic analysis.

Orbach et al (1957) interpreted the colostomy irrigation process as a symbolic means of gaining control of an internal process through an external procedure. Spillage was upsetting to the patient because it represented loss of control and failure to meet expected social behavior related to control of body excrement. This loss experience resulted in depression and anxiety which was perceived as being related to body mutilation. Rorschach results from 20 subjects supported this psychoanalytic interpretation. The process of having the abdomen opened and intestines mutilated aroused strong feelings.

The symbolic relationship of anal sphincter control in childhood to the colostomy patient was addressed by Orbach et al (1957). The thesis is that the control which is developed through the irrigation process is due to the patient's negative feelings toward feces. These researchers concluded that the behavior and attitudes expressed with respect to feces which was reported in their sample confirmed their conclusions that the subjects gained control by irrigating.

Orbach, Sutherland and Bard (1965) also investigated body-concept changes in 48 of their subjects. These results indicated "an appreciable number of the subjects seemed to be preclinically or subclinically psychotic." The Barrier and Penetration Scores (Fisher and Cleveland, 1958) were also calculated and the Penetration scores were found to be significantly different from normal subjects ($t = 3.7$; $p = .005$). Orbach and Tallent (1965) interpreted the changes experienced by the subjects as body-concept changes. The body-concept alterations described by Orbach et al (1965) include: 1) altered body function and form; 2) pervasive changes in personal and social concepts; 3) loss of an organ which developmentally takes the person back to the time of developing control over the organ lost; 4) demasculinized males due to impotence and an opening in the anterior of the body which may remind males of the menstrual process since the colostomy may at times discharge blood; and 5) alteration in internal organs. Rorschach test findings were used to confirm these impressions and indicated that the body-concept changes result in feelings of inadequacy and a feeling of loss of personal integrity. Rorschach test findings also provided indications of body damage, violation and helplessness with regard to the body changes. Although these studies (Orbach et al, 1957 and Orbach et al, 1965)

have limitations in that no instruments other than the Rorschach were used to measure any component of the "self" (such as self-concept, self-image or body concept), these findings provide some description of what might be self-concept changes experienced by the cancer patient after colostomy surgery.

Sexual changes, as established by Sutherland et al (1952), were a major concern to the colostomy patient, and as reported by several subsequent studies. Dlin and Perlman (1972) report findings on 409 subjects who completed a mail questionnaire. Subjects' initial diagnoses were not reported. Findings were that males experienced impotence which may be attributed to both physical causes and psychological influences. Females reported decreased sexual responsiveness and concerns regarding their physical attractiveness and femininity (Dlin and Perlman, 1972). The researchers concluded that the first year after surgery is one of learning, and of experimentation, and that the patients experienced relief at being alive and had fears of leaving the house. The reactions to the surgical experience include fear, anxiety, depression, regression, withdrawal, feeling like a "freak", and "hating" fecal material. They expressed fears that the fecal material might show. Limitations of the study include: 1) sample included patients with both colostomies and ileostomies; 2) data were reported in narrative form only; and 3) validity and reliability of the questionnaires utilized were not reported.

Wirsching, Druner and Herrmann (1975), a group of German researchers, conducted a comparative study of 114 subjects with colostomies and compared them to 110 subjects who had bowel cancer but did not undergo colostomy surgery (see Table 2:1). Interviews were conducted over a period of one to thirty years following surgery. The mean time following surgery was 9.7 years. The Heidelberg Colostomy Questionnaire and the Giessen Test were mailed to subjects, but the validity and reliability of these questionnaires were not discussed. This study is unique in that it uses a control group. However, no statistical analysis of data linking the groups was reported. Wirsching et al (1975) reported that 34% of their sample (post-operatively) decreased their social activities; 44% were more sensitive about their appearance than prior to surgery; 28% were fearful of others' reactions; 19% allowed this fear of reactions

of others to decrease their social activities and 31% had concerns about social activities due to fear of leakage and odor. Depression, anxiety and suicidal ideation as psychological responses also were reported by these subjects. Duke (1947) and Sutherland et al (1952) also reported patients having suicidal ideation; Wirsching et al (1975) found 10% of their sample reported suicidal ideation. Wirsching et al (1975) report 27% of their subjects (n = 114) experienced loneliness because they isolated themselves, fearing that their flatus explosions might bother others in social situations.

Follick, Smith and Turk (1984) conducted a retrospective correlative study (n=131) to determine the areas which were of concern to patients with colostomies. Results indicate biological, psychological and social concerns were important (see Table 2.1). The sample consisted of 131 respondents out of 400 subjects who had all types of colostomies. The periods between the surgeries and the questionnaires ranged from one to ten years. The instrument (no name reported) was evaluated for reliability using Cronbach's alpha for each category and values ranged from .64 to .84.

Although many technical improvements in the care of the stoma have been made since the Sutherland, et al (1952) study, Follick, et al (1984) reported that 53% of their subjects (n = 131) had skin problems; 38% had irrigation difficulties; 38% experienced leakage; 37% had appliance problems; 34% complained of noise from the stoma; 16% needed to alter their diet and 16% had problems selecting appropriate clothing. The patient's level of information was significantly correlated (p = .001) with fewer technical problems (p = .001), better emotional adjustment and better social adjustment (p = .02) (Follick, et al, 1984). In addition, social support was significantly correlated with marital and family adjustment (p = .05) and sexual adjustment (p = .02). Thirty-four percent of their sample reported frequent depression and 24% perceived an increase in feelings of anger and irritability as compared to their pre-operative status. (Follick, et al, 1985)

Recent Studies

Morris (1985) studied the "behavioral and emotional characteristics of the psychological construct self-concept as it is altered by the diagnosis of cancer" (pg. 612) (see Table 2.1). The sample consisted of two groups of 30 subjects each. Group A had been diagnosed at least three months prior to being interviewed and Group B were interviewed six to eight weeks after diagnosis. The investigative procedure consisted of the conduct of a structured interview with prescribed questions and the submission of a check list pertaining to expected and unexpected reactions to self-concept changes. Content validity of items in the interview was established by a panel of experts in the field of oncology. The reliability of the check list was determined by submitting the list to a group of 39 subjects who had been diagnosed as having cancer a minimum of three months before the list was completed, and using test-retest reliability method at 48-hour intervals which yielded a correlation of $r = .97$. Limitations of the study were: 1) interview questions on the check list were not based on a specific theory of self-concept, and 2) responses to the two formats were neither congruent nor consistent with reports in the literature.

Oberst and James (1985) gathered data on crisis management and coping by cancer patients ($n = 40$) who had been discharged from the hospital. One-half of these subjects had permanent colostomies (see Table 2.1). Patients' ages ranged from 18 to 77 with a mean of 57 years. The findings indicated concerns about family and significant relationships arising from "sexual and personal contact limitations." Physical care of the stoma and concerns about life and death were major concerns for the first two months after discharge. Lifestyle disruptions became primary concerns for patients and spouses six months after discharge. Another concern related to symptom distress management (i.e., wound discomfort, bowel problems, feeling weak and shaky). Emotional responses of shock and disbelief specific to ostomy patients were reported. However, the level of anxiety for the ostomy subjects was not greater than for subjects coping with other surgical procedures. According to the conclusions of the authors of this study, spouses of cancer patients need more professional support. Data were obtained using the State-Trait Anxiety Inventory

(Spielberger, Gorsuch, and Lushene, 1970), Brief Symptom Inventory (Derogatis, 1977) and the COPE interview format by Weisman and Warden (1977).

British investigators, Thomas, Madden and Jehu (1987) conducted unstructured interviews of 68 subjects of whom 38 had undergone stoma surgery for bowel cancer, 15 were treated for inflammatory bowel disease and 15 were treated for diverticular disease. The subjects participated in a semi-structured interviews at three and twelve months post-operative and the interviewer scored the subjects according to pre-set criteria. The percentages of subjects with differing degrees of psychiatric symptoms was then determined. Results indicate 6% had moderate anxiety while 13% had severe anxiety at 12 months. Of the sample, 7% were determined to have moderate depression while 12% had severe depression after 12 months. The researchers also examined the association between demographic variables and psychiatric morbidity. There was no significant correlation between any of the factors investigated (age, sex, marital status and occupational status) and post-operative psychiatric symptoms. Subjects with previous psychiatric history were more likely ($p < 0.02$) to have psychiatric symptoms. Also, subjects with psychiatric symptoms were more likely ($p < 0.0001$) to have physical complaints and were more likely ($p < 0.001$) to have serious complications post-operatively.

These studies indicate: 1) Family support is important in recovery (Sutherland, et al, 1982; Dyk & Sutherland, 1956; Follick, et al, 1984 and Madden & Jehu, 1987). 2) Fear of social rejection may cause people with ostomies to socially isolate themselves (Sutherland, et al, 1952; Wirsching, et al, 1975; Follick, et al, 1984). 3) Depression, anxiety and, sometimes, suicidal ideation is experienced by the person with a colostomy (Dyk 1947; Sutherland et al, 1952; Dlin & Perlman, 1972; Wirsching, et al, 1975 and Follick et al, 1984). 4) A person with an ostomy may experience changes in sexual behavior which may be psychological or physiological in origin (Duke, 1947, Sutherland et al, 1952, Dlin and Perlman, 1972, Follick, et al, 1984). 5) The person with a colostomy is described as having self-concept changes, although the terminology used in describing these changes is not consistent (Follick et al, 1952, Dyk &

Sutherland, 1956, Orbach & Tallent, 1978, Dlin & Perlman, 1972). The self-concept changes are not measured with an established instrument in any of the studies; rather, the authors describe the patients as experiencing self-concept changes. Morris (1985) described behavioral indications of self-concept changes with the two instruments she developed.

Studies focusing on the post-operative experience and needs of cancer patients with colostomies are largely exploratory, descriptive studies with methodology limitations in the areas of sample selection, instrumentation and statistical analysis (Duke, 1947; Sutherland, et al, 1952; Dlin and Perlman 1972; Wirsching, et al, 1975; Gloeckner, 1983; and Follick, et al, 1984). Sample selection is often simply convenience sampling from clinics and hospitals (Duke, 1947; Sutherland, et al, 1952) and, more recently, sampling by mailing list, such as by sending out forms to the members of the Ostomy Association (Dlin and Perlman, 1972; Wabrek, et al, 1980; and Follick, et al, 1984). This latter method of sample selection is self-selective. Follick, et al, 1984, found only 48% of all ostomy patients belong to the Ostomy Association and only a percentage of those to whom questionnaires are mailed return them. Another concern is that study samples are often not diagnostically homogenous because the time following surgery is variable. Although Sutherland, et al, (1952) had only colostomy patients with cancer, the time of the interviews ranged from five to fourteen years following surgery; Wirsching, et al also had only cancer patients but the time following surgery varied from 1 year to 30 years. The study of Follick, et al (1984) included a sample with colostomies, ileostomies and urostomies and time following surgery ranged from 1 to 10 years. Both colostomy and urostomy surgeries are disfiguring, but there are significant differences such as the frequency of impotence reported which is higher in colostomy patients, and the fact that patients with ileostomies are usually younger with a long medical histories (Makleburst, 1985). The ileostomy patient may view surgery as a relief. The time-following-surgery variable is important because the patient's memory of what occurred at the time of surgery may be colored and blurred by time. To date, instrumentation used to obtain data from subjects with colostomies generally did not employ established psychometrics. Sutherland et al, (1950) interviewed 57 subjects in a total of 273 interviews and generated volumes of

data but the questionnaires used are not documented in any fashion, with the sole exception of the Rorschach test which was taken by 20 of the subjects. Wirsching, et al (1975) used the Heidelberg Colostomy Questionnaire, but reported no validity or reliability data. Wabrek, et al, (1980) distributed questionnaires at ostomy meetings and a copy of the questionnaire is available in their publication but there is no report of its validity or reliability.

More recently, Follick, et al (1984) developed a questionnaire which included inter-item correlation (.56 to .64) and the use of Cronbach's alpha (values ranged from .56 to .66). This is a starting point for the establishment of validity and reliability analysis. Morris (1985) began to document behavior associated with self-concept changes by doing test-retest reliability analysis of the check-list that was used ($r = .97$). However, the use of convenience sampling precludes generalization and limits application of the data to other populations of colostomy patients. A study based on a theory of changing self-concept in which self-care is a significant status indicator would help nurses evaluate self-concept changes in the ostomy population and describe the post-operative perceptions of this patient population. The postulate that self-concept changes follow surgery, and that nursing intervention can influence such changes in a positive fashion, is commonly held, but has not been empirically supported as is evident from the above discussion. This study provides a starting point for the empirical validation of this postulate.

<p style="text-align: center;">CHAPTER III</p> <p style="text-align: center;">THEORY</p>
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Erikson's Self-Concept Theory

Self-concept includes beliefs and perceptions about one's uniqueness as a human being. Erikson (1956) describes the process of self-concept development as the resolution of eight developmental crises (See Table 3.1). These stage-specific crises are considered necessary for growth in each developmental stage and culminate in a persistent feeling of sameness within the self. Self-concept is built upon beliefs about, and perceptions of, the physical body, social interactions, emotional feelings and cultural heritage. A positive or negative self-concept is generated from an evaluation of the self in the light of each of these factors. The person with a new ostomy is in crisis because there is a need to reevaluate perceptions and beliefs about the physical self and how the self will function in social situations. The individual may have emotional reactions to learning new behavior in sensitive areas such as sexual response. During the adaptive process of accepting the altered self, the individual may experience negative feelings toward the self. Clinical nurses deal with self-concept problems on a daily basis (Kim, McFarland & McLane, 1984) but the profession has little research data to substantiate identification of the problem or to support intervention.

Erikson's theoretical framework has been used in nursing to describe the development of self (Brunner & Suddarth, 1984; Rambo, 1984; and Evans, 1971) and to describe one of the components of self, body image (Lambert & Lambert, 1985; Rubin, 1968; Roberts, 1978; and Rambo, 1984). This framework is based on a developmental model which is clinically useful for describing and predicting outcomes in situations where change is predicted such as the self-concept

Table 3.1
Erikson's Eight Developmental Crises

Crisis	Resolution	Sense of Identity
Trust	Trust vs. mistrust	mutual recognition vs. autistic isolation
Autonomy	Autonomy vs.	will to be one-self shame and doubt vs. self-doubt
Initiative	Initiative vs. Guilt	anticipation of roles vs. role inhibition
Industry	Industry vs. Inferiority	Task identification vs. sense of futility
Identity	Identity vs. Identity confusion	Psychosocial Identity
Intimacy	Intimacy vs. Isolation	Sexual polarization vs. bisexual confusion
Generativity	Generativity vs. Stagnation	Leadership vs. authority confusion
Integrity	Integrity vs. despair	Ideological commitment vs. confusion of values

Source: Based on E.H. Erikson, Identity: Youth and Crisis (New York: Norton, 1968, pgs. 91-141).

change which occur after a physically disfiguring surgery or disease. The assumptions of the developmental theory are: 1) changes occur in stages or phases; 2) changes occur in a spiral or upward direction; 3) stages can occur and recur; and 4) each stage or phase increases in specialization over time (Chin, 1980). These assumptions also relate to Erikson's (1956) theory of self development.

Erikson's model is useful to nurses because it imposes an order on a process that sometimes seems chaotic. The implication is that successive stages will follow sequentially and thus the nurse can predict to some extent what will occur during the upcoming stage. This model also delineates critical events and points where the nurse can expect challenges or turning points to occur for the individual. The nurse can then intervene accordingly.

Carroll (1981) used the Erikson theoretical framework to describe the development of body image in mastectomy patients. Rubin (1968) refers to Erikson's framework when he attempts to explain the shame a person feels who loses that control over his or her body that society expects of an adult. The developmental changes are theorized to follow a natural inborn genetic process described by Erikson as the epigenetic principle (Erikson, 1982) but they can occur in response to external events that cause a crisis (Aguilera & Messick, 1978). The Erikson Theoretical Framework can be used to facilitate the development and changes of self-concept within the nursing profession as was done in Rambo's 1984 implementation of the self-concept mode of the Roy adaptation model (Rambo, 1984). It also could be used to implement the universal self-care requisite of being normal as specified in the Orem Self-Care model (Riehl & Roy, 1980).

In the same fashion that nurses have used Erikson's theoretical framework to understand the psycho-social development of the child, the framework can aid in understanding the psycho-social crises that occur from illnesses that result in self-concept and/or body image changes (McCarty, 1980; Rubin, 1968; Carroll, 1981 and Orbach et al, 1965). Erikson's theoretical framework is useful in nursing because it offers an explanation of the

individual's social development as a result of his environment. In addition, Erikson's perspective emphasizes normal development, which occurs from social interaction. This is congruent with nursing's concern for the patient's interactions with his environment. One goal of nursing intervention is to facilitate the patient's successful interaction with the environment (Riehl & Roy, 1980). This is consistent with Erikson's integration of the socio-cultural variable in self-concept development that the self originates from interactions with the environment.

The recovery process, whether from illness or treatment, which affects self-concept has been assumed to follow the same developmental pattern that is followed in child growth and development (Lambert & Lambert, 1985; Rubin, 1985; Roberts, 1978; and Rambo, 1984). This is based on the following assumptions for developmental theory: 1) There are specific tasks for each phase that need to be accomplished for integration of that phase into the self-concept. 2) These phase-specific tasks are sequential in nature. 3) Phases can occur and recur. and 4) The patient may continue to work on a phase while the next one begins, thereby specializing in accomplishing the tasks for that phase. Although this model has not been tested empirically, it has been clinically used for direction in assessment and intervention.

The phase-specific tasks for the development of self-concept according to Erikson are appropriate for the colostomy patient because specific body functions are actually altered and must be relearned. Management of bowel elimination by a new method, which is a major task for the patient with a colostomy, is a cause of great concern to patient (Follick, Smith & Turk, 1984) and can be related to the stage of autonomy development.

Empirical data are not available to support an Erikson interpretation of self-concept development after self-concept changes have occurred. Available research data do expand the understanding of the process inherent in identity development. Marcia (1966, 1967) expanded Erikson's bipolar concept of identity versus identity confusion to four types of identity: identity achieved, moratorium, identity foreclosed and identity confusion. Oldaker (1985)

investigated identity confusion from a nursing diagnosis perspective. The Comrey Personality Scale and the Psychiatric Epidemiological Research Interview Symptom Scale was administered to 2,109 adolescents and, through factor analysis, identity confusion arose from four sources: 1) unresolved issues of intimacy; 2) development of a negative self-identity; 3) problems related to time perspective; and 4) diffusion of industry which is expressed in a lack of career identity.

The Psychodynamic School of Thought: Four Major Constructs

Erikson's developmental theory is rooted in the psychodynamic school of thought (Kahn & Wright, 1980). Four constructs are basic to this theoretical perspective and each will be discussed in this section. They are: 1) Drive Reduction Theory; 2) Psychic Structure; 3) Developmental stages; and 4) Object-Relation Theory.

The Drive-Reduction Theory refers to Freud's premise that all humans are born with instincts which are innate, unlearned and universal (Kahn & Wright, 1980). The important instincts are of are sexual drive, aggression, social behavior and death. These instincts generate ambivalent feelings due to the presence of opposing forces or drives. The energy produced by these opposing forces provides energy to motivate behavior. Freud theorized that psychic energy was a real form of energy and thus would obey the same laws of energy conservation as heat, light, sound, matter and other phenomena studied in the physical sciences. Thus, there is a build-up of potential energy (perhaps through trauma). The person acts to seek release (kinetic energy) which produces gratification. Gratification produces pleasurable new feelings (potential energy) equal to the energy produced by the trauma, so the quantity of energy remains constant and thus is conserved. While no one has been able to measure Freud's "psychic energy," making mute the question of its conservation or lack thereof, it is both an appealing and useful metaphor.

Freud's theory is incorporated in Erikson's psycho-social developmental theory in the premise that the impetus for developmental stages is already

present in the newborn and that crisis resolution will occur naturally in each stage. This process occurs in all individuals and there is no need for a conscious effort to move through the stages.

The **Psychic Structure** construct proposes that the psychic or mental processes include three components: the **ego**, **id**, and **superego** (Kahn & Wright, 1980). The **ego** is the conscious self in action that is steeped in reality and functions as a control, allowing the individual to meet id needs in a socially acceptable manner. Freud referred to this as the reality principle. Erikson's work focuses on the psycho-social development of the ego from the perspective of adaptation to the group. This is applicable to nursing because one concern of those in nursing practice is the ability of the patient to function adequately with his or her family and community. The **id** is both a repository for repressed content from the conscious and a holding area for unconscious creative and destructive potential. The id contains all the psychic energy from one's instincts. This psychic energy is released through different biological functions during each successive developmental stage. The id functions on the pleasure principle and seeks release of tension to generate pleasure. The **superego** provides inhibition through the socialization process which arises primarily from resolution of the Oedipal conflict during the third developmental stage.

The developmental process, according to Freud, is based on libido energy focusing on different areas of the body and resolution of conflict with respect to biological function (Lerner, 1976). Thus, the self develops out of a process that occurs through psychosexual stages. Tension builds up in one area of biological function and is released through appropriate stimulation. Adulthood is reached through learning appropriate release and control mechanisms. If progress through the stages becomes thwarted, the individual becomes fixated. The stages of development will be discussed later with reference to Erikson's psycho-social theory.

The **Object-Relation Theory** was an elaboration of Freud's theory by Klein (Kahn & Wright, 1980). According to this theory, the self evolves through the inner working of the individual and its relationship with other objects in

the world. The self as an object has been termed the self-concept and has different categories by which it is defined, such as gender, sexuality and abilities. The importance of these different categories changes over the life span of the individual and the self-concept involves accommodation of changes in these categories over the life cycle. Object relation is the ability to differentiate self from the environment through relationship with objects. Klein perceived that individuation occurs through the child's incorporation of both positive and negative features of an object. Objects may be individuals or mental objects with both good and bad coming from the same source; the child differentiates itself from the object. The child does not initially know the difference between what is internal to himself and what belongs to the external world. The self develops as the child learns through the process of introjection to incorporate objects through a "swallowing" process or conversely through projection by "experiencing one's own feelings as if emanating them from someone or something in the external world" (Kahn & Wright, 1980, pg. 28).

Psycho-social Stages

Erikson expanded Freud's construct of psychosexual developmental stages to include psycho-social processes designed for resolution of potential developmental crises which create vulnerabilities in the individual at selected stages. These stages are based on the epigenetic principle which proposes that all humans have a ground plan in utero. After birth, growth takes place according to the ground plan where the parts grow to form a functioning whole. The child grows amid a culture that affords him certain opportunities and imposes certain limitations. Through the process of crisis resolution at each stage, the individual becomes a distinct personality. Freud focused on the development of the id while Erikson's focus is on the socialization process of the ego (Lerner, 1976). The ego is shaped by social and cultural factors in the individual's environment.

In discussing the ego and the self, Erikson (1956) refers to the self as the "object," whereas the ego is the "subject," and he proposes that the body ego relates to the art of self dealing with the actual attributes of the organism.

Identity formation, therefore, has a self-aspect and an ego aspect; the self-aspect includes the body ego. This writing is concerned with the self aspect of identity which seems applicable to nursing since it is concerned with the physical body in relation to the self.

According to epigenetic principle, these stages are interdependent. The "seed" for each stage is present at all times (Erikson, 1982) and during the developmental process a crisis develops, during which a particular stage becomes the focus of the person's energy. A stage that has been the focus of the developmental process for a time does not stop development after the initial process is begun. Each stage adds new dimensions, understanding and reinforcement to the past stages. Self-identity as defined by Erikson (1956) is achieved in adolescent years but is "constantly lost and regained" (pg. 74).

Erikson proposes that a concept of self evolves through the resolution of specific tasks at each of eight stages. The first stage is labeled as **basic trust versus mistrust**. The development of trust according to Erikson (1956) results in an "attitude" toward the self and the world. This development of trust occurs in the first year of life. The infant develops trust from stimuli received via neurological and sensory receptors primarily in the mouth but also the skin. Trust, initially, is developed through the care giver's input; this input includes oral feedings or sensory stimulation from intimate contact. During this stage, the individual builds self-confidence by developing trust in the self and the physical body. This lays the foundation for the feeling of self-assurance that allows the individual to separate himself or herself from the care-giver and to face the world as an autonomous individual with confidence.

Developmental Theory as Applied to the Ostomy Patient

Trust

If one accepts the assumption of developmental theory that these stages can reoccur, then it is appropriate to theorize that the patient with an ostomy may (or must) reestablish trust in the physical body. In this instance, the person again develops trust through neurological control, i.e., learning new dexterity

skills. This is an expansion of Erikson's description of trust to make it useful to nurses in clinical practice. The description of trust as trust in the physical body is meaningful to the nurse in describing and understanding patient behavior. Just as the child develops trust in "self," the patient develops trust in his physical body and therefore moves out on his own toward independent self-care. This development of trust in the physical body after colostomy surgery is demonstrated by an attitude of self-acceptance of the physical body as it is after surgery and re-entry into a former lifestyle. This self-acceptance is demonstrated by a willingness to be involved in self-care, autonomy in the Erikson Theoretical Framework. Self-acceptance moves the person on the road to recovery, theoretically forward one developmental stage.

The trust developed in the self and the external world has some of the same theoretical characteristics as self-acceptance. Self-acceptance is the ability to rely upon or trust the self, the environment and the physical body without comparing the self to others or to socially established norms (Wright, 1983). This trust in self, environment and the physical body is maintained through behavior that is acceptable in this socio-cultural milieu (Barber, 1983). This behavior, indicative of acceptance, concerns the health-care providers when the patient feels unaccepted because of alterations in the body due to illness or treatment and therefore does not participate in self-care. The patient with a colostomy has old established behavior patterns that have allowed feelings of self-acceptance or trust in the physical body but, post-operatively, that patient must re-establish those feelings of self-acceptance.

The patient with a new ostomy mourns the loss of the former body and must develop trust in the new physical body which can then lead to self-acceptance. This process of self-acceptance occurs through acceptance of new values with respect to the new physical body (Dembo, Leviton and Wright, 1956; and Wright, 1983). Thus the patient can accept or trust his physical body because of these altered values. This process is a subjective cognitive evaluation of the physical body as it previously existed as compared with its present after the alteration resulting from a colostomy. The successful resolution of this process results in a willingness to be involved in self-care and the motivation of

the individual to learn self-care, and to make alterations in one's lifestyle as needed. This process occurs through four value changes: 1) enlargement of scope of values; 2) a change from comparative values to asset values (Dembo, et al, 1956, 1975); 3) the containment of disability effects; and 4) subordination of physique (Wright, 1983).

The enlargement of the scope of values allows the mourning process to occur and allows for the reassessment of previously accepted standards of measurement which may include values regarding physical attractiveness and physical abilities. During this process, the patient mourns and lets go of the former standard of evaluation and finds new criteria to make the physical body acceptable. During this phase suicidal ideation may occur. Suicidal ideation did occur in ten percent of the ostomy patients (Wirsching, et al, 1975). Successful resolution of the mourning process occurs when a patient decides that life can be lived in spite of the losses. The person again sees value in life and this gives the person the motivation to go through the necessary processes. When the patient has crossed this hurdle, he is willing and motivated to live, to learn and to identify things in his life that make this effort worthwhile.

The importance of physical appearance is a reflection of our culture (Wright, 1983) so appearance is a major value that must be assessed in the recovery process (Dembo, et al, 1956, 1975). In successful resolution, the importance of physical appearance decreases during the process of resolution. The individual finds reasons for self-acceptance other than physical appearance. The person who has made this value change will no longer devalue himself due to the physical alteration that has occurred because of the ostomy.

The patient changes from comparative values to asset values when considering the physical alteration (ostomy) and the physical status of others (Dembo, Dembo, et al, 1956, 1975). To achieve this value change, the patient who has mourned his former self, can now view his current status as an asset. For the ostomy patient, this means mourning for his rectum and its functional loss, but then seeing the colostomy as an asset and realizing that he is not to be compared to other persons who don't have a colostomy. The patient with the

ostomy would accept and trust the colostomy as a value equal to that of the rectum that was lost when this value change has occurred. The patient who has made this value change also views any new situation as a challenge rather than thinking how much easier it would have been in his former state. In a culture that is performance conscious, the person with a physical alteration learns to value the ability to function as an asset and the satisfaction obtained from performance is intrinsic rather and not dependent upon an extrinsic criterion.

The patient with a physical alteration, i.e., ostomy, learns to contain the disability effect (Wright, 1983) which implies that only those areas of life that are directly affected by the disability are considered problematic and there is not a "spread" to other areas of life. The self-acceptance that has developed in areas that are not affected by the patient having an ostomy remain unaffected. The patient with an ostomy may have social concerns such as odor, flatus or spillage which may be valid but there are many life situations where the person previously obtained pleasure that can remain pleasant. Also, social isolation does not need to occur because modern appliances and sprays to eliminate odor make this an unfounded - but none the less a real - fear. This component of the process also includes what Dembo, et al (1956, 1975) term, "...the possession versus personal characteristic value change." This value change occurs in the ostomy patient when the rectum that was lost is viewed as a former possession but not an actual personal characteristic. The possession that was lost had certain functional capacities but these functions can be done equally well by the colostomy bag. The lost rectum and the new colostomy are not characteristics of the person and therefore are not related to self-evaluation.

The last value change necessary for self-acceptance to occur is the subordination of physique (Wright, 1983), which is, essentially, being able to see the values in other areas of life which are unrelated to our cultural value of the body beautiful phenomenon. The person with an ostomy may have a less beautiful body to use sexually, according to our social criteria, for example, and may have decreased sexual ability (Wabrek, et al, 1980), but there may be variations in sexual activity that the patient can learn which he or she will find equal in satisfaction to the methods used before surgical alteration of the body.

One component of the development of trust, then, can be theorized to result in an attitude of self-acceptance which promotes willingness to be involved in self-care. Self-acceptance can be established after colostomy surgery through four value changes as has been discussed. Self-acceptance could continue to increase as the patient's willingness and ability to manage his colostomy increase.

Autonomy

Autonomy versus shame and doubt is the second stage in the developmental process of forming a "self-concept," according to Erikson. Erikson's definition is oriented toward behavior rather than a reflection of reliance on psychological mechanisms that allow or disallow autonomous behavior to occur. Since a major development in this phase is control of the physical body and an increasing awareness of the body as opposed to the environment, Erikson's definition is a more functional approach. An outcome of this stage is an autonomous feeling concerning the body, emotions, and interactions with the environment that outweighs shame and doubt. The patient learns to control behavior in a socially appropriate manner during this stage which is equivalent to the adult social institution of law and order. Autonomy developed during this stage allows for environmental exploration which enhances the object-relationship process. The child begins to differentiate self from the environment. Anal control is a major developmental task of this stage, which is expressed again in the colostomy patient's desire for stoma control. This type of control is particularly important in this culture due to the emphasis on cleanliness (Erikson, 1956).

One interpretation of autonomy that concerns the nurse is autonomy in actual physical care and the activities of daily living which leads to a sense of control that frees the individual to focus on other areas of life. In learning self-control, the individual is believed to increase autonomy and consequently have less need for assistance from others (Szasz, 1983). The individual learns control over basic body functions in a socially acceptable manner early in life; the person with an ostomy learns new methods of controlling fecal elimination.

The patient with a recent ostomy has numerous obstacles to overcome before she or he feels is able to exercise adequate control which can be reflected in autonomous behavior. Due to cultural and social norms, the patient with an ostomy has fears of leakage, gas and odors (Follick, Smith & Turk, 1984). Follick, et al (1984) report 38 percent of the patients had problems with leakage, 37 percent had odor problems, while 34 percent had noise problems. Wirsching, Druner & Herrmann(1975) report 30 percent of their subjects with ostomies had a change in social activities, 44 percent were sensitive about their appearance, 31 percent had fears of odor and leakage which directly affected social activity and 28 percent feared social reaction to the stoma.

This lack of control of bodily function was related, apparently, to psychological problems. Follick, et al (1984) report 33 percent of their subjects had feelings of depression, 24 percent had feelings of anger and irritability, while 34 percent had anxieties due to the ostomy. Wirsching, et at (1975) indicate that women, especially young women, had more feelings of hopelessness and fear than men, although men had a higher level of social dysfunction. Wirsching, et al (1975) report 10 percent of the patients considered suicide and there were reports of decreased self-esteem, hopelessness, helplessness and sadness.

With respect to autonomy, the patient with a new colostomy is most concerned about: 1) functional self-care; 2) responses from others, positive or negative; and 3) his or her ability to maintain autonomy through colostomy care. Functional self-care relates to the patient's actual ability to perform physical care. The patient's physical stamina determines to some extent how much the nurse can expect the patient to do and must be considered in planning the teaching process (Smith, 1985). In a successful nursing program, the nurse will show the patient that his ostomy can be managed and thus will promote the patient's sense of autonomy (Smith 1985).

Knowledge of the actual care of the ostomy is needed by the patient who wishes to become and remain autonomous in self-care. Knowledge is assessed by the nurse prior to patient discharge from the hospital. Self-care behavior that is evaluated by the nurse includes changing of the bag, emptying the bag, and

resumption of work and social activities. These activities of daily living are to be performed without interference from the bag either physically or psychologically, and are considered long-term indicators of development of trust and autonomy (Smith, 1985; Givens, 1984; and Broadwell & Jackson, 1982). Directly linked to the physical care is the affective response of the patient. Emotionally, the patient may not wish to do his care, but psychologically, being seen as autonomous may be the most positive feedback the patient can receive (Smith, 1985). Clinically, Alterescu (1985) observed that the ability to manage the ostomy may be the best emotional therapy for the patient but this has not been documented by empirical data.

The patient is taught basic bowel physiology and made aware of the sexual dysfunction which may occur (Givens, 1984). Information about physiology assists the patient in achieving autonomy and in managing the ostomy if problems occur. There can be a decrease in sexual function, and the patient will understand what is happening if information has been made available prior to the occurrence of sexual dysfunction.

The patient with a new colostomy experiences both positive and negative emotional responses to the changed body. These may include feelings of shame (Sutherland et al, 1952) which could interfere with self-care. A prerequisite to the achievement of autonomy is the ability to express the negative emotions in a socially acceptable manner. The process of developing emotional stability may begin with a basic understanding the emotions.

Autonomy, in summary, includes three categories: 1) functional self-care; 2) emotional responses which can be positive or negative and may include shame; and 3) knowledge about maintaining autonomy through colostomy care.

Psycho-Social Discomfort

Psycho-social well-being results from crisis resolution of each of the developmental stages (Erikson, 1956). Erikson does not define the antitheses of psycho-social well-being; it will be termed **psycho-social discomfort** in this

writing. Psycho-social discomfort is symptomatically experienced by the colostomy patient as anxiety, depression, suicidal ideation, sexual difficulty, and social isolation. These feelings are described in studies of post-operative experiences of the colostomy patients (Dlin, et al, 1972; and Wirsching, et al, 1975). The individual with psycho-social well-being has achieved the positive state of each of the bipolar components of the stages, i.e., the individual experiences trust rather than mistrust at the resolution of trust. Conversely, the individual that experiences mistrust rather than trust would be described as having psycho-social discomfort.

The behavior associated with psycho-social well-being or its counterpart, psycho-social discomfort, have not been empirically defined. Erikson (1956) does describe the manifestations of psycho-social well-being as: 1) the individual is at "home" in his body; 2) has a sense of direction in his life; 3) has an inner assurance that there will be recognition from significant others; 4) the individual is consciously aware of his status; 5) the unconscious component is available only to psychological testing; 6) the state of psycho-social well-being can be recognized in a non-clinical environment by untrained observers; 7) this status is generally obtained in late adolescence; and 8) it is assumed that this status varies continuously since self-identity is considered to fluctuate.

Erikson (1956) does describe the times when an adolescent is subject to identity or self-concept difficulty. These occur when there is need to commit to physical intimacy, to make occupational choices, in competition, and during times of psycho-social self-definition. These challenges parallel those of the patient with a new colostomy. There is: 1) fear of physical intimacy (Hurny & Holland, 1985; Orbach, et al, 1952); 2) the threat of loss of occupation which needs to be considered as the patient learns stoma management; 3) psycho-social self-definition reoccurs because socializing again is an issue in the colostomy population (Hurny & Holland, 1985).

According to Erikson (1956), behavior that may be seen in times of identity or self-concept difficulties are: 1) isolation, which is well documented in patients with colostomies (Hurny & Holland, 1985; Orbach, et al, 1952; and

Wirsching, et al, 1975), because of their tendency to socially withdraw; 2) avoidance of choices; 3) an inner vacuum; 4) lack of initiative, and 5) choice of a negative identity. Neither #2 nor #3 have been described in patients with an ostomies and #5, negative identity, is assumed to occur in patients with ostomies (Orbach et al, 1952; and Hurny & Holland, 1985), although it has not been measured.

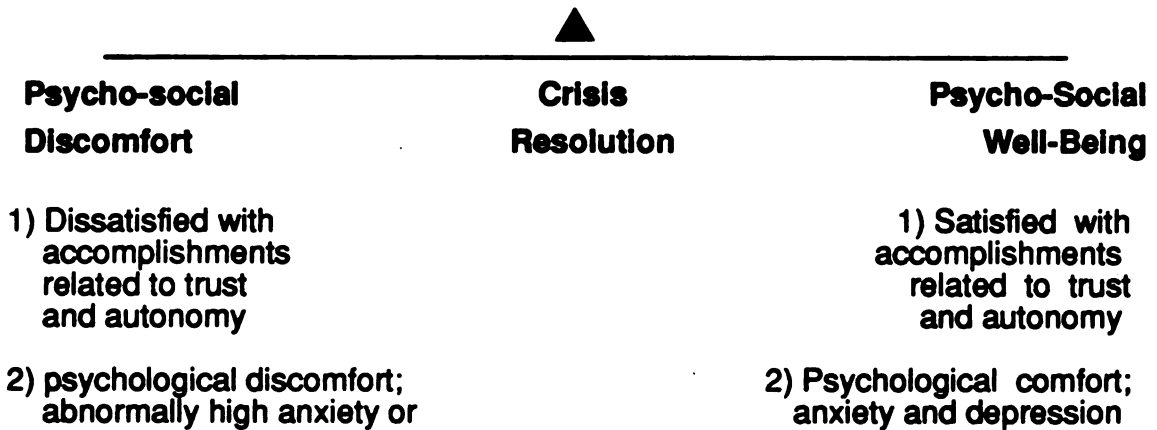
A comprehensive description of the behavioral indicators of psycho-social discomfort in people with colostomies has not been written, but current descriptive research data supports such psychological responses as depression and anxiety (Sutherland et al, 1952; Wirsching, et al, 1975). Somatization has been described in terms of preoccupation with colostomy function (Orbach et al, 1957; Orbach & Tallent 1965). Obsessive-compulsive behavior has been described with respect to frequent and ritualistic behavior related to colostomy irrigation (Orbach et al, 1957). Interpersonal sensitivity resulting in social isolation has been reported by colostomy patients (Sutherland et al, 1957; Wirsching, et al, 1975; Follick et al, 1984). This social isolation often stems from fear of rejection due to flatus. Other psychological responses may be hostility toward the person without a colostomy (who may be considered by the patient to be a "physically whole" person) and phobic anxiety regarding social gatherings or other closed areas.

The behavior which is characteristic of psycho-social well-being can be theorized to be the developmental behavior described by Erikson and would not be associated with behavior reflective of anxiety, depression or psychological discomfort. Behavior reflective of psycho-social discomfort would indicate inability to accomplish the developmental task and could include, for example, anxious or depressed behavior in the patient with a new colostomy. Psycho-social well-being and psycho-social discomfort can be visualized on a continuum (see Figure 3:1).

This study, therefore, will describe the trust, autonomy and psycho-social discomfort changes experienced by cancer patients whose treatment includes colostomies.

Figure 3.1

**Continuum of Psycho-social Well-Being
and Psycho-social Discomfort**



Summary

The three concepts to be investigated in this study are **Trust, Autonomy and Psycho-Social Discomfort.**

Trust is defined as an attitude of self-acceptance which promotes a willingness to be involved in self-care and which may be established through four value changes. It is theorized that self-acceptance may continue to increase as the patient's willingness and ability to manage his self-care progresses.

Autonomy, as it pertains to this study, includes three categories: Functional self-care; Emotional responses (which may be positive or negative and may include shame); and Knowledge (which, for this application, will be considered to be knowledge of the maintenance of the patient's colostomy). The determination of whether autonomy increases or decreases following surgery, and whether there are any gender-related differences in the levels of autonomy that are measured will be one focus of this study.

Psycho-social discomfort may be symptomatically experienced by the person with a colostomy as anxiety, depression, suicidal ideation, somatization, or interpersonal sensitivity. This study will be concerned with whether the levels of these aspects of psycho-social discomfort change from their pre-operative values with time following surgery, and whether there are any significant differences in the manner in which males and females experience psycho-social discomfort.

CHAPTER IV

METHODS

Questions this study will address:

1. In terms of Erikson's framework, what changes in trust are experienced by colostomy patients at four weeks and twelve weeks post-operative?
2. In terms of Erikson's framework, what changes in autonomy are experienced by colostomy patients at four weeks and twelve weeks post-operative?
3. What changes in psycho-social discomfort does the cancer patient with a colostomy procedure experience both before the operation, and four weeks and twelve weeks after the operation?

Assumptions

Several of the assumptions made in this study are based on the tenets of developmental theory (Chin, 1980). They are:

1. Trust and autonomy develop in a dynamic process according to the stages defined by Erikson.
2. Each subject has a self-concept which is measurable and is significant.
3. Self-concept changes occur in the colostomy patient. Reintegration of self-concept occurs in a developmental

sequence which parallels Erikson's theoretical framework of self-concept development.

4. The patient will answer the questionnaires honestly and accurately.

Theoretical Definition of Terms

Self-concept: The patient's perceived self-identity which is developed through resolution of eight developmental crises and is typified as a persistent feeling of sameness within the self and a persistent sharing of the same essential characteristics within others (Erikson, 1956).

Colostomy: A surgical opening of the colon. A portion of the colon is brought through the abdominal wall to form a single stoma (Mullein & McGinn, 1980).

Cancer: Cancer is a disease that attacks the basic life process of the cell, in almost all instances altering the cell's genome and leading to wild and unrestrained growth of cancerous cells (Burkhalter & Donley, 1978).

Trust: Erikson's (1956) first developmental crisis, resolution of which generates trustworthiness with respect to the self and ultimately self-acceptance of the physical body. Trust is demonstrated by a willingness to learn self-care.

Autonomy: Erikson's (1956) second stage of developmental crisis, resolution of which involves control by the patient over the physical body in several areas: functional control, affective control, and the learning of techniques required for adequate self-care (Smith, 1985; Alterescu, 1985; Givens, 1984; and Hurny & Holland; 1985).

Psycho-social well-being: A state generally achieved late in adolescence in which behavior is reflective of the eight developmental stages defined by Erikson (1956). People who have achieved this state feel at home in their bodies, have a sense of direction in life and have a feeling of assurance that

recognition will come for their being from significant others. People not experiencing psycho-social well-being may exhibit anxiety, and depression, and feel socially isolated.

Psycho-social discomfort: Dissatisfaction with developmental tasks resulting in the symptoms of anxiety, depression, social isolation and/or sexual difficulties (Sutherland et al, 1952; Dlin et al, 1972; Follick et al, 1984; and Wirsching et al, 1975).

Developmental process: The post-operative recovery experience of a patient with a colostomy is viewed as a developmental process which, through resolution of issues associated with trust and autonomy, culminates in the reintegration of his self-concept (Wright, 1983; and Erikson, 1956).

Operational Definitions

Self-concept is defined as the patient's perceived self-identity relative to Erikson's first two phases of **trust** and **autonomy**.

Trust is the feeling of acceptance of the physical body that results from value changes as measured by the Acceptance of Disability Modified Scale (ADM) (Trainor, 1982 and Linkowski, 1971). (see Appendix A).

Autonomy is the patient's perceived control over the physical body in terms of functional self-care, positive and negative affective responses, including feelings of shame, and knowledge about colostomy care and self-care. All three categories will be measured using the Ostomy Adjustment Scale (Olbrisch, 1983). (see Appendix B.)

Psycho-social discomfort symptomatic behavior resulting from the post-operative colostomy experience as measured by the Brief Symptom Inventory (Derogatis & Melisaratos, 1983) (see Appendix C).

Research Design

An exploratory study using three assessments (one pre-operative and two post-operative) was conducted to obtain descriptions of trust, autonomy and psycho-social discomfort during the post-operative phase of the colostomy cancer patient's recovery period. Only psycho-social discomfort was measured before the surgery. Trust and autonomy do not lend themselves to pre-operative measurement because those two concepts relate specifically to the colostomy experience.

The experience of the colostomy patient has been described in relation to pre-operative time, the hospitalization period, the convalescent period and the post-convalescent period (Dyk & Sutherland, 1956, and Hurny & Holland, 1985). This span of time was divided into periods of 10, 30, 60, 90, and 180 days following the operation by Oberst & James (1985). High-need times (during which the patient feels a need for professional assistance) for post-operative patients are: 1) two weeks after discharge (or 4 weeks post-operative) and, 2) three months post-operative. (Oberst and James, 1985) Therefore this study measured trust, autonomy and psycho-social discomfort 2 weeks after the patients were discharged from the hospital and 3 months after the operations.

Psycho-social discomfort was initially assessed in the hospital one or two days before the operation in order to establish a baseline of psycho-social discomfort which was assumed to be the result of patient's reaction to the diagnosis of cancer (Hurny & Holland, 1985) and to hospitalization.

The first post-operative assessment was four weeks after surgery or after the subject was involved in adjustment to home, family, and social routine. The Oberst & James (1985) study indicates three months post-operative as a time of greater need, but the exact sequence of responses, specific to the colostomy patient, is unknown because the data were not analyzed separately. Other studies were single assessments only, with post-operative assessment times varying in the study (Orbach & Tallent, 1954; Duke, 1957; Orbach, Bard & Sutherland, 1957; Wirsching, Druner & Herrmann, 1975; Dlin & Perlman, 1975; Wabrek et al, 1980; Follick et al, 1984).

Table 4.1 Study Design		
Assessment	Time Period	Instrument(s)
Assessment I	Pre-operative (1–2 Days)	Brief Symptom Inventory Scale
Assessment II	Post-operative (4 Weeks)	Brief Symptom Inventory Scale Acceptance of Disability Modified Ostomy Adjustment Scale
Assessment III	Post-operative (12 Weeks)	Brief Symptom Inventory Scale Acceptance of Disability Modified Ostomy Adjustment Scale

Description of the Research Setting

The facilities used were:

1. The University of California Medical Center at Los Angeles (UCLA), a 675 bed non-profit hospital;
2. The Veterans Administration Wadsworth Medical Center, 470 bed non-profit hospital;
3. The City of Hope Medical Center, a 175 bed non-profit hospital and:
4. The Glendale Adventist Medical Center, 452 bed not-for-profit institution.

These are all acute-care facilities staffed with enterostomal therapists who provide post-operative care. Nurse researchers and the enterostomal therapists from each facility helped recruit subjects for the study.

Sample

Human Subject's Assurance

Human subject's approval was obtained at the University of California, San Francisco Medical Center (see Appendix D) prior to obtaining consent from the hospitals in Southern California. Consent was obtained from the individual physicians before approaching the selected patients. Each hospital has its own protocol and forms that were used. Research subjects at UCLA were given an Information Sheet (see Appendix E).

There was no physical danger involved in this study. The subjects could have experienced psychological discomfort due to the sensitive nature of some of the questions. The topics related to actual stomal care had already been introduced by the stomal therapist so the patient should have had some ease in talking about this topic. The patient was given the option of withdrawing at any time and was instructed to refuse to answer any questions which caused discomfort as stated on the consent form.

Nature and size of the sample

The subjects must have been diagnosed as having cancer which required colostomy surgery as treatment. A sample of 30 adults who speak English was projected. Although a larger sample was considered desirable, 30 subjects is an adequate to perform descriptive statistics. Since convenience sampling was used, analysis based on statistical probability would not be valid and has not been done (Shavelson, 1981).

Criteria for Inclusion in Sample

1. Subject must have undergone colostomy procedure during the current hospitalization for treatment of a cancer.
2. Subject must speak and read English.
3. Subject must score at least 1 on the Short Portable Mental

Status Questionnaire indicative of no more than mild intellectual impairment (see Appendix J).

- 4. Subject must be between the ages of 35-75 years.**
- 5. Subject must be first-time colostomy patient with no previous temporary colostomy.**
- 6. Subject must live in the greater Los Angeles area.**

Subject recruitment began in two institutions in November of 1987, but since there were insufficient subjects available in the these first two institutions, recruitment was initiated at three additional institutions, one in May of 1988, one in July 1988 and one in September 1988. By December of 1988, 30 potential subjects had been recruited from these five institutions. Eight of these subjects had a bowel resection and therefore were therefore ineligible. Four others were disqualified for reasons indicated Table 4.2. Four others declined to participate for various reasons indicated Table 4.2. Initially, therefore, 14 subjects qualified for the study and participated in three, two, or one interviews. Two of these subjects were eventually excluded because each participated in only one interview (see Table 4.3).

Instruments

The Measurement of Trust

The dependent variable, trust, is measured by the Adjustment to Disability Modified (ADM) scale (Appendix A). The ADM is a 50-item scale designed to measure acceptance of an ostomy. The subject responds on a 6- point Likert scale which consists of the following responses: I disagree very much, I disagree pretty much, I disagree a little, I agree a little, I agree pretty much and I agree very much. The total score for this scale instrument is obtained by giving a score of 1 to 6 for each item; i.e., "I disagree very much" = 1 and "I agree very much" = 6.

Table 4.2		
Sample Attrition Factors		
Disqualified	Percent	Number
Had bowel resection without colostomy	57%	8
Didn't speak English fluently (Armenian & Spanish)	14%	2
Mother refused to allow (subject 19 years old)	7%	1
Patient declined to sign surgical consent and was "nervous about surgery"	7%	1
Participated in only one interview	14%	2
Total		14
Declined to Participate		
Schizophrenic	25%	1
Old stroke	25%	1
"Didn't want to"	50%	2
Total		4

The ADM scale was originally developed in Linkowski (1971) and modified by Trainor (1982). The original instrument (Linkowski, 1971) was developed to measure acceptance of a physical disability and then adapted by Trainor (1982) to measure acceptance of a colostomy by the ostomy population. One component of the broad concept of trust can be considered as the development of trust in the physical body which is expressed in acceptances of the physical body. This occurs through the process of a change in values (Dembo, et al, 1956). The modifications by Trainor (1982) consisted of changing the word disability to ostomy. During its developmental process, the instrument was evaluated by four graduate students in rehabilitation counseling who were familiar with its theoretical development by Dembo, Leviton & Wright (1956, 1975). This evaluation consisted of students first considering themselves as disabled persons who had accepted their disability and then as individuals

unaccepting of their disability to assure bipolarity of the items. Items that did not indicate consistent bipolarity were revised.

Table 4.3			
Subject Participation in Study			
Measurements Completed by Assessment Number			
Subject Number	1 (Pre-Op)	2 (Post-Op, 4 Weeks)	3 (Post-Op, 12 Weeks)
1	X	X	X
2	X	X	X
3	X	X	X
4 (eliminated)	X	O	O
5	X	X	X
6 (eliminated)	X	O	O
7	X	X	O
8	X	X	O
9	O	X	X
10	X	X	X
11	X	X	X
12	X	X	X
13	X	X	X
14	X	X	X
Totals	13	11	10
X = measurement obtained O = no measurement obtained			

Measures of concurrent validity were performed between the original AD scale and the Attitudes Toward Disabled Person Scale (Yuker, Block & Campbell, 1966). This scale was designed to measure the attitudes both disabled and non-disabled persons have toward physical disabilities. The results indicated a correlation coefficient of .80 which is statistically significant ($p = .001$) Linkowski, 1971). Factor analysis was done on the original tool from data collected at Woodrow Wilson Rehabilitation Center (WWRC) and on 55 disabled students at the University of Illinois. Both factor analysis results indicated a unidimensional concept without the four theoretical components on which the Dembo, et al (1956, 1975) theory was based.

The original (AD) instrument was administered to 46 patients with physical disabilities from WWRC and a split-half (odd-even) correlation of the AD scale for internal consistency was .86, and the Spearman-Brown Prophecy formula estimated full scale reliability to be .93 (Linkowski, 1971). The instrument was modified for persons with a colostomy (Trainor, 1982) and was tested on 148 persons with a colostomy. Internal consistency measures indicated a Cronbach's alpha coefficient of .9459. An item analysis was also done on the modified instrument with adequate correlations for all items except number 47, which was eliminated; correlational values are not reported (Trainor, 1982).

The Measurement of Autonomy

The dependent variable, autonomy, is measured by the Ostomy Adjustment Scale (OAS) (Olbrisch, 1983) (Appendix B). This instrument was developed to assess psycho-social adjustment to stoma surgery. Factor analysis was performed and five major categories emerged which include: 1) normal functioning which includes self-care activities; 2) positive response; 3) negative affective response to having a colostomy; 4) indications of feelings of shame; and 5) items related to knowledge in caring for the ostomy. These categories are appropriate indicators to assess the experience of the colostomy patient in becoming autonomous in the actual care of the colostomy. Items were developed from a review of the literature that indicated areas where patients previously have been found to make adjustments. Three persons with an ostomy and three professionals familiar with the procedure generated items regarding both the positive and negative aspects of living with an ostomy. The OAS employs a 6-point Likert scale where the subject responds to items by agreeing or disagreeing. The total score for this instrument is obtained by assigning one 1-6 score to each item; scores indicating disagreement are scored 1. The higher the total score, the higher the adjustment.

The OAS has been tested on 53 subjects who had ostomies. Discriminate validity was established by a negative correlation ($r = -.14$) with the Marlowe-Crowne Social Desirability Scale and a low correlation ($r = .02$) to the Texas Social Behavioral Inventory. Exploratory factor analysis revealed 12 factors, 5 of which accounted for 69% of the variance. These are described above.

Of the remaining factors, none account for more than seven percent of the variance. The initial sample was small and further validity studies are necessary. This instrument was chosen for its relationship to the theoretical definition of autonomy as defined in this study. The five factors that emerged and account for 69 percent of the variance are theoretically congruent with the three categories of autonomy.

Reliability studies for OAS included internal constancy measures of Cronbach's alpha coefficient of .87. Five items were eliminated due to low item-to-total correlations or low variance. The numerical values on which items were eliminated are not available. Of the data available (Olbrisch, 1983), items 22, 32, 33 and 34 have item-to-total correlations of .06 to .27, while item 1 has an $r = .75$. This indicates these items need further reliability evaluation. Test-retest was performed and produced a correlation coefficient of $r = .72$.

The Measurement of Psycho-social Discomfort

Behavior reflective of psycho-social discomfort related to ostomy procedures are measured by the Brief Symptom Inventory (BSI) (Derogatis & Melisaratos, 1983). The scale is a condensed version of the SCL:90 (Derogatis, Lyman & Covi, 1973). The BSI scale has been used to measure psychological responses in the cancer patient population (Derogatis, et al, 1979) and in another cancer population which included colostomy patients (Oberst, 1985). The original instrument is a 90-item questionnaire employing a Likert scale which was developed to measure symptomatic behavior of psychiatric outpatients. Patients respond to this in approximately ten minutes and the responses range from "not at all" to "extremely". Scores are obtained by giving a score of 0 to 4 for each item, i.e., a zero is given to the "not at all" response and a 4 is given to the response perceived as "extremely." This original instrument has been used to measure symptoms over time and result have been reported with respect to cancer patients (Craig & Abeloff, 1974; and Derogatis, Abeloff & Melisaratos, 1979). The previous cancer studies were done to establish a relationship between psychiatric symptoms and cancer patients as opposed to describing the feelings or behavior of the cancer patient after diagnosis. The sub-scales of this instrument are labeled somatization, obsessive-compulsive,

interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism (Derogatis & Melisaratos, 1983) and they are defined as follows:

Somatization refers to distress reflective in perceptions of bodily dysfunction; **Obsessive-compulsive behavior** is an indication of thoughts, impulses and actions that are experienced as unremitting irresistible and undesirable by the patient; cognitive difficulties, i.e., mind going blank, trouble remembering, also register on this scale. **Interpersonal sensitivity** measures feelings of inferiority (especially in the subject's comparison of the subject to others) and is evidenced by the person's discomfort during interpersonal interaction. **Depression** measures clinical depression syndrome. **Anxiety** measures clinical anxiety which includes restlessness, nervousness and tension; **Hostility** measures are indicative of anger and hostility. It also includes thoughts, feelings, and actions related to hostility. **Phobic anxiety** indicates feelings of fear related to travel, open spaces, crowds, public places plus social phobic behavior. The category of **Paranoid ideation** measures thoughts related to projective thinking, suspiciousness, delusions, loss of autonomy and grandiosity. And finally, the category of **psychoticism** measures such perceptions as auditory hallucinations, thought broadcasting, external thought control and external thought insertion.

The SCL:90 was subjected to validity analysis (Derogatis & Cleary, 1977). Results indicated 9 factors which accounted for 53 percent of the variance. The theoretical-empirical match was good except for the psychoticism category and this was attributed to its being the most recently developed scale.

Concurrent validity of the SCL:90 was assessed by giving it with the MMPI (Derogatis, Rickels & Rock, 1976). Results indicate a high degree of convergence for the nine primary symptoms of the SCL:90 with corresponding symptoms constructs on the MMPI except for the obsessive-compulsive scale. The MMPI had no comparable scale. Correlations ranged from $r = .75$ to $.41$ and all coefficients were significant ($p = .01$). Discriminate validity was demonstrated by the SCL:90's ability to differentiate between amputees and non-amputees, although no statistical measures were used to determine the

level of significance (Frank, Kashani, Kashani, Wonderlich, Umlauf & Ashkanazi, 1984).

Reliability studies indicate internal consistency coefficients for the SCL:90 sub-scales ranged from .90 to .77 with the psychoticism scale again indicating the lowest value (Derogatis, Rickels & rock, 1976). Test-retest reliability scores ranged between .78 and .90 (Derogatis, 1977).

The Brief Symptom Inventory (BSI) is developed from the SCL:90 and seems to measure the same content in 53 items as opposed to the 90 items on the SCL:90. The instrument takes only 10 minutes to administer which is an advantage for immediately post-operative patients. This instrument has norms developed from a) 1002 heterogeneous psychiatric patients; b) 719 non-patient normal subjects; and c) 313 psychiatric in-patients. Internal consistency α scores for the BSI scale range from $\alpha = .71$ to $\alpha = .85$ and test/retest correlation ranges from $r = .68$ to $r = .86$ (Derogatis & Melisaratos, 1983). Correlation coefficients for the BSI and the SCL:90-R were established on 565 psychiatric out-patients (Derogatis & Melisaratos, 1983). These values range from $r = .92$ to $r = .96$.

This instrument (BSI) has been used on a cancer patient population which included colostomy patients, but reliability and validity data regarding that administration are not available (Oberst & James, 1985). Demographic data with respect to age, sex, diagnosis, occupation, education, and ethnic group will be gathered by the question on the form in Appendix K. These data are gathered only to describe the sample with these different criteria.

Mental Status

The Short Portable Mental Status Questionnaire (SPMSQ) was used to exclude subjects that have decrease cognitive functioning due to organic disease. The SPMSQ standardization and validation procedure included testing 997 elderly persons from the general community. Also, 141 elderly persons who were referred to multipurpose clinics for psychiatric, health or social reasons, and 102 elderly persons who were living in institutions such as nursing homes,

homes for the aged or state mental hospitals. Standard performance scores were established for the categories of 1) intact mental functioning; 2) borderline or mild organic impairment; 3) definite but moderate organic impairment and 4) severe organic impairment.

Validity was established using two populations, one with 141 elderly subjects and the other with 102 elderly subjects. A significant relationship ($p < .001$) relationship was established between a diagnosis of organic brain syndrome and impaired score on the SPMSQ. Reliability was established by test-retest measurement with a four week interval between measurement times. Two groups of subjects were ($n = 30$, $n = 29$) and correlations of $r = .82$ and $r = .83$ were obtained.

Data Collection Method

The pre-operative questionnaire was answered in the patient's room in the hospital. All questionnaires were answered with the interviewer and the interviewee present when possible. The interviews at weeks four and twelve were done either in the patient's home or at the clinic (depending upon travel considerations) with only the interviewer and the subject present whenever possible.

Data was collected by having subjects complete Likert-type questionnaires except in the case of the Short Portable Mental Status Questionnaire (SPMSQ), which was completed by the interviewer on the basis of the subject's responses. These self-report measurements are subject to several limitations: 1) the depth or clarity of the individual's own self-awareness or insight was not assessed and insight of the subject could be influenced by his or her level of education and intelligence; 2) the subject's language may not be adequate to represent the subject's feelings, and there could be some confusion over the connotation and denotation used in the questionnaires and responses; 3) socially, we are expected to hide our feelings, so a subject may respond in a way she deems socially desirable; 4) the content of self-reporting is limited to what the individual chooses to disclose. With all its limitations, however,

self-reporting is still a valuable tool because it is a reflection of the patient's perception of the events affecting his life at given moments in time.

Data Analysis

Data was coded as interviews were completed and was entered into a computer where it was checked for internal consistency by a computer error checking and correction program. The statistical computer program used was SPSS. This program examines all entries and questions those entries which fall outside of prescribed coding ranges. Data was statistically analysed by total scores for the constructs of trust, autonomy and psycho-social discomfort.

CHAPTER V

RESULTS

Study Sample

The study sample consisted of twelve patients admitted to one of four medical centers for colostomy surgery due to cancer. Age range was 41 to 74 with a mean age of 59.4. Eight were male and four were female (see Table 5.1). The majority of the sample were Caucasian (10), married (9), had completed some high school and had at least some college (4).

Five of the sample had colon cancer, five had rectal cancer and two had anal cancer. Ten of the subjects were aware of their diagnoses only one to two weeks prior to surgery. The types of therapy received they received are listed in Table 5.3. A description of the sample is found in Appendix M.

Results of Trust Measurements

The study question: What changes in trust are experienced by colostomy patients at four weeks and twelve weeks post-operative?

The mean score increased from 203.6 (S.D. = 31.7) at four weeks to 221.7 (S.D. = 43.6) at twelve weeks (see Table 5.2). The large standard deviation figures are to be expected because of the small sample size and lack of homogeneity within the sample. Because of the large standard deviation, caution is advised in the use of this data in any future studies or projections.

With the mean trust scores sorted by gender males score higher overall (see Figure 5.1). At four weeks the males mean is 209.0 and the females 192.7. The mean trust score at twelve weeks for males is 241.7, and for females is 191.8. The males' score increased from 209.0 at four weeks to 241.7 at twelve weeks while there was little change in the female score.

Table 5.1
Description of the Sample by Age, Sex, Race, Martial Status, Education and Occupation. n = 12.

Age	Number	Percent	Marital Status	Number	Percent
40-45	2	16.7%	Married	9	75.0%
46-55	1	8.3	Single	1	8.3
56-65	5	41.6	Widowed	1	8.3
66-70	2	16.7	Divorced	1	8.3
71-74	2	16.7			
Sex			Education		
Male	8	66.7%	Less than 12 years	11	16.7%
Female	4	33.3	12 years	7	58.0
			13-16 yrs.	3	25.0
			16+ yrs	1	8.3
Race			Occupation		
Caucasian	10	83.3%	Self-employed	1	8.3%
Black	1	8.3	Professional	2	16.7
Armenian	1	8.3	Blue Collar	3	25.0
Current Residency			Semi-Prof.	3	25.0
Less than 3 months	2	16.7%	Disabled	1	8.3
Less than 5 years	1	8.3	Housewife	1	8.3
5-10 years	3	25.0	Retired	1	8.3
More than 15 years	6	50.0			

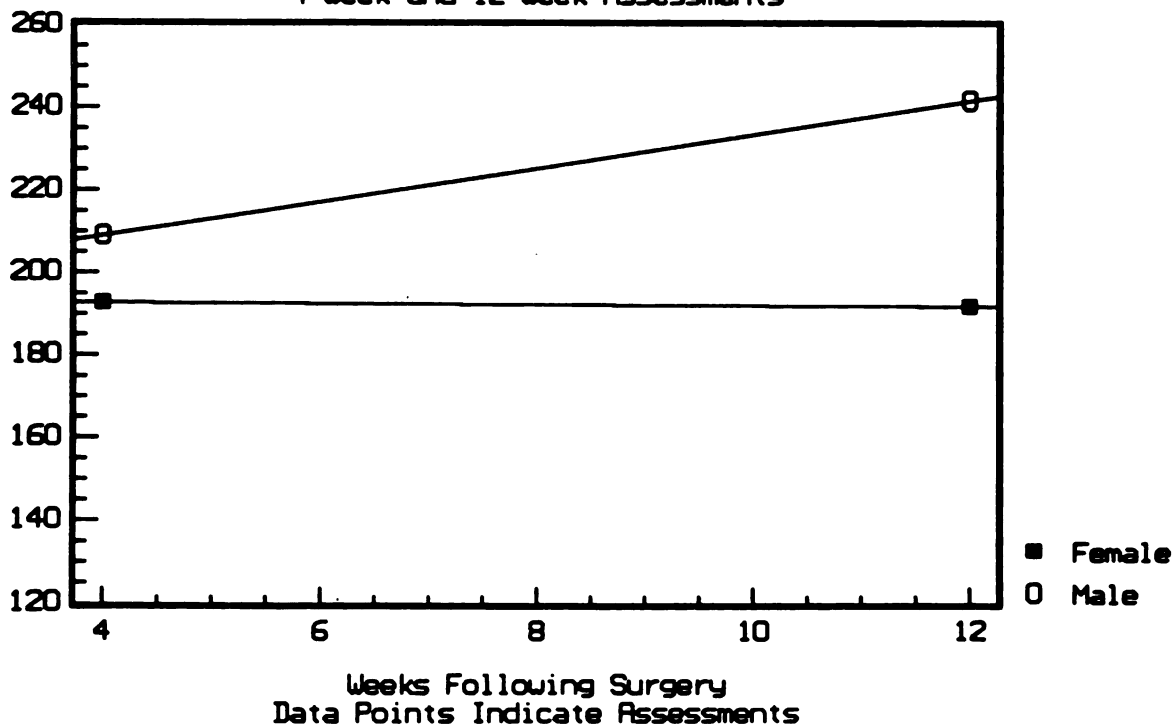
Table 5.2
Trust by Mean Scores and Standard Deviation (S.D.) at Four and Twelve Weeks Post-Operative

Assessment	Mean	S.D.	n
4 weeks	203.6	31.7	9
12 weeks	221.7	43.6	10

Table 5.3
Description of the Sample by Variables Diagnosis, Type of Surgery, Stage of Disease, Type of therapy, and Time since Diagnosis. n=12

Diagnosis	Number	Percent
Colon Cancer	5	41.7%
Rectal Cancer	5	41.7
Anal Cancer	2	16.6
Time since diagnosis		
1 to 2 weeks	3	25.0%
More than 1 month	6	50.0
6 months to one year	1	8.3
More than 1 year	2	16.7
Type of Therapy		
Pre-operative radiation	2	16.7%
Chemotherapy	3	25.0
Post-operative radiation	2	16.7
No radiation or chemotherapy	3	25.0
Unknown	2	16.7

Figure 5.1
Mean Trust by Gender at
4 Week and 12 Week Assessments



Results of Autonomy Measurements

The study question: What changes in autonomy are experienced by colostomy patients at four weeks and twelve weeks post-operative?

The data shows a decrease from a mean of 146.2 (S.D. 32.9) at four weeks to 143.9 (S.D. 32.1) at twelve weeks. This trend of decreased mean scores in the autonomy category is similar to that of the self-issues category (the largest decrease of over 65.2 at four weeks and 61.4 at twelve weeks).

	4 Weeks			12 Weeks		
Categories	Mean	S.D.	n	Mean	S.D.	n
Functional self-care	28.8	7.4	9	28.1	8.1	9
Emotional Affect	49.7	12.7	10	46.3	10.1	10
Learning	11.0	1.4	9	9.7	1.83	10
Self issues	65.2	11.1	9	61.4	13.7	10

In the category of self-issues, two different groups of items were examined, the first consisting of items related to sexual activity and the second consisting of items such as self-confidence, self-respect, body (like or dislike) and depression. The three items related to sexual activity (n = 10) have a mean response of 3.0 at four weeks on a scale of 1 to 6 where 1 is low and 6 is high; at twelve weeks the mean is again 3.0 (n=10). In the group of self-issues, self-confidence, self-respect, body (like or dislike) and depression, the average mean response was 4.6 at four weeks and 4.5 at twelve weeks, a slight increase over time.

In comparing mean autonomy mean scores by gender, the males have higher mean scores than the females (see Table 5.5). At four weeks the females report 130.0 and the males 154.3, but at twelve weeks the males' mean scores decrease slightly to 153.0 while the female mean scores increase to 134.7. However, the female mean scores are still lower than the male mean scores.

	4 Weeks						12 Weeks					
	Male			Female			Male			Female		
	Mean	S.D.	n	Mean	S.D.	n	Mean	S.D.	n	Mean	S.D.	n
Total Autonomy	154.3	17.4	4	130.0	60.8	2	153.0	26.1	4	134.7	38.8	4
Functional Control	30.5	6.6	10	23.3	9.33	3	32.8	6.1	5	22.3	6.6	4
Affective Control	51.3	5.9	7	46.0	24.2	3	47.2	8.4	6	45.0	13.5	4
Learning	10.7	1.5	7	12.0	0	2	9.5	1.8	6	10.0	2.2	4
Self Issues	66.5	7.4	5	62.7	18.6	3	64.6	8.7	6	57.5	19.1	4

The mean scores for the autonomy category sorted by gender follow the same trend of producing lower scores at twelve weeks than at four weeks, with females having lower scores than males (see Table 5.5). The only deviation is that males report a slight increase in functional self-care from 30.5 at 4 weeks to 32.8 at twelve weeks. The category of learning shows a decrease in mean at twelve weeks as compared to four weeks (see Table 5.5). The male knowledge level is 10.7 at four weeks but only 9.5 at twelve weeks, while the female knowledge level drops from 12.0 at four weeks to 10.0 at twelve weeks.

The category of self issues shows a decrease at twelve weeks as compared to four weeks in both males and females (see Table 5.5). The males mean score is 66.5 at four weeks, and 64.6 at twelve weeks, while the females mean score is 62.7 at four weeks and 57.5 at twelve weeks.

In the category of items related to sex under self-issues, both males and females show an increase from week four to week twelve, but the males were higher at both periods. At four weeks, the males' mean is 3.1, while the female mean is 2.9; at twelve weeks, the male mean is 4.12, while the female mean is 3.25.

In the category of self-issues, those having to do with self-confidence, self-respect, body image and depression, both the males and females show slight

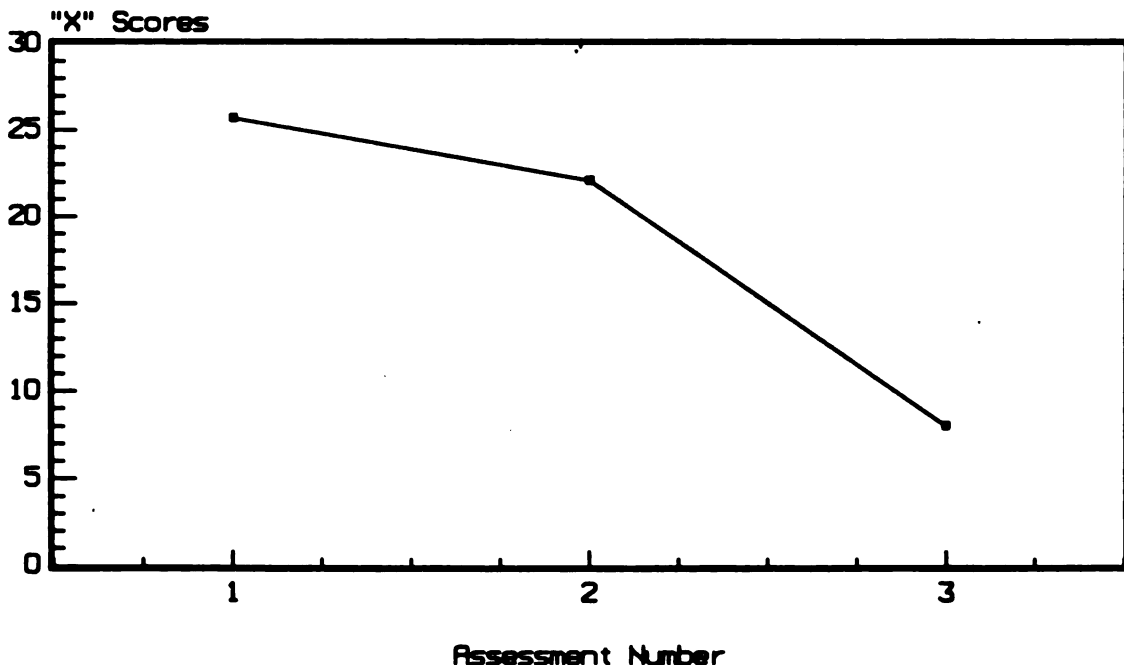
decreases in their mean scores at twelve weeks. The males dropped from 4.6 at four weeks to 4.5 at twelve weeks, while the females dropped from 4.3 at four weeks to 4.1 at twelve weeks.

Results of Psycho-Social Discomfort Measurements

The study question: What changes in psycho-social discomfort does the cancer patient with a colostomy procedure experience both before the operation, and four weeks and twelve weeks after the operation?

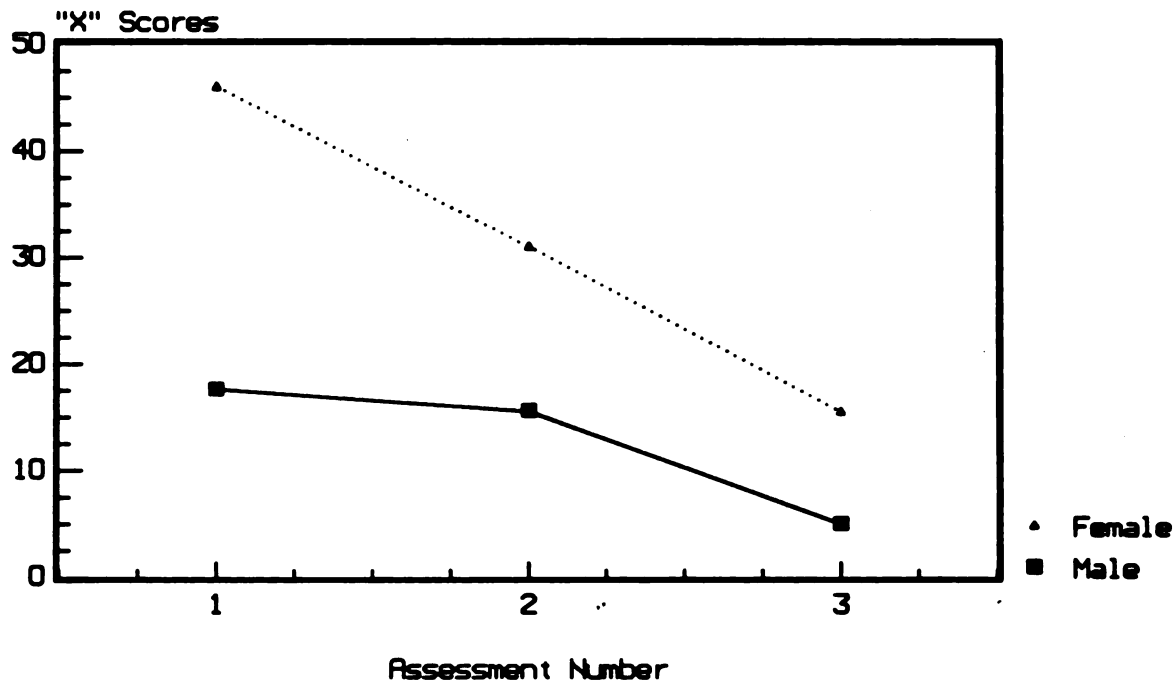
The mean scores for psycho-social discomfort decreased as a function of time (see Figure 5.2). The pre-operative mean is 25.7 but it decreases slightly

Figure 5.2
 Psycho-social Discomfort by "X" Score
 at Pre-Operative (1), 4 Week (2) and
 12 Week (3) Assessments



to 22.1 by four weeks and then drops steeply to 8.0 at twelve weeks. The mean scores for psycho-social discomfort sorted by gender indicate the females consistently score higher (See Figure 5.3). Before surgery the female mean score was 46.0 while the male score was 17.6. At four weeks after surgery, the mean female score was 31.0, while the male mean score was 15.5. At twelve weeks,

Figure 5.3
 Psycho-Social Discomfort in Male and
 Female Patients by "X" Scores at Pre-Op,
 4 Week and 12 Week Assessments



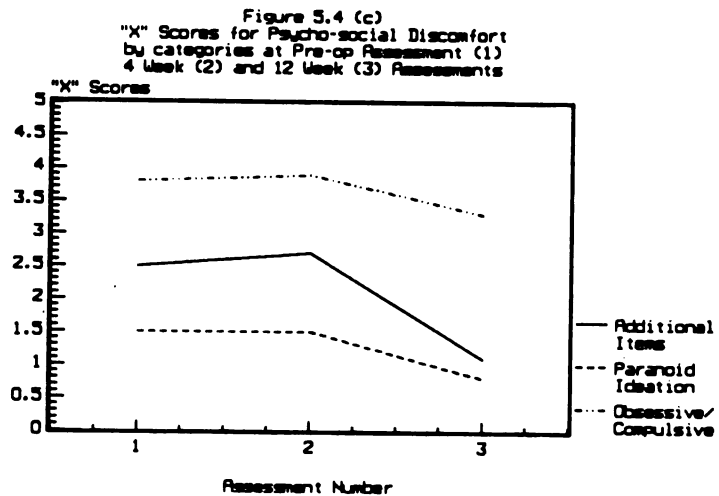
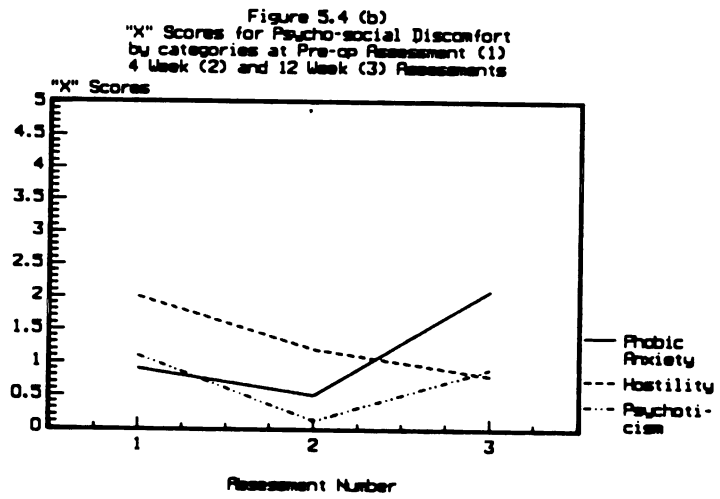
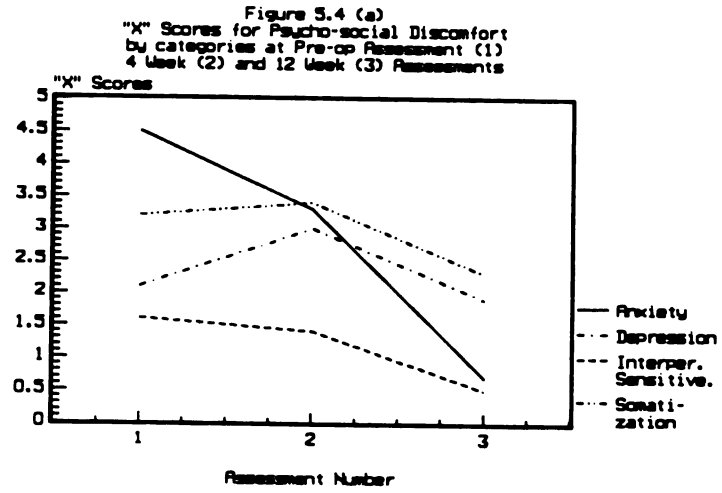
the female mean score was 15.5 while the female mean score was 5.0. The mean scores of psycho-social discomfort by categories changed at most of the three measurement points (1, 2 & 3) but several categories (paranoid ideation, psychoticism and phobic anxiety) remain relatively constant over time (see Figure 5.4).

Pre-operative anxiety, as might be expected, had the highest mean score (4.5) but decreased to 3.3 at 4 weeks and .7 at 12 weeks.

The second highest category was obsessive/compulsive behavior, with a mean score of 3.8 which increased slightly to 3.9 at four weeks and decreased to 3.3 at twelve weeks (see Table 5.6).

Somatization is third highest with a mean score of 3.2, which increased to 3.4 at the four week measurement and decreases to 2.3 at twelve weeks.

Figure 5.4
Mean Scores for Psycho-social Discomfort by Categories



The mean score for the depression category increased from 2.1 pre-operative to 3.0 at 4 weeks and then decreased to 1.9 at 12 weeks post-operative.

The category of additional items includes items related to appetite, sleeping difficulties, thoughts of death and dying, and feelings of guilt. The mean score increased from 2.5 pre-operative to 2.7 at four weeks and then decreased to 1.7 at twelve weeks post-operative.

	Somatization			Obsessive/Compulsive		
	Mean	S.D.	n	Mean	S.D.	n
Pre-operative	3.2	4.7	10	3.8	5.5	10
Post-op, 4 weeks	3.4	3.8	9	3.9	4.3	9
Post-op, 12 weeks	2.3	3.9	10	3.3	4.2	10
	Interpersonal Sensitivity			Depression		
	Mean	S.D.	n	Mean	S.D.	n
Pre-operative	1.6	1.8	9	2.1	3.4	11
Post-op, 4 weeks	1.4	1.9	10	3.0	4.1	10
Post-op, 12 weeks	0.5	0.9	10	1.9	3.8	10
	Anxiety			Psychoticism		
	Mean	S.D.	n	Mean	S.D.	n
Pre-operative	4.5	5.2	8	1.1	1.7	10
Post-op, 4 weeks	3.3	5.0	9	0.11	0.3	9
Post-op, 12 weeks	0.7	1.1	9	0.9	1.6	10
	Hostility			Phobic Anxiety		
	Mean	S.D.	n	Mean	S.D.	n
Pre-operative	2.0	2.9	10	0.9	1.0	11
Post-op, 4 weeks	1.2	1.7	10	0.5	2.2	10
Post-op, 12 weeks	0.8	0.9	10	2.1	3.0	9
	Paranoid Ideation			Additional Items		
	Mean	S.D.	n	Mean	S.D.	n
Pre-operative	1.5	1.7	10	2.5	1.8	10
Post-op, 4 weeks	1.5	2.8	10	2.7	3.4	10
Post-op, 12 weeks	0.8	0.9	10	1.1	1.7	10

The mean score for the category of paranoid ideation was 1.5 pre-operative. It did not change at week four, post-operative but dropped to .8 at week twelve, post-operative.

The mean score for hostility is 2.0 pre-operative and it decreases to 1.2 at four weeks post-operative and to 0.8 at twelve weeks.

The mean score in the category of phobic anxiety is .9 pre-operative and decreases to .5 at four weeks post-operative, but increases to 2.1 at week twelve post operative (see Table 5.6).

The mean score for the category, interpersonal sensitivity, gradually decreased at each assessment: 1.6 pre-operatively, 1.4 at the four-week assessment and 0.5 at the twelve week assessment. The mean score for the category of psychoticism showed a similar trend: 1.1 pre-operatively, 0.11 at four weeks post-operative, and 0.9 at twelve weeks.

Gender Variations

In comparing the mean scores for psycho-social discomfort when the scores are sorted by category and gender (see Figure 5.5), the females' scores were consistently higher, especially in the categories of somatization, anxiety, depression, obsessive/compulsive behavior and phobic anxiety (see Table 5.6).

In the **somatization** category, at four weeks post-operative, the male mean score was 2.2 and the female mean score was 6.0; at twelve weeks post-operative the male mean is .8 and the female mean is 4.5. In the category of **obsessive/compulsive behavior**, the females had consistently high mean scores, 6.0 pre-operative, 5.0 at week four post-operative and 5.25 at week twelve; 2.3, 3.0 and 2.0 were the males' mean scores for the same measurements.

In the category of **depression** the male mean score was .2, and the females' mean score was 4.5 at twelve weeks post-operative. In the category of **additional items** at four weeks post-operative, the male mean score was 1.4 and the female mean score was 5.7.

Table 5.7							
Description of Psycho-Social Discomfort by Mean Scores and Standard Deviation (S.D.), by Category, Pre-operative, Four Weeks Post-operative and Twelve Weeks Post-operative in Cancer Patients with Colostomies Sorted by Gender							
	Mean	S.D.	n	Mean	S.D.	n	
Male	Somatization			Obsessive/Compulsive			
Pre-operative	2.8	2.5	6	2.3	1.4	6	
Post-op, 4 weeks	2.2	2.8	6	3.3	3.9	6	
Post-op, 12 weeks	0.8	1.2	6	2.0	2.4	6	
Female							
Pre-operative	3.8	7.5	4	6.0	8.8	4	
Post-op, 4 weeks	6.0	5.0	3	5.0	5.6	3	
Post-op, 12 weeks	4.5	5.7	4	5.3	6.0	4	
Male	Interpersonal Sensitivity			Depression			
Pre-operative	1.4	2.2	5	0.9	1.2	7	
Post-op, 4 weeks	1.4	1.9	7	2.7	3.8	7	
Post-op, 12 weeks	0.5	0.8	6	0.2	0.4	6	
Female							
Pre-operative	1.8	1.5	4	4.2	5.0	4	
Post-op, 4 weeks	1.3	2.3	3	3.7	5.5	3	
Post-op, 12 weeks	0.5	1.0	4	4.5	5.2	4	
Male	Anxiety			Psychoticism			
Pre-operative	3.6	3.6	6	0.8	1.2	6	
Post-op, 4 weeks	2.7	4.1	6	0	0	6	
Post-op, 12 weeks	0.2	0.4	6	0.	0	6	
Female							
Pre-operative	6.0	7.9	3	1.5	2.4	4	
Post-op, 4 weeks	4.7	7.2	3	0.3	0.6	3	
Post-op, 12 weeks	1.7	1.5	3	2.3	1.9	4	
Male	Hostility			Phobic Anxiety			
Pre-operative	1.3	0.8	6	0.7	1.0	7	
Post-op, 4 weeks	1.1	1.9	7	0.9	1.6	7	
Post-op, 12 weeks	0.5	0.8	6	0.8	1.3	6	
Female							
Pre-operative	3.0	4.7	4	1.3	1.3	4	
Post-op, 4 weeks	1.3	1.5	3	3.0	3.0	3	
Post-op, 12 weeks	1.3	1.0	4	4.7	4.2	4	
Male	Paranoid Ideation			Additional Items			
Pre-operative	1.7	1.8	7	2.3	1.9	6	
Post-op, 4 weeks	2.1	3.2	6	1.4	1.8	7	
Post-op, 12 weeks	0.7	1.0	5	0.	0	6	
Female							
Pre-operative	1.3	1.9	4	2.8	2.1	4	
Post-op, 4 weeks	0	0	3	5.7	4.7	3	
Post-op, 12 weeks	1.0	0.8	4	2.8	1.7	4	

Figure 5.5

Graphic Representation of Psycho-social Discomfort Variables by category and Gender, Pre-operative (Assessment 1), at 4 Weeks Post-operative (Assessment 2) and at 12 Weeks Post-operative (Assessment 3).

Figure 5.5 (a)
Somatization
by Male and Female

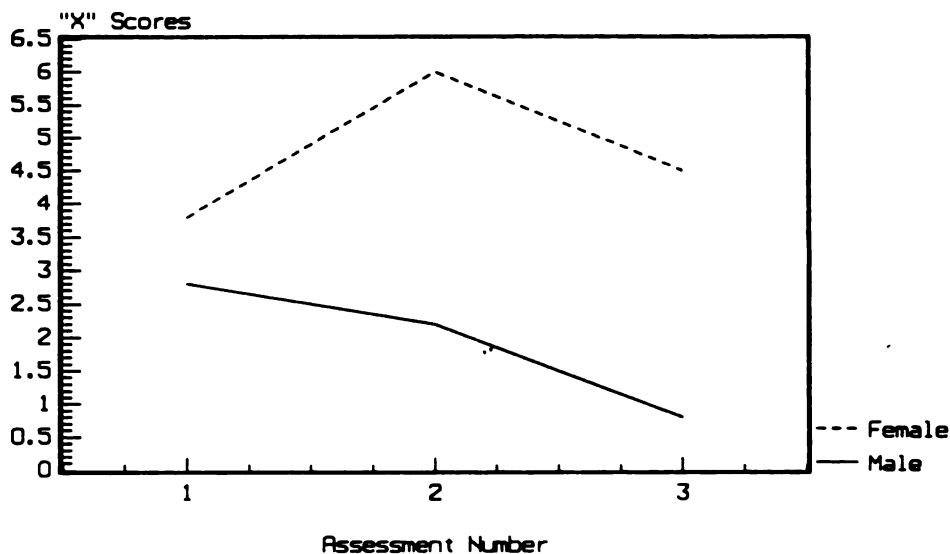


Figure 5.5 (b)
Obsessive/Compulsive
by Male and Female

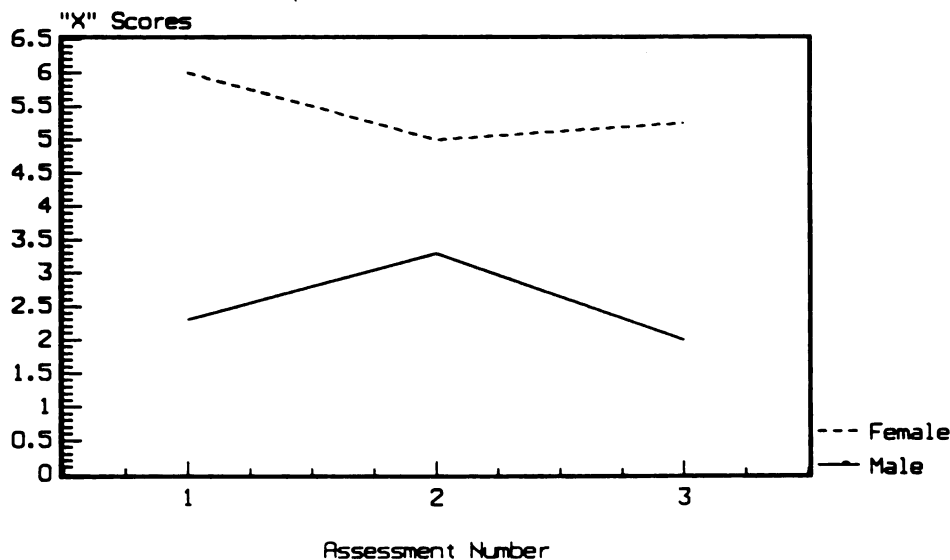


Figure 5.5 (Continues - Page 2 of 5)

Graphic Representation of Psycho-social Discomfort Variables by category and Gender, Pre-operative (Assessment 1), at 4 Weeks Post-operative (Assessment 2) and at 12 Weeks Post-operative (Assessment 3).

Figure 5.5 (c)
Interpersonal Sensitivity
by Male and Female

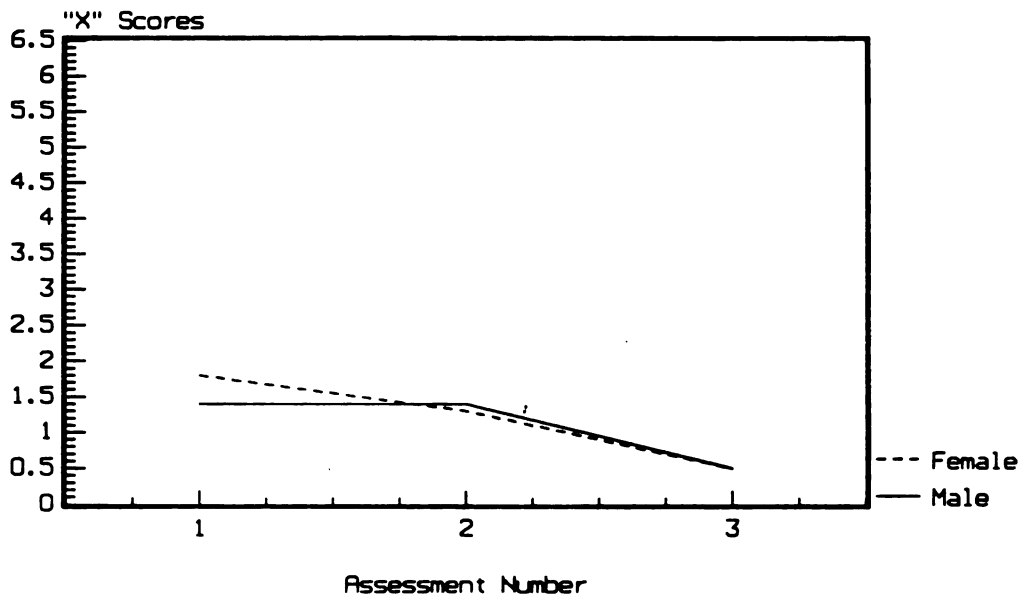


Figure 5.5 (d)
Depression
by Male and Female

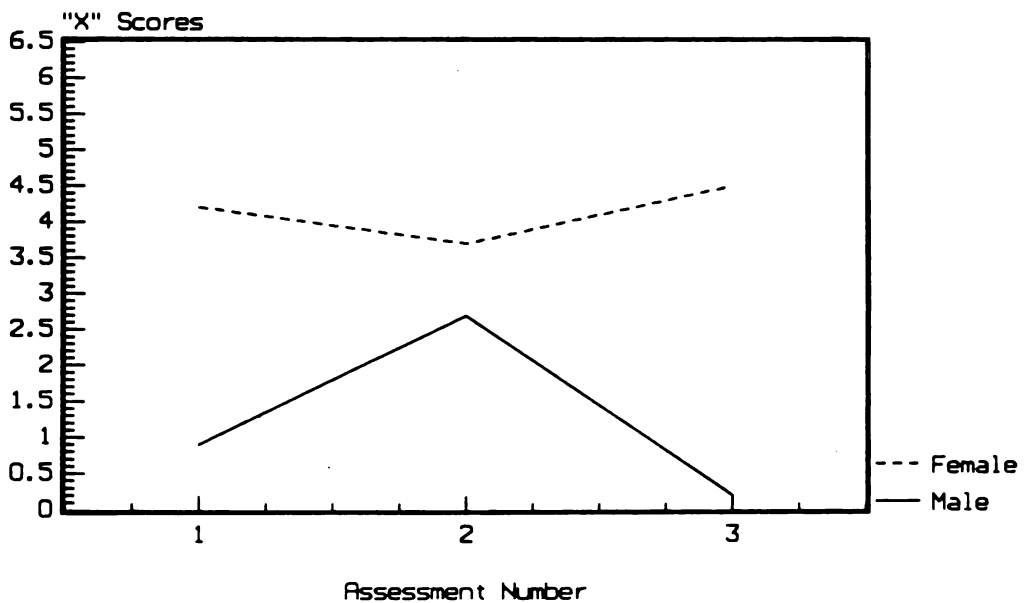


Figure 5.5 (Continues - Page 3 of 5)

Graphic Representation Of Psycho-social Discomfort Variables by Category and Gender, Pre-operative (Assessment 1), at 4 Weeks Post-operative (Assessment 2) and at 12 Weeks Post-operative (Assessment 3).

Figure 5.5 (e)
Anxiety
by Male and Female

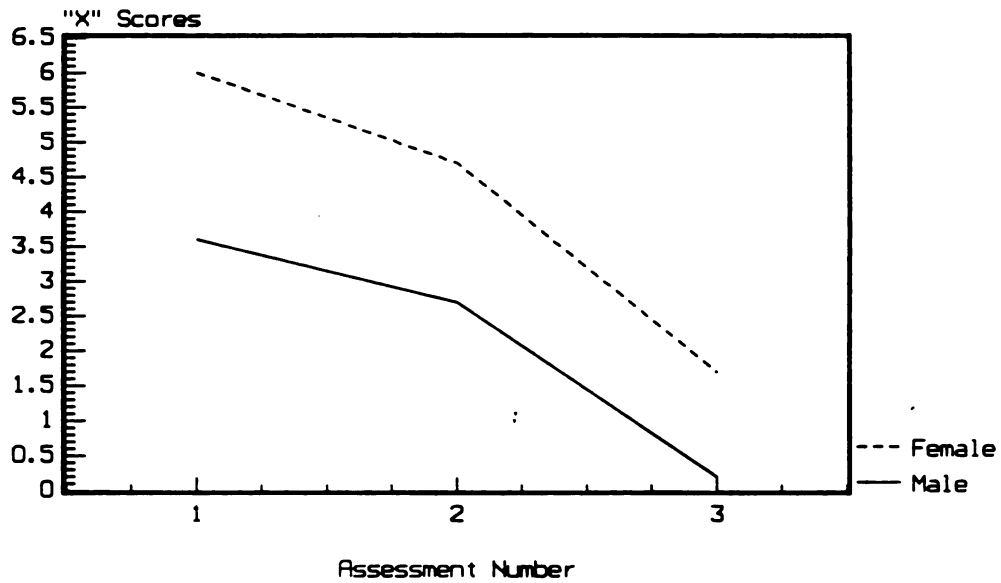


Figure 5.5 (f)
Psychoticism
by Male and Female

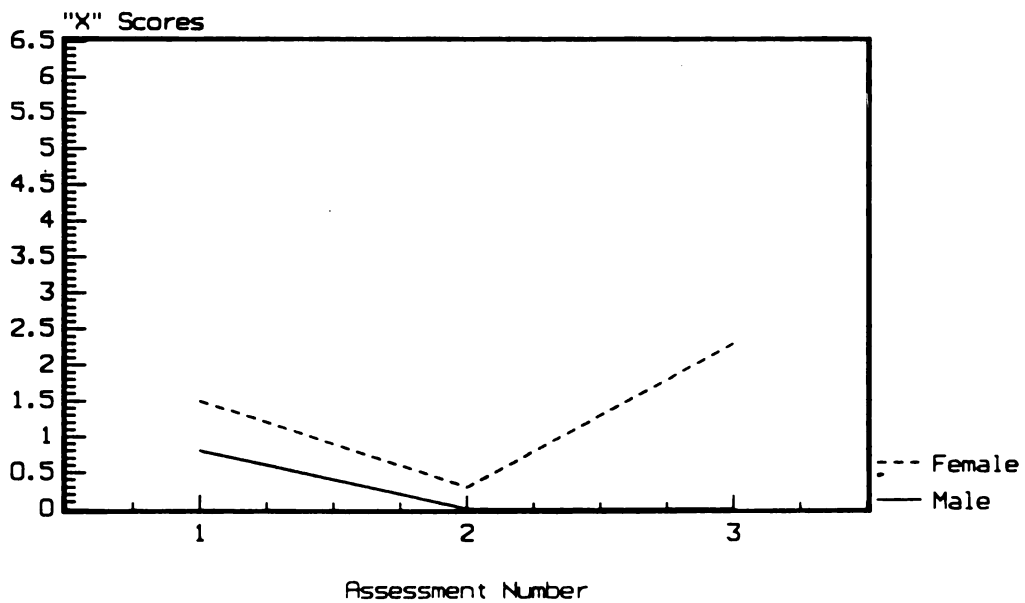


Figure 5.5 (Continues - Page 4 of 5)

Graphic Representation Of Psycho-social Discomfort Variables by Category And Gender, Pre-operative (Assessment 1), At 4 Weeks Post-operative (Assessment 2) and at 12 Weeks Post-operative (assessment 3).

Figure 5.5 (g)
Hostility
by Male and Female

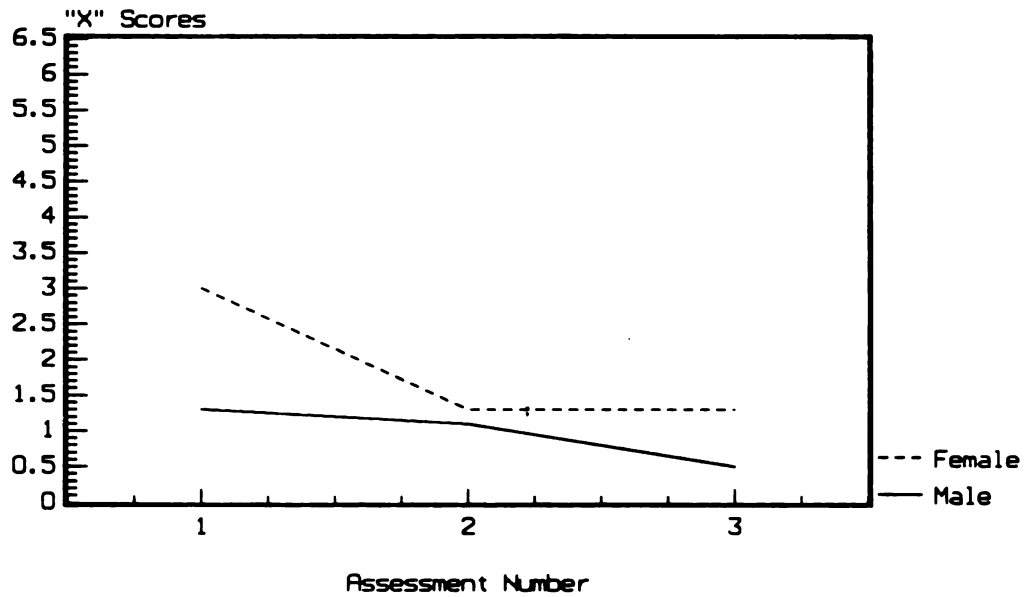


Figure 5.5 (h)
Phobic Anxiety
by Male and Female

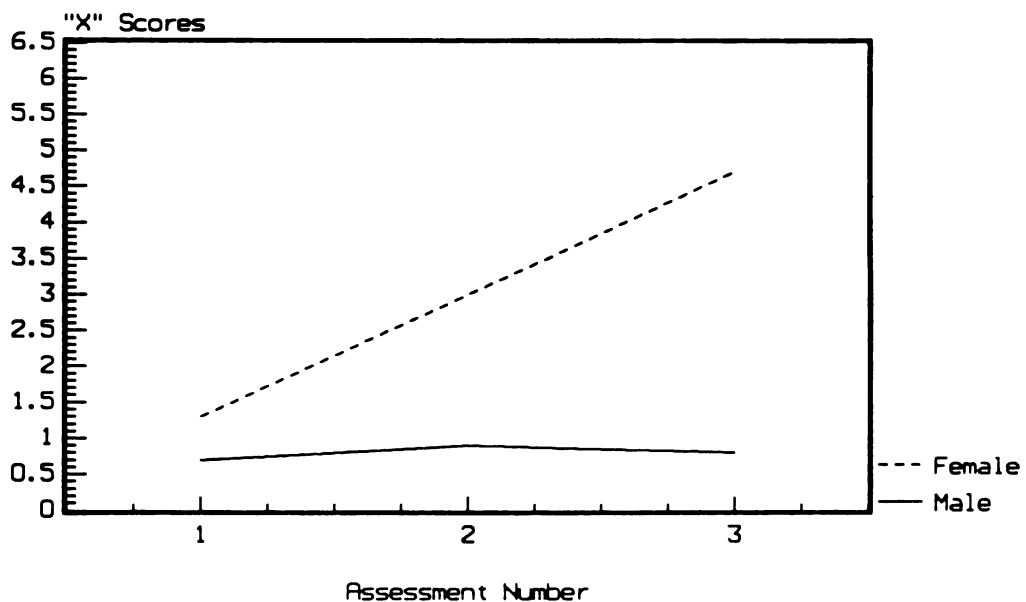


Figure 5.5 (Continues - Page 5 of 5)

Graphic Representation Of Psycho-social Discomfort Variables by Category and Gender, Pre-operative (Assessment 1), at 4 Weeks Post-operative (Assessment 2) and at 12 Weeks Post-operative (Assessment 3).

Figure 5.5 (i)
Paranoid Ideation
by Male and Female

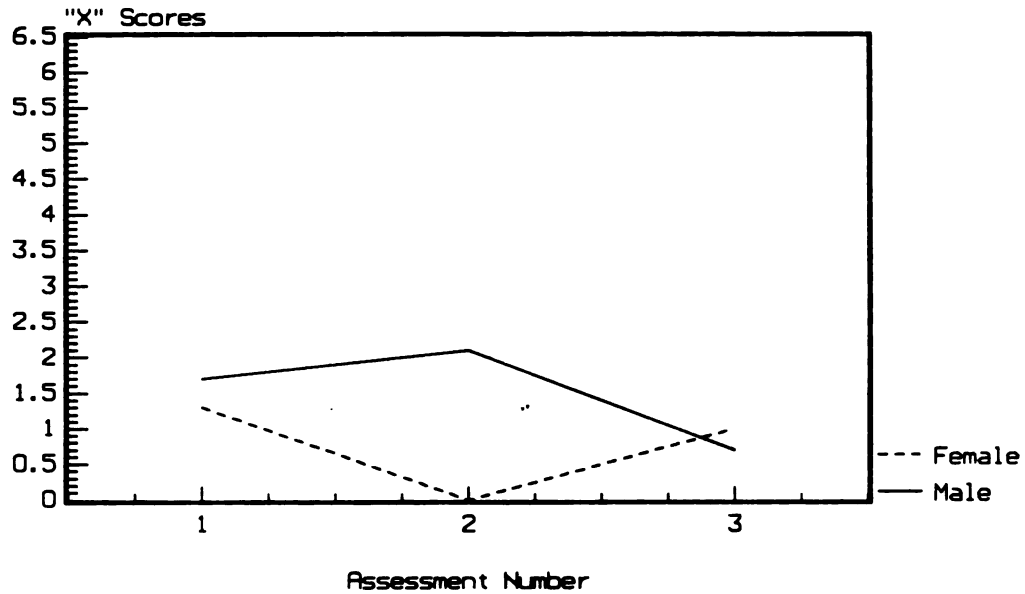
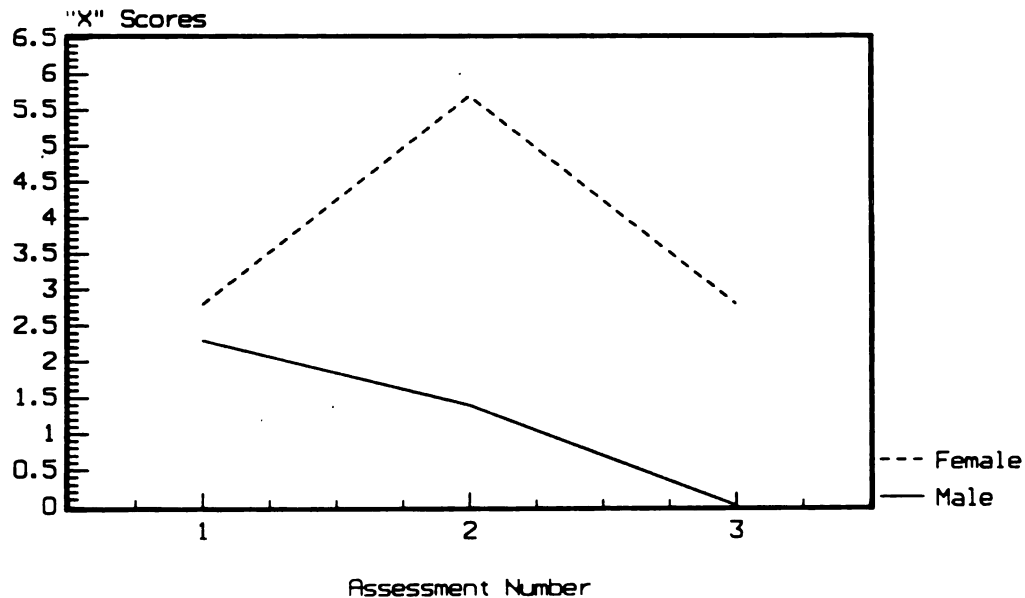


Figure 5.5 (j)
Additional Items
by Male and Female



CHAPTER VI**DISCUSSION OF FINDINGS****Discussion of Question 1**

The study question: What changes in trust are experienced by colostomy patients at four weeks and twelve weeks post-operative?

The data shows a slight increase in trust from week four to week twelve which supports the theoretical assumption from developmental theory that changes spiral in an upward direction (see Table 5.2). However, the overall increase is not dramatic and the females experienced a slight decrease (see Figure 5.1). Several explanations for the female responses are possible. Females may respond differently to issues of trust than males. Due to cultural or physiological differences, a woman may have a lower level of trust or self-acceptance of the physical body after a surgery such as a colostomy. The physical attributes of one's body may be more of an asset to a woman than to a man, and women may need more time to mourn the loss of the former body, and learn to respect the new physical body. Some caution is indicated in drawing conclusions from this data because the number of females in the sample was quite small, and may not reflect the general female population. The trust instrument used was not multi-scaled, so it is not possible to determine which component of the process has evolved or not evolved at twelve weeks post-operative.

These findings can be considered consistent with Trainor (1981) if time is a variable that affects trust. Trainor used the same instrument to measure acceptance (trust) in 50 ostomates at intervals varying from one month to thirty-eight years after surgery. The findings reported in this study show means that are lower than the means reported in Trainor (1981), which may be reflective of the time differences between the surgeries and the interviews in the two studies.

The data from this study seem to support the theory that time following surgery is a variable which affects level of self-acceptance or trust, but further study is needed before any conclusions can be drawn.

Previous research on subjects with colostomies shows no difference in responses to colostomy by gender because gender was not considered a variable, but in similar research with respect to other body changes, gender was treated as a variable. Starr (1982) investigated the relationship between self-ratings of physical attractiveness and self-esteem for 67 young adults with cleft lips and/or palates and found no significant difference in scores with respect to the gender of the subjects. Jourard and Secord (1955) with a study group of 60 females investigated the relationship between the actual sizes of the subjects' body parts and the sizes that the female subjects considered ideal. The results indicate a significant correlation between those body parts closest to ideal and the subject's satisfaction with those parts. Kurtz and Hirt (1970) compared the body attitudes of 20 chronically ill females with those of 20 females in good health, and found a significant relationship ($p = .01$) between the chronically ill females and the negative attitudes towards their bodies.

Two of these studies support the theory that a body seen as physically attractive and healthy is more important to females, and the third is equivocal. Based on the results obtained in this study, trust changes relative to gender differences need further study.

Discussion of Question 2

The study question: What changes in autonomy are experienced by colostomy patients at four weeks and twelve weeks post-operative?

Data analysis shows a trend toward a decrease in autonomy at twelve weeks as compared to autonomy at four weeks (see Table 5.4). This was an unexpected result. This decrease was reflected in all categories and was consistent in both males and females (see Table 5.5). The females did experience a slight increase in perceived autonomy at twelve weeks as compared to the same measurement at four weeks (see Table 5.5). This increase in perceived auton-

omy is consistent with clinical findings that wives assist their husbands with care of the stoma, but women do their own self-care (Sutherland et al, 1952).

Relating the data on autonomy in this study to previous studies is difficult because the variable as defined here has not been measured previously, except by Oberst and James (1985), who measured a similar variable five times post-operatively. The Oberst and James (1985) results show a slight increase in problems with physical care, uncertainty, roles, health care systems, and finances during the period from 30 days to 60 days after discharge from the hospital. The results of this study suggest that, as people become more independent of the health care system, they perceive more uncertainty about their physical care.

In the current study, patients reported a decrease in learning during the period between the four week interview and the twelve week interview (see Table 5.4) which is related to physical care. This finding may be a reflection of the current health care system's policy of releasing patients after the visiting nurse has made three home visits (see Appendix M), but such results may simply reflect the patient's progression from a dependent role to an independent role. The autonomy results of this study show a perceived decrease in functional control, affective control and learning at twelve weeks which suggests that period is one in which the patient is very vulnerable. On the other hand, this could be an inconsistency in instruments, or it may be an indication that the subjects may need to deal with issues of psycho-social discomfort before they will be able to perceive themselves as autonomous. Some inconsistent psycho-social data suggests a return to normalcy at twelve weeks.

The category, self issues, (see Table 5.4) which included items on sexual activity, self-respect, self-confidence and depression also showed a decrease at twelve weeks with respect to four weeks. This may be a reflection of the uncertainty and problems with role similar to what Oberst and James (1985) reported. Also, the trends in this data suggest that psycho-social discomfort issues may require resolution before issues related to sex, self-respect, and self-confidence can be resolved. It may be postulated that there is a turning

point, a point in the post-operative recovery procedure, when the patient feels *more knowledgeable and more autonomous* than earlier, but there are no research results that would indicate the time of such a turning point relative to surgery, or even to support the notion that such a turning point exists. Although the Oberst (1985) data indicated a decrease in problems with physical care, uncertainty, roles and information by 90 days after discharge, this study indicates a rise in problems related to uncertainty and to roles at 180 days after discharge. Clearly it seems more research is needed to understand the development of autonomy post-operative over time.

Discussion of Question 3

The study question: What changes in psycho-social discomfort does the cancer patient with a colostomy procedure experience both before the operation, and four weeks and twelve weeks after the operation?

The data shows a decrease in psycho-social discomfort over time (see Table 5.6), and there is no variation in this trend attributable to gender (see Table 5.7). These results are consistent with other clinical findings and observations. Oberst and James (1985), reported problems in their cancer patients before discharge which were related to symptoms, emotions, and identity, and that these problems decreased in number as time after surgery increased. Watson (1988) reported from clinical findings that pre-operative ostomy patients have worries about survival, fear of pain, and that post-operatively these concerns are displaced by learning to adjust and by a return to life at home.

Derogates and Melisartos (1983) gave the BSI questionnaire to a stratified random sample of 719 non-patients (344 males and 341 females) who were all from one county in an eastern state. A comparison of the means from their study to the means from the current study show that the subjects in this study have the higher means in each category, but the means of the subjects in this study tend to approximate the means of subjects of the Derogates and Melisartos (1983) study by the twelfth week. The categories in which the subjects of this study remain higher than the subjects in the Derogates and Melisartos (1983)

study are somatization, obsessive/compulsive behavior, depression and phobic anxiety.

The data related to specific categories of psycho-social discomfort corroborate reports of clinical observations (Sutherland et al, 1952; Wirsching et al, 1975, and Thomas, et al, 1987). Thomas, et al (1987) found 19% of their sample experienced moderate or severe anxiety, with 19% also experiencing moderate or severe depression. In the portion of the Thomas, et al (1987) study which was categorized by gender, 3% of males suffered moderate anxiety as compared to 8% of the females; 6% of the males suffered severe depression as compared to 16% of the females. The Thomas et al (1987) data was taken twelve months after the subjects' operations. While the reason more females experience depression and anxiety (or at least score higher on the relevant scales) is a matter for conjecture, these results suggest a possible relationship between the lower trust scores of women (as discussed under trust earlier in this chapter) and psycho-social discomfort.

There is one seeming inconsistency which relates psycho-social discomfort scores to lower trust scores in the female and that is that is only a slight elevation of interpersonal sensitivity (see Table 5.7) and, furthermore, females, did have somewhat higher scores than males (see Table 5.7). One explanation for this seeming inconsistency, could be that the focus of these items is external (i.e. others perception of the subject) whereas the trust items are internal (i.e. the subject's evaluation of self). Both anxiety and depression measurements in females decrease to approximate non-patient measures by twelve weeks post-operative (Derogates and Melisartos (1983).

Somatization in colostomy cancer patients was described by Orbach et al (1957) and Orbach and Tallent (1965). Somatization as measured in this study was higher than in non-patients (Derogates and Melisartos, 1983) and was higher in the females of the sample (see Table 5.7) at four weeks and twelve weeks than in the males. The females continued to have high scores in somatization at twelve weeks compared to non-patients (Derogates and Melisartos, 1983). Both the males and females, therefore, have some preoccupation with

their bodies which may contribute to the anxiety and depression, (i.e. having a diagnosis of cancer, a colostomy and a body that doesn't seem to "act right" could all contribute to anxiety or depression) but this somatic preoccupation is more intense in the female population.

Obsessive-compulsive behavior in this population has been described by Orbach et al (1957) and is higher in this sample than non-patients (Derogates and Melisartos, 1983) and is notably higher in females than in males. The obsessive-compulsive behavior items are related to cognitive ability, i.e. remembering things, making decisions, concentrating, and, conversely, to having the mind go blank. These are also the characteristics of an anxious person (Kneedler and Dodge, 1983).

In examining the psycho-social discomfort profile of females with colostomies, according to the data from this study, one finds reports of somatization, obsessive-compulsive behavior, depression, and anxiety. These behavior patterns may be interrelated, i.e. a depressed individual may have a preoccupation with body symptoms or body symptoms may cause the depression. Feelings of anxiety can interfere with cognitive ability, therefore, causing one to engage in compulsive behavior such as checking and rechecking items which do not require such careful attention. This psycho-social profile may also include additional characteristics such as poor appetite, sleep disturbance, thoughts of death or dying, and strong feelings of guilt, all of which were high in the female population. These symptoms would be consistent with an anxious, slightly depressed individual who has somatic complaints such as nausea and vomiting. Thoughts of paranoid ideation are higher in males than females and interpersonal sensitivity is slightly higher in the male at four weeks than in the female. Both categories contain items which are externally focused leading to a tentative conclusion that males may be more concerned with evaluation by others, while the females are more concerned with self evaluation. This conclusion is supported by the results from the trust category where items are internally focused and the female scored slightly lower.

In examining the male psycho-social discomfort profile, the behaviors that are increased, particularly, at four weeks are obsessive-compulsive behavior, depression, anxiety, somatization and paranoid ideation. This behavior does not increase to the same extent in males as in females, but may have some of the same inter-relatedness as was postulated for the female population, though of shorter duration.

The data in the category of psychoticism reflects a sample that is reality-based although females experience a slight increase in psychoticism at week twelve. The increase that is seen pre-operatively may be due to fear related to surgery and to the diagnosis of cancer.

The hostility index was high pre-operatively in both males and females. The two items that subjects identified were feeling easily annoyed or irritated and getting into frequent arguments. This may be related to the feelings of anxiety about the diagnosis and multiple changes the person anticipates experiencing.

The cancer patient with a colostomy does experience psycho-social discomfort which gradually decreases although for some categories the discomfort experienced as a function of time is not linear. The changes, although not significant, are in the direction expected but the slope varies somewhat. It is assumed that as psycho-social discomfort decreases, psycho-social well-being increases, but psycho-social well-being was not measured in this study.

Limitations

The limitations of this study relate to sampling procedure and the selected questionnaires.

Sampling Procedures

Although serial assessments were an asset of this study, they also made it difficult to obtain and retain qualified subjects. One problem was that oncologists were reluctant to have their patients interviewed just a short time

before the operations, so gaining access to the patients for the pre-operative assessments was quite difficult.

A sample of 30 subjects was desired but was not obtained because of the limited number of colostomy surgeries done in the recruitment sites. Convenience sampling limits the general applicability of the findings and the results obtained are largely sample specific.

Another limitation related to sampling was that the subjects filled out the pre-operative questionnaires in the hospital at times when other laboratory tests and physical examinations were also being done. In this atmosphere the patient receives multiple sensory input, and questionnaires were one more stimuli with which to contend.

Questionnaire Limitations

The ADM scale (Appendix A) has no provisions for discriminating among the various components of trust.

The OAS (Appendix B) measurement of autonomy has the limitation of having been used only on the sample for which it was developed. Factor analysis was done yielding a large group of questions that were categorized under self-issues. This makes the self-issues category difficult to interpret. Some of the defined categories may also be weak due to low numbers of items in these categories.

Significance

The significance of this study lies in its contributions to the definitions of trust, autonomy and psycho-social discomfort as measurable quantities using the Erickson framework. These measurements can provide relevant descriptive information about selected samples of cancer patients with colostomies.

Data obtained in the measurement of trust suggested a change over time following surgery in this medical sub-group and that gender may influence the degree of change. Another implication to be drawn from the data is that trust

may change in the direction proposed by developmental theory which suggests that trust is a point on a spiral moving upwards. If this is indeed an accurate mathematical model, since a spiral is three-dimensional, and since to date only two dimensions (y =trust, x =time) have been defined, it might be useful to define the z -axis component and to determine if $y = f(x,z)$ is indeed a spiral, and, if it is, to determine some of its properties. Does the spiral have a constant radius with respect to the y axis, or does it expand? If the time of surgery is considered $(0,0)$, then a point on a spiral would have negative components some portion of the time, which is a problem because a negative value of time has little real life relevance. However, if the spiral was skewed with respect to the y axis, so that the spiral resembled a string wrapped around an ice cream cone that is tilted so that one side of the cone is coincident with the x axis, then the time would always be positive and increasing (as in real life) and trust values would always be positive, but not continually increasing (again, as in real life). So, the determination of the properties of the z axis component would aid in determining the nature of the factors affecting trust, and in predicting the direction of change in trust with respect to time in the defined population and nursing intervention could be planned to take advantage of factors known to increase trust.

The data offers some support for the theory that autonomy changes following surgery, but in this study, for the males, the data did not change in the direction developmental theory would predict. Gender also seems to influence changes in autonomy, although the effect of gender needs to be clarified by additional research.

Psycho-social discomfort also changed over time in this sample. Of particular importance are the measurements of anxiety, depression, obsessive-compulsive behavior and interpersonal sensitivity which were previously described clinically but had not been measured with established instruments. All previous studies of this population had only one set of post-operative measurement with wide time-following-surgery variations in the set.

This study is one of the first to use the two stages of the Erikson theory of the development of self to evaluate self-concept changes in the cancer colostomy population. It is also the first attempt to measure self-concept changes over time in this population. Although the study has limitations, it can be the cornerstone for building future studies which will contribute to a sound clinical description of this population and to the theoretical development of self-concept theory as it pertains to nursing practice.

Data from this study suggest a trend in support of the theoretical assumptions that underlie developmental theory. As defined in this study, self-concept is a dynamic process which takes place during post-operative recovery phase of a colostomy patient. The data also tended to support the assumption of developmental theory that stages can occur and recur. The assumption of developmental theory that changes occur in a spiral or upward fashion was not supported with the concept of autonomy, and further research with respect to this concept is needed.

Implications

It is evident that nurses in clinical practice should begin to observe colostomy patients with cancer for evidence of trust, autonomy and psycho-social discomfort. Nurses need to recognize that gender may influence the pattern of change, thereby necessitating corresponding changes in the nursing care plan. Since both males and females perceived a decrease in autonomy at twelve weeks post-operative, this should be a consideration in planning care and in making decisions about patient follow-up in the home. The implications drawn from the autonomy data are that more and longer education is needed, and especially that the current four-week regimen may be insufficient. Ostomy associations could become involved in long term follow-up instruction. In considering psycho-social discomfort, nursing intervention in the form of reassurance of the patient that the patient is experiencing what others have experienced needs to be taught. In addition, intervention for the relief of depression and anxiety needs to be considered.

Future research

Replication of this study with a larger sample would further clarify these results. All three concepts (trust, autonomy, and psycho-social discomfort) need further exploratory description in this population at 6 month, 1 year, 18 month, and 2 year intervals following surgery. The data from these measurements over longer intervals would assist in describing 1) how the stages, change or stabilize over time and, 2) the relationship between trust and autonomy. Psycho-social discomfort could also be further clarified. Currently there is no mathematical model relating trust, autonomy, and psycho-social discomfort. Nor is it understood if trust and autonomy develop independently or if there is a relationship between the two concepts. What is the relationship between time following surgery and the development of each concept? More data is needed to clarify the effect of gender on the development of trust, autonomy, and psychosocial discomfort in this population. What is the effect of other variables such as ethnic background or trust autonomy and psychosocial discomfort?

The instrument used to measure trust and autonomy needs further validity and reliability study. Factor analysis of both instruments would be helpful in determining if items are repeated in both instruments. After factor analysis has eliminated repetitious and weak items, new items need to be developed to expand categories with insufficient items. Convergent validity could be established by comparing trust measures from another instrument with the ADM scale and comparing other autonomy measures with the AOS (Selltiz, Wrightman and Cook, 1976). Reliability would need to be re-established on the new instruments by internal consistency measure and testing over time. Trust, autonomy, and psycho-social discomfort need further description in other populations, especially other ostomy populations such as those with ileostomies and urostomies.

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APPENDIX A

- | | <i>I disagree
very much</i> | <i>I disagree
pretty much</i> | <i>I disagree
a little</i> | <i>I agree
a little</i> | <i>I agree
pretty much</i> | <i>I agree
very much</i> |
|--|---------------------------------|-----------------------------------|--------------------------------|-----------------------------|--------------------------------|------------------------------|
| 22. Though I can see the progress I am making in rehabilitation, this is not very important since I can never be normal. | ___ | ___ | ___ | ___ | ___ | ___ |
| 23. In just about everything, my ostomy is annoying to me so that I can't enjoy anything. | ___ | ___ | ___ | ___ | ___ | ___ |
| 24. How a person conducts himself in life is much more important than physical appearance and ability. | ___ | ___ | ___ | ___ | ___ | ___ |
| 25. A person with my type of ostomy is unable to enjoy very much in life. | ___ | ___ | ___ | ___ | ___ | ___ |
| 26. The most important thing in this world is to be physically normal. | ___ | ___ | ___ | ___ | ___ | ___ |
| 27. A person with an ostomy finds it especially difficult to expand his interests and range of abilities. | ___ | ___ | ___ | ___ | ___ | ___ |
| 28. I believe that physical wholeness and appearance make a person what he is. | ___ | ___ | ___ | ___ | ___ | ___ |
| 29. An ostomy affects a person's mental ability. | ___ | ___ | ___ | ___ | ___ | ___ |
| 30. With my condition, I know just what I can and cannot do. | ___ | ___ | ___ | ___ | ___ | ___ |
| 31. Almost every area of life is closed to me because of my ostomy. | ___ | ___ | ___ | ___ | ___ | ___ |
| 32. Because of my ostomy, I have little to offer other people. | ___ | ___ | ___ | ___ | ___ | ___ |
| 33. Besides the many physical things I am unable to do, there are many many other things I am unable to do. | ___ | ___ | ___ | ___ | ___ | ___ |

APPENDIX B

Ostomy Adjustment Scale

	<i>I disagree very much</i>	<i>I disagree pretty much</i>	<i>I disagree a little</i>	<i>I agree a little</i>	<i>I agree pretty much</i>	<i>I agree very much</i>
1. I can lead a productive and fulfilling life despite my ostomy.	—	—	—	—	—	—
2. I think I am leading quite a normal life despite my ostomy.	—	—	—	—	—	—
3. There are many things I would do if I did not have an ostomy.	—	—	—	—	—	—
4. I feel free to travel where I want despite my ostomy.	—	—	—	—	—	—
5. I have felt comfortable participating in sports and physical exercise since my ostomy surgery.	—	—	—	—	—	—
6. I find that I unnecessarily restrict the range of my activities because of my ostomy.	—	—	—	—	—	—
7. I have been better able to work since I had my ostomy surgery.	—	—	—	—	—	—
8. I am more able to enjoy sexual activities because of improved health since having ostomy surgery.	—	—	—	—	—	—
9. At times I lack self-confidence because of my ostomy.	—	—	—	—	—	—
10. I feel ashamed of my ostomy, as if it were a sign of my own physical or emotional weakness.	—	—	—	—	—	—

	<i>I disagree very much</i>	<i>I disagree pretty much</i>	<i>I disagree a little</i>	<i>I agree a little</i>	<i>I agree pretty much</i>	<i>I agree very much</i>
11. At times I resent my friends who do not have ostomies or the health problems that lead to ostomy surgery.	—	—	—	—	—	—
12. My self-respect has not suffered because of my ostomy.	—	—	—	—	—	—
13. I feel somehow "dirty" and "unclean" because of my ostomy.	—	—	—	—	—	—
14. I leave places early to avoid producing embarrassing odors in the bathroom.	—	—	—	—	—	—
15. I feel comfortable with my body, including my stoma.	—	—	—	—	—	—
16. I feel that I am somehow being punished for something by having this ostomy.	—	—	—	—	—	—
17. I get depressed when I realize that I will have this ostomy for the rest of my life.	—	—	—	—	—	—
18. I can discuss even the most embarrassing aspects of my ostomy with my doctor.	—	—	—	—	—	—
19. I feel like a complainer when I have to contact my doctor or ET about my ostomy.	—	—	—	—	—	—
20. I avoid telling my doctor about changes in my stoma and its functioning.	—	—	—	—	—	—
21. I feel that I am well educated about my stoma and caring for it.	—	—	—	—	—	—
22. I am confident that I know the proper methods for managing my ostomy.	—	—	—	—	—	—

23. Since I've had my surgery, I feel I'm more likely to get sick than other people.
24. I find myself worrying that my surgery did not really cure my health problems.
25. I worry more than I used to about being left alone.
26. I feel embarrassed by my ostomy, as though it were something to hide.
27. I feel that I am not as sexually attractive as I used to be because of my stoma.
28. I can laugh afterwards about awkward situations that happen because of my ostomy.
29. Most of the time, I forget about my ostomy and am not aware of it.
30. I worry about embarrassing accidents happening in the course of normal sexual activity.
31. I think other people would be uncomfortable around me if they knew about my stoma.
32. I feel confident that I can trust my appliance when I am in public places.
33. My ostomy surgery helped me decide what things are most important in my life.
34. My ostomy reminds me how fortunate I am to have received good medical care.

	I disagree very much	I disagree pretty much	I disagree a little	I agree a little	I agree pretty much	I agree very much
23.	—	—	—	—	—	—
24.	—	—	—	—	—	—
25.	—	—	—	—	—	—
26.	—	—	—	—	—	—
27.	—	—	—	—	—	—
28.	—	—	—	—	—	—
29.	—	—	—	—	—	—
30.	—	—	—	—	—	—
31.	—	—	—	—	—	—
32.	—	—	—	—	—	—
33.	—	—	—	—	—	—
34.	—	—	—	—	—	—

APPENDIX C

INSTRUCTIONS:

Below is a list of problems and complaints that people sometimes have. Please read each one carefully. After you have done so, please fill in one of the numbered circles to the right that best describes HOW MUCH DISCOMFORT THAT PROBLEM HAS CAUSED YOU DURING THE PAST WEEK INCLUDING TODAY. Mark only one numbered circle for each problem and do not skip any items. If you change your mind, erase your first mark carefully. Read the example below before beginning, and if you have any questions please ask the technician.

SEX

MALE

FEMALE

NAME: _____

LOCATION: _____

EDUCATION: _____

MARITAL STATUS: MAR. ___ SEP. ___ DIV. ___ WID. ___ SING. ___

DATE		
MO	DAY	YEAR

ID. NUMBER

AGE

EXAMPLE

HOW MUCH WERE YOU DISTRESSED BY:

1. Bodyaches

NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

VISIT NUMBER: _____

HOW MUCH WERE YOU DISTRESSED BY:

		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Nervousness or shakiness inside	1	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Faintness or dizziness	2	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. The idea that someone else can control your thoughts	3	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Feeling others are to blame for most of your troubles	4	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Trouble remembering things	5	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Feeling easily annoyed or irritated	6	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Pains in heart or chest	7	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Feeling afraid in open spaces	8	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Thoughts of ending your life	9	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Feeling that most people cannot be trusted	10	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Poor appetite	11	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Suddenly scared for no reason	12	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Temper outbursts that you could not control	13	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Feeling lonely even when you are with people	14	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Feeling blocked in getting things done	15	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Feeling lonely	16	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Feeling blue	17	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Feeling no interest in things	18	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Feeling fearful	19	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Your feelings being easily hurt	20	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Feeling that people are unfriendly or dislike you	21	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Feeling inferior to others	22	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Nausea or upset stomach	23	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Feeling that you are watched or talked about by others	24	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Trouble falling asleep	25	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Having to check and double check what you do	26	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Difficulty making decisions	27	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Feeling afraid to travel on buses, subways, or trains	28	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. Trouble getting your breath	29	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. Hot or cold spells	30	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. Having to avoid certain things, places, or activities because they frighten you	31	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. Your mind going blank	32	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. Numbness or tingling in parts of your body	33	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. The idea that you should be punished for your sins	34	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
35. Feeling hopeless about the future	35	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

HOW MUCH WERE YOU DISTRESSED BY:

		NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
36. Trouble concentrating	36	0	1	2	3	4
37. Feeling weak in parts of your body	37	0	1	2	3	4
38. Feeling tense or keyed up	38	0	1	2	3	4
39. Thoughts of death or dying	39	0	1	2	3	4
40. Having urges to beat, injure, or harm someone	40	0	1	2	3	4
41. Having urges to break or smash things	41	0	1	2	3	4
42. Feeling very self-conscious with others	42	0	1	2	3	4
43. Feeling uneasy in crowds	43	0	1	2	3	4
44. Never feeling close to another person	44	0	1	2	3	4
45. Spells of terror or panic	45	0	1	2	3	4
46. Getting into frequent arguments	46	0	1	2	3	4
47. Feeling nervous when you are left alone	47	0	1	2	3	4
48. Others not giving you proper credit for your achievements	48	0	1	2	3	4
49. Feeling so restless you couldn't sit still	49	0	1	2	3	4
50. Feelings of worthlessness	50	0	1	2	3	4
51. Feeling that people will take advantage of you if you let them	51	0	1	2	3	4
52. Feelings of guilt	52	0	1	2	3	4
53. The idea that something is wrong with your mind	53	0	1	2	3	4

APPENDIX D

COMMITTEE ON HUMAN RESEARCH
OFFICE OF RESEARCH AFFAIRS, BOX 0616
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

TO: Dyanne D. Affonso, R.N., Ph.D.
Box 0606, N411K

Lois Ramer
1733 N. Avon St.
Burbank, CA 91505

RE: Trust, Autonomy and Psychosocial Discomfort Experienced
by the Post-Operative Cancer Patient with a Colostomy

The UCSF Committee on Human Research (an Institutional Review Board holding Department of Health and Human Services assurance #M-1169) has approved the above request to involve humans as research subjects.

APPROVAL NUMBER: H1778-01391-02. This number is a UCSF CHR number which should be used on all consent forms, correspondence and patient charts.

APPROVAL DATE: August 25, 1988. Expedited Review

EXPIRATION DATE: August 25, 1989. If the project is to continue, it must be renewed by the expiration date. See reverse side for details.

CONDITION: It was requested that in future applications, the Principal Investigator herself sign the application.

ADVERSE REACTIONS/COMPLICATIONS: All problems having to do with subject safety must be reported to the CHR within ten working days.

MODIFICATIONS: All protocol changes involving subjects must have prior CHR approval.

LEGAL NOTICE: The University will defend and indemnify a principal investigator in legal actions arising from research activities involving humans only if the activities had current CHR approval.

QUESTIONS: Please contact the office of the Committee on Human Research at (415) 476-1814 or campus mail stop, Box 0616.

Good luck on your project.

Sincerely,



Barry D. Engelstad, M.D.

Chairman

Committee on Human Research

HEPC Project # 87001391

APPENDIX E

STATEMENT OF EXEMPTION
from review by
Human Subject Protection Committees

The Department of Health and Human Services (DHHS) published in the Federal Register of January 26, 1981 its amended regulations governing research involving human subjects, altering the scope of previous Department regulations by exempting categories of research which present little or no risk of harm to human beings. At UCLA, the Human Subject Policy Committee accepted the exempted research categories. Exemption from Human Subject Protection Committee review and approval must be based on the exemptions specified in the Federal Regulations January 26, 1981 and the responsibility for claiming the exemption rests with the principal investigator and the Departmental Chair.

This form will assist researchers and Department Chairs in certifying proposed research as exempt and certifying under which of five categories listed in the Federal Register the exemption occurs (see reverse). In questionable cases, investigators and/or Department Chairs are strongly urged to consult the appropriate Human Subject Protection Committee, or the Human Subject Coordinator at 58714. *This completed and signed form is to be filed in the Department Chairman's office.* In addition:

- 1) For extramurally funded research projects, a copy must be forwarded to the Office of Contract and Grant Administration so that an institutional certification (DHHS 596) may accompany the application when mailed to the funding agency.
- 2) Annually, originals or copies of this form are to be forwarded by Department Chairmen to the campus Human Subject Coordinator, 1P-282 Center for the Health Sciences.

The above stated policy is effective as of January 1, 1982. Please be advised that copies of certified exemptions be forwarded to the Human Subject Coordinator no later than July 1st of each year.

INVESTIGATOR Lois Ramer DEPARTMENT or Unit Nursing Education & Research Trust, Autonomy and Psychosocial Discomfort Experienced by the Post-Operative Cancer Patient with a Colostomy
 Title of Study 6 months to 1 year SPONSOR Dr. Linda Faber
 Duration of Study 6 months to 1 year

EXEMPTION of Exempt Category (identify by number as shown on back of page) 3

DESCRIPTION of Study and REASON for including it in the exempt category cited (attach sheet if more space is needed):

Colostomy surgery has been a surgical intervention for patients with colon cancer since the early 1900's. There are some data available to describe the medical and psychological experiences of these patients in their post-operative course but little research has been done from a nursing perspective. This is a descriptive study utilizing a repeated measures designs in which subjects will respond to 3 questionnaires. The first (#1) questionnaire will measure psychosocial discomfort and will be administered pre-operative and again at 4 and 12 weeks post-operative. At 4 and 12 weeks post-operative, questionnaire (#2) measuring trust (acceptance) and (#3) measuring autonomy will also be administered.


This study meets the exemption category according to UCLA Department of Health and Human Services (DHHS) since the data: 1) is survey data and will be gathered by paper and pencil; 2) will be analyzed as aggregate data; and 3) all data will be treated anonymously.

Lois Ramer _____ Date 10/12/87
 Title of Investigator

Linda Faber, Ph.D., Dir. Hosp. Res. Ed. _____ Date 10-20-87
 Title of Investigator's Departmental Person or ORU Director
Director, Nursing Service
Assoc. Director, Hosp. Res. + Clinics

APPENDIX F

NEW PROTOCOL

REPORT OF SUBCOMMITTEE ON HUMAN STUDIES	PROJECT OR PROGRAM TITLE Trust, Autonomy and Psychosocial Discomfort Experienced by Postoperative Cancer Patients with Colostomy	NUMBER 0036
PRINCIPAL INVESTIGATOR'S NAME E. A. Hefferin, R.N., Dr. P.H.	VA FACILITY 691 VAMC West Los Angeles, Wadsworth Division	
INSTITUTION OF SUBCOMMITTEE (or the equivalent body) Committee on Human Studies		DATE OF REVIEW 11/10/87
<p>This subcommittee has reviewed the above described project with respect to the rights and safety of the human subjects. The following are our findings:</p>		
<p>1. RISKS (Check one)</p> <p><input checked="" type="checkbox"/> The planned research involves little foreseeable risk and the subjects safety is adequately protected unless the plan is modified.</p> <p><input type="checkbox"/> The foreseeable risk is justified by the potential benefit to the subjects or by the anticipated benefit to society and the plans include adequate and appropriate measures to reduce the risk insofar as feasible.</p> <p><input type="checkbox"/> The risk is justified but further measures seem advisable to protect the subject, including _____</p> <p>_____</p> <p>_____</p> <p><input type="checkbox"/> The risk seems greater than can be justified by the research as planned and the project or program is not approved as presented.</p>		
<p>2. INFORMATION FOR THE SUBJECT (Check one)</p> <p><input checked="" type="checkbox"/> The information to be given the subjects (or their legal representatives) is complete and accurate enough for them to reach a valid decision concerning participation in the research.</p> <p><input type="checkbox"/> The information for the subjects as presented is incomplete or defective in that _____</p> <p>_____</p> <p>_____</p>		
<p>3. CONSENT METHOD (Check one)</p> <p><input checked="" type="checkbox"/> The format and manner of obtaining informed consent from the subjects (or their legal representatives) is satisfactory.</p> <p><input type="checkbox"/> The method of obtaining informed consent is defective in that _____</p> <p>_____</p>		
<p>4. FURTHER COMMENTS</p> 		
<p>5. RECOMMENDATION (Check one)</p> <p><input checked="" type="checkbox"/> The project or program be approved as submitted.</p> <p><input type="checkbox"/> The plan or protocol be revised in keeping with our comments and resubmitted.</p> <p><input type="checkbox"/> The proposal as described be rejected.</p>		<p>SIGNATURE OF CHAIRMAN</p>  STANLEY COHEN, M.D.

APPENDIX G

Zoe Rymen

CITY OF HOPE MEDICAL CENTER
INSTITUTIONAL REVIEW BOARD ACTION NOTICE

NOTICE OF APPROVAL

TO: Ms. Grant; Ms. Ramer

DATE: 5/11/88

FROM: William J. Burinda, IRB Secretary RE: IRB #8048

Your protocol entitled TRUST, AUTONOMY, AND PSYCHOSOCIAL DISCOMFORT CHANGES EXPERIENCED BY THE POST-OPERATIVE CANCER PATIENT WITH A COLOSTOMY

has been APPROVED by the Institutional Review Board at its meeting of 5/10/88 for 12 months..

NOTE: During the period covered by IRB approval you must advise the IRB of any significant changes in the protocol or unexpected problems involving human subjects.

WJB:mj

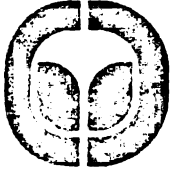
Revised 1/86, 8/86, 3/88

RECEIVED

MAY 16 1988

Nursing Research & Education

APPENDIX H



August 11, 1988

Lois Ramer, R.N.
Associate Director of Nursing Education
Orthopaedic Hospital
P.O. Box 60132, Terminal Annex
Los Angeles, California 90060

Dear Lois:

I am glad to inform you that your request to work with colostomy patients at Glendale Adventist Medical Center for your doctoral dissertation has been approved by the Institutional Review Board. However, we need for you to fill out the enclosed "Research Application" and send it to me as soon as possible.

The Institutional Review Board is also requesting that you revise the "Informed Consent" form, as follows:

- In the first paragraph, state the purpose of your research and the requirements of the patient.
- Include a space for witnessing.
- Include Glendale Adventist Medical Center's address and telephone number in paragraph 5.

Please make sure I receive a revised copy. A signed copy of the consent form is to be placed on the patient's chart as a permanent record.

You can work directly with Jean Frazer, our Enterostomal Therapy Clinician.

I am looking forward to meeting you, and wish you the best of luck in your doctoral dissertation.

Sincerely,

Hans Martin RN
Hans Martin, R.N.
Nursing Director

HM:c

Enclosure

APPENDIX I

GLENDALE ADVENTIST MEDICAL CENTER
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
SCHOOL OF NURSING
DEPARTMENT OF PHYSIOLOGICAL NURSING

Consent to be a Research Subject

RESEARCH STUDY: Trust, Autonomy and Psychosocial Changes Experienced by the Ostomy Patient

Lois Ramer, a doctoral student in nursing, is studying patients with a colostomy because as a nurse, she believes, such patients have special needs. If I (the research subject) agree to be in this study, I will answer one questionnaire before my surgery which takes about 10 minutes. Then after surgery, I will answer 3 questionnaires at 4 weeks and 12 weeks after surgery which should not take longer than 80 minutes each time.

I am being asked to participate in this study because I have cancer of the colon (large intestine) and will be undergoing surgery for a colostomy. Because having a colostomy changes the body appearance and body function, people generally experience feelings of psychosocial discomfort (depression, anxiety, worry about social situations) as well as concern over how best to care for their colostomies. Nurses need to know the special needs and concerns of these patients in order to help them learn to care for their colostomies and to resume as normal a life as possible. I will be one of 30 patients participating in this study.

Answering the questionnaires may cause some emotional discomfort and I, the subject, may decline to answer any questions plus discuss your feelings with the researchers. The study is not immediately of benefit to the participant but may benefit nurses in caring for future patients with colostomies.

All information received will be held in strict confidentiality as far as possible under the law. All data will be treated as group data and will be analyzed by statistical methods.

Participation in this research is voluntary. I (the subject) have the right to decline to participate and to withdraw at any point in this study without jeopardy to my continued medical care. If I wish to participate, I should sign this form.

If I have any comments about participation in this study, I should first talk with the investigator. If for some reason

UNIVERSITY OF CALIFORNIA, LOS ANGELES
DEPARTMENT OF NURSING RESEARCH AND EDUCATION
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
SCHOOL OF NURSING
DEPARTMENT OF PHYSIOLOGICAL NURSING

INFORMATION SHEET

In nursing, we believe that patients with an ostomy may have special needs. Participating in this study about colostomy patients will involve answering a questionnaire before surgery that will take about ten minutes. Four and twelve weeks after surgery, you again will answer the same questionnaire plus two additional questionnaires which will take about one hour and ten minutes.

Your participation or nonparticipation within this study will not affect the care you receive. Part of the study involves review of your medical record. Your form will only be seen by the researcher and reported results will not contain any identifying information.

There are no immediate benefits to you. There are also no risks except any emotional response to the questions asked. However, future benefits may include a better understanding of the special needs of the patient with an ostomy. As you answer the questionnaire, if you find that certain questions strongly affect you and you believe you need to discuss them, please talk with the researcher after you have returned the questionnaire.

You may complete the entire form or selected portions.

Lois Ramer, R.N., M.N.
(818) 846-6350

Dr. Linda Faber
(818) 825-6624

Experienced by the Post-operative Cancer Patient with a Colostomy
Principal Investigator: Lois Ramer, R.N., M.N., D.C. UCSF
Sponsor at C.O.H.: Marcia Grant, R.N., D.N.Sc.

PATIENT INFORMED CONSENT TO PARTICIPATE IN A NURSING STUDY

I, _____, a patient at _____, consent to participate in a study about the post-operative experiences of the colostomy patient. I understand that the study will not alter the medical care I will receive.

I further understand that the purpose of the study is to learn more about the experience of the patient with a colostomy and how they adjust to living with their colostomy. I understand that my participation in the study will involve answering a short questionnaire before surgery which will take about 10 minutes, plus, 4 and 12 weeks after surgery, there will be 2 additional questionnaires which will involve about 1½ hours of time.

I understand that possible benefits associated with my participation in the above process include additional information gained about my nursing care needs and my progress. I understand that my participation may cause me some inconvenience due to the time involved in filling out some questionnaires and answering a few demographic questions. I further understand that I may experience some satisfaction from participating in this study even though the information gained from this study may or may not help other patients at some future time.

I understand that data on me that relate to the study may be used and that all data gathered will be held confidential and my name will not be associated with the data. In addition, the City of Hope Institutional Review Board for the Protection of Human Subjects (IRB) has approved this study. If I have further questions about it, I may call the IRB Secretary, Mr. William Burinda, (818) 359-8111, extension 2700.

I understand that I may withdraw this consent and discontinue my participation in this study at any time before or during the study period without interference with subsequent treatment. I understand that any pertinent new findings developed during the course of this study that may relate to my willingness to continue participation will be provided to me.

I understand that in the event of physical injury resulting from these research procedures, appropriate medical treatment will be given to me free of charge but financial compensation will not be available.

IRB#

City of Hope National Medical Center
Duarte, California

**AUTHORIZATION AND INFORMED CONSENT FOR
PARTICIPATION IN AN INVESTIGATIONAL ACTIVITY**

C.9.c.

PATIENT CONSENT TO PARTICIPATE IN A NURSING STUDY

I understand that this study is being conducted under the direction of Lois Ramer, R.N., Principal Investigator (818) 846-6350, and the sponsor at City of Hope is Marcia Grant, R.N., D.N.Sc., (818) 359-8111, extension 2826.

I have read the above, and consent to participate in the above described study. I have received a copy of the Research Subject Bill of Rights and a copy of this signed consent form.

Participant

Date

Witness

Investigator

IRB#

City of Hope National Medical Center
Duarte, California

**AUTHORIZATION AND INFORMED CONSENT FOR
PARTICIPATION IN AN INVESTIGATIONAL ACTIVITY**

**PART I-AGREEMENT TO PARTICIPATE IN RESEARCH
BY OR UNDER THE DIRECTION OF THE VETERANS ADMINISTRATION**

DATE

I, _____, voluntarily consent to participate as a subject
(Type or print subject's name)

in the investigation entitled **TRUST, AUTONOMY AND PSYCHOSOCIAL DISCOMFORT EXPERIENCED BY POST-OPERATIVE
CANCER PATIENTS WITH COLOSTOMY**
(Title of study)

2. I have signed one or more information sheets with this title to show that I have read the description including the purpose and nature of the investigation, the procedures to be used, the risks, inconveniences, side effects and benefits to be expected, as well as other courses of action open to me and my right to withdraw from the investigation at any time. Each of these items has been explained to me by the investigator in the presence of a witness. The investigator has answered my questions concerning the investigation and I believe I understand what is intended.

3. I understand that no guarantees or assurances have been given me since the results and risks of an investigation are not always known beforehand. I have been told that this investigation has been carefully planned, that the plan has been reviewed by knowledgeable people, and that every reasonable precaution will be taken to protect my well-being.

4. In the event I sustain physical injury as a result of participation in this investigation, if I am eligible for medical care as a veteran, all necessary and appropriate care will be provided. If I am not eligible for medical care as a veteran, humanitarian emergency care will nevertheless be provided.

5. I realize I have not released this institution from liability for negligence. Compensation may or may not be payable, in the event of physical injury arising from such research, under applicable federal laws.

6. I understand that all information obtained about me during the course of this study will be made available only to doctors who are taking care of me and to qualified investigators and their assistants where their access to this information is appropriate and authorized. They will be bound by the same requirements to maintain my privacy and anonymity as apply to all medical personnel within the Veterans Administration.

7. I further understand that, where required by law, the appropriate federal officer or agency will have free access to information obtained in this study should it become necessary. Generally, I may expect the same respect for my privacy and anonymity from these agencies as is afforded by the Veterans Administration and its employees. The provisions of the Privacy Act apply to all agencies.

8. In the event that research in which I participate involves certain new drugs, information concerning my response to the drug(s) will be supplied to the sponsoring pharmaceutical house(s) that made the drug(s) available. This information will be given to them in such a way that I cannot be identified.

I _____
NAME OF VOLUNTEER

HAVE READ THIS CONSENT FORM. ALL MY QUESTIONS HAVE BEEN ANSWERED, AND I FREELY AND VOLUNTARILY CHOOSE TO PARTICIPATE. I UNDERSTAND THAT MY RIGHTS AND PRIVACY WILL BE MAINTAINED. I AGREE TO PARTICIPATE AS A VOLUNTEER IN THIS PROGRAM.

9. Nevertheless, I wish to limit my participation in the investigation as follows:

PLEASE SEE ATTACHED ADDENDA TO THIS VA FORM 10-1086

3 (No. of addendums attached)

VA FACILITY VAMC-WLA, Wadsworth Division	SUBJECT'S SIGNATURE
WITNESS'S NAME AND ADDRESS (Print or type)	WITNESS'S SIGNATURE
INVESTIGATOR'S NAME (Print or type)	INVESTIGATOR'S SIGNATURE

Signed information sheets attached. Signed information sheets available at:

SUBJECT'S IDENTIFICATION (I.D. plate or give name - last, first, middle)	SUBJECT'S I.D. NO.	WARD
--	--------------------	------

PART II - AGREEMENT BY SUBJECT'S REPRESENTATIVE TO ALLOW SUBJECT TO PARTICIPATE IN RESEARCH BY OR UNDER THE DIRECTION OF VETERANS ADMINISTRATION

DATE

1. I, _____, am authorized to give consent
(Type or print name of subject's representative)

for _____ by virtue of _____
(Type or print subject's name) (Relationship, legal appointment, etc.)

I voluntarily consent for this person to participate as a subject in the investigation entitled _____
(Title of study)

2. I have signed one or more information sheets with this title to show that I have read the description including the purpose and nature of the investigation, the procedures to be used, the risks, inconveniences, side effects, and benefits to be expected, as well as other courses of action open to me and my right to withdraw the subject from the investigation at any time. Each of these items has been explained to me by the investigator in the presence of a witness. The investigator has answered my questions concerning the investigation and I believe that I understand what is intended.

3. I understand that no guarantees or assurances have been given me since the results and risks of an investigation are not always known beforehand. I have been told this investigation has been carefully planned, that the plan has been reviewed by knowledgeable people, and that every reasonable precaution will be taken to protect the well-being of the subject.

4. In the event the subject sustains physical injury as a result of participation in this investigation, if the subject is eligible for medical care as a veteran, all necessary and appropriate care will be provided. If the subject is not eligible for medical care as a veteran, humanitarian emergency care will nevertheless be provided.

5. I realize I have not released this institution from liability for negligence. Compensation may or may not be payable, in the event of physical injury arising from such research, under applicable federal laws.

6. I understand that all information obtained about the subject during the course of this study will be made available only to doctors who are taking care of the subject and to qualified investigators and their assistants where their access to this information is appropriate and authorized. They will be bound by the same requirements to maintain the subject's privacy and anonymity as apply to all medical personnel within the Veterans Administration.

7. I further understand that, where required by law, the appropriate federal officer or agency will have free access to information obtained in this study should it become necessary. Generally, I may expect the same respect for the subject's privacy and anonymity from these agencies as is afforded by the Veterans Administration and its employees. The provisions of the Privacy Act apply to all agencies.

8. In the event that research in which the subject participates involves certain new drugs, information concerning the subject's response to the drug(s) will be supplied to the sponsoring pharmaceutical house(s) that made the drug(s) available. This information will be given to them in such a way that the subject cannot be identified.

I _____
NAME OF SUBJECT'S REPRESENTATIVE

HAVE READ THIS CONSENT FORM. ALL MY QUESTIONS HAVE BEEN ANSWERED. AND I FREELY AND VOLUNTARILY CHOOSE THAT THE SUBJECT PARTICIPATE. I UNDERSTAND THAT THE SUBJECT'S RIGHTS AND PRIVACY WILL BE MAINTAINED. I AGREE TO THE SUBJECT'S PARTICIPATION AS A VOLUNTEER IN THIS PROGRAM.

9. Nevertheless, my consent for the subject's participation in the investigation is limited as follows:

PLEASE SEE ATTACHED ADDENDA TO THIS VA FORM 10-1086

_____ (No. of addendums attached)

ADDRESS OF SUBJECT'S REPRESENTATIVE (Print or type)	SIGNATURE OF SUBJECT'S REPRESENTATIVE
WITNESS'S NAME AND ADDRESS (Print or type)	WITNESS'S SIGNATURE
SUBJECT'S NAME (Print or type)	SUBJECT IS NOW A PATIENT AT (Name of VA Facility)
INVESTIGATOR'S NAME (Print or type)	INVESTIGATOR'S SIGNATURE

Signed information sheets attached. Signed information sheets available at:

SUBJECT'S IDENTIFICATION (I.D. plate or print name - last, first, middle)	SUBJECT'S I.D. NO.	AGE	WARD
---	--------------------	-----	------

AGREEMENT BY SUBJECT'S REPRESENTATIVE TO PARTICIPATE IN RESEARCH BY OR UNDER THE DIRECTION OF THE VETERANS ADMINISTRATION

Veterans Administration COMMITTEE ON HUMAN STUDIES
Wadsworth Medical Center APPROVED
Wilshire & Sawtelle Blvds.
Los Angeles, CA. 90073 11/10/87

VOID AFTER 10/88

HUMAN STUDIES CONSENT FORM
(Addendum to VA Form 10-1086)

RESPONSIBLE INVESTIGATOR: Elizabeth A. Hefferin, DPH, RN Phone No. (213) 824-3289

Co-Investigator(s) Lois Ramer, RN, MN (818) 846-6350

TITLE OF PROTOCOL: TRUST, AUTONOMY AND PSYCHOSOCIAL DISCOMFORT EXPERIENCED BY POST-OPERATIVE CANCER PATIENTS WITH COLOSTOMY Study No. 0036

- a. **BACKGROUND:** I am being asked to participate in this study because I have cancer of the colon (large intestine) and will be undergoing surgery for a colostomy. Because having a colostomy changes the body appearance and body function, people generally experience feelings of psychosocial discomfort (depression, anxiety, worry about social situations) as well as concern over how best to care for their colostomies. Nurses need to know the special needs and concerns of these patients in order to help them learn to care for their colostomies and to resume as normal a life as possible. I will be one of 30 patients participating in this study.
- b. **PURPOSE:** To determine the post-operative experiences, needs and feelings of cancer patients who undergo colostomy surgery.
- c. **PROCEDURE:** My participation will require that before my surgery, I will complete a questionnaire which asks about my usual worries or feelings and will provide the nurse investigator with some information about my illness history. Then, at about 4 weeks and again at 12 weeks after my surgery, the nurse investigator will visit me at my home and I will again complete the first questionnaire about my usual worries and feelings plus 2 other questionnaires which focus on how I feel about living with and caring for my colostomy. Each interview/questionnaire session will take about 45 to 60 minutes of my time.

Date _____

Patient or Responsible Party

Social Security Number _____

Witness

Investigator/Physician

Veterans Administration
Wadsworth Medical Center
Wilshire & Sawtelle Blvds.
Los Angeles, CA. 90073

COMMITTEE ON HUMAN STUDIES
APPROVED

11/10/87

HUMAN STUDIES CONSENT FORM
(Addendum to VA Form 10-1086)

VOID AFTER 10/88

RESPONSIBLE INVESTIGATOR: Elizabeth A. Hefferin, DPH, RN Phone No. (213) 824-3289

Co-Investigator(s) Lois Ramer, RN, MN (818) 846-6350

TITLE OF PROTOCOL: TRUST, AUTONOMY AND PSYCHOSOCIAL DISCOMFORT EXPERIENCED BY POST-
OPERATIVE CANCER PATIENTS WITH COLOSTOMY Study No. 0036

d. **RISKS AND/OR INCONVENIENCES:** Answering the questionnaires may cause me some emotional discomfort and I may decline to answer any such questions. I may be distressed also because of the time involved in completing the questionnaires (approximately 45 to 60 minutes).

e. **BENEFITS:** The questionnaires may help me to express how I feel about caring for and living with my colostomy and help to identify my particular learning needs. The study data may help other colostomy patients by providing information about their adjustment problems and other special needs.

f. **ALTERNATE PROCEDURES:** Non-participation,

g. Any questions I have concerning my participation in this study will be answered by Lois Ramer or Dr. Hefferin.

h. I may withdraw from the study at any time without prejudice.

i. The results of this study may be published, but my name or identity will not be revealed and my records will remain confidential unless disclosure of my identity is required by law.

I understand that I will not be prevented from receiving established forms of therapy while on this study. Also, if more than trivial side effects directly attributable to the study occur, the study will be discontinued and routine treatment continued.

j. My consent is given voluntarily without being coerced or forced.

Date _____

Social Security Number _____

Patient or Responsible Party

Witness

Investigator/Physician

**Veterans Administration
Wadsworth Medical Center
Wilshire & Sawtelle Blvds.
Los Angeles, CA. 90073**

COMMITTEE ON HUMAN STUDIES
APPROVED

11/10/87

HUMAN STUDIES CONSENT FORM
(Addendum to VA Form 10-1086)

VOID AFTER 10/88

TITLE OF PROTOCOL: TRUST, AUTONOMY AND PSYCHOSOCIAL DISCOMFORT EXPERIENCED BY POST-
OPERATIVE CANCER PATIENTS WITH COLOSTOMY Study No. 0036

RESPONSIBLE INVESTIGATOR: Elizabeth A. Hefferin DPH, RN Phone No. (213) 824-3289

Co-Investigator(s) Lois Ramer, RN, MN (818) 846-6350

k. NON-VETERANS

In the event physical injury is sustained as a result of participating in this program, non-veterans may receive emergency medical care and, in appropriate cases, may be entitled to compensation under the provisions of the Federal Tort Claims Act (28 U.S.C. 1346(b), 2671-2680).

VETERANS

Continuing medical care will be provided eligible veterans in the event physical injury is sustained as a result of participation in this program. Additionally, compensation may be payable to eligible veterans under 38 U.S.C. 351 or, in appropriate cases, under the provisions of the Federal Tort Claims Act (28 U.S.C. 1346(b), 2671-2680).

For clarification of these laws, contact the VA District Counsel (213) 209-7379.

1. If I have complaints about the procedure I may express them to Lois Ramer, RN or Dr. Hefferin (Investigators) or the Committee on Human Studies, or to the Chief of Staff for Research and Development of Wadsworth Medical Center, 478-3711, extension 4224.

m. I have received a copy of this consent form for my file and a copy of the "Rights of Human Subjects in Medical Experiments."

I have read the above and understand it and hereby consent to the procedure(s) set forth.

Date _____

Social Security Number _____

Patient or Responsible Party

Witness

Investigator/Physician

APPENDIX J

(INTRODUCE YOURSELF TO THE INDIVIDUAL) I will be asking you a lot of questions today; about your health, about your family situation, about your income and about how you are getting along in general. But first, I need to ask you a few school-type questions. By the way, how far did you go in school?

(RECORD ANSWER AS GIVEN BY SUBJECT HERE, AND CHECK APPROPRIATE SPACE IN QUESTION 6 ON PAGE 3 WHEN YOU COME TO IT.) Number of years of schooling. (WRITE IN) _____.

1. SPMSQ

PFEIFFER
SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE
(SPMSQ)

INSTRUCTIONS: Ask the subject questions 1-10, record answer, and enter as "1" under appropriate column (correct/error). All responses, to be scored correct, must be given by subject without reference to calendar, newspaper, birth certificate or other memory aid.

	CORRECT	ERROR
1. WHAT IS THE DATE TODAY? MONTH _____ DAY _____ YEAR _____ (Score correct only when the exact month, day and year are given correctly.)		
2. WHAT DAY OF THE WEEK IS IT? DAY _____		
3. WHAT IS THE NAME OF THIS PLACE? (Score correct if any correct description of the location is given: "My home", accurate name of town, city, or name of residence, hospital, or institution (if subject is institutionalized) are all acceptable.)		
4. WHAT IS YOUR TELEPHONE NUMBER? (If none, see 4A below) (Score correct when the correct number can be verified or when subject can repeat the same number at another point in questions.)		
4A. WHAT IS YOUR STREET ADDRESS? (Ask only if subject does not have telephone.)		
5. HOW OLD ARE YOU? AGE: _____ (Score correct when stated age corresponds to date of birth.)		
6. WHEN WERE YOU BORN? MONTH _____ DAY _____ YEAR _____ (Score correct only when exact month, date and year are all given.)		
7. WHO IS THE PRESIDENT OF THE UNITED STATES NOW? (Only the last name of the President is required.) _____		
8. WHO WAS THE PRESIDENT BEFORE HIM? (Only last name of previous President required.) _____		
9. WHAT WAS YOUR MOTHER'S MAIDEN NAME? (Does not need to be verified. Score correct if a female name plus last name other than subject's last name is given)		
10. SUBTRACT 3 FROM 20 AND KEEP SUBTRACTING 3 FROM EACH NEW NUMBER ALL THE WAY DOWN. (The entire series must be performed correctly in order to be scored correct. Any error in series or unwillingness to attempt series is scored as incorrect.)		

TOTAL NUMBER ERRORS

*ADJUSTMENT FACTORS:

A) SUBTRACT 1 FROM ERROR SCORE IF SUBJECT HAS HAD ONLY A GRADE SCHOOL EDUCATION.....

B) ADD 1 TO ERROR SCORE IF SUBJECT HAS HAD EDUCATION BEYOND HIGH SCHOOL.....

1.

TOTAL ADJUSTED ERRORS

APPENDIX K

Letter of Information

Dr. _____, I am a nursing doctoral student from the University of California at San Francisco. My dissertation involves cancer patients with a colostomy. Your patient, _____, has agreed to participate in my study "Trust, Autonomy, and Psychosocial Discomfort Experienced by the Post-operative Patient with a Colostomy". The subjects in this study will be responding to the Brief Symptom Inventory (BSI) Scale pre-operatively; this takes about 10 minutes. At 4 weeks and 12 weeks post-operative, they will again respond to this questionnaire plus 2 additional questionnaires. Total time involved should not be more than one hour and 10 minutes. This study will give some descriptive information about the post-operative colostomy patient's adjustment process. If you have questions, feel free to contact:

Lois Ramer (h) 818-846-6350
(o) 213-224-3421
(o) 213-742-1521

APPENDIX L

SOCIODEMOGRAPHICS

1. Sex of Subject
 - 1 Male
 - 2 Female

2. Marital Status
 - 1 Single
 - 2 Married
 - 3 Widow/Widower
 - 4 Divorced

3. Ethnic Background of Subject
 - 1 White (Caucasian)
 - 2 Black
 - 3 Oriental
 - 4 Spanish American (Spanish surname)
 - 5 American Indian
 - 6 Other

4. Currently residing with _____

5. When were you born? _____
(Month) (Day) (Year)

6. How old are you? _____

7. How far did you go in school?
 - 1 0-4 years
 - 2 5-8 years
 - 3 High school incomplete
 - 4 High school completed
 - 5 Post high school, business or trade school
 - 6 1-3 years of college
 - 7 4 years college completed
 - 8 Post graduate college

8. How long have you lived in this area?
 - 1 Seasonal resident (more than 1 mo. but less than 6 mos./year)
 - 2 Less than 5 years
 - 3 5-10 years
 - 4 11-15 years
 - 5 More than 15 years

9. Occupation _____

10. Diagnosis _____

11. Time since surgery _____

12. Type of surgery _____
13. Currently employed _____
14. Stage of disease (circle)
- I II III IV metastatic
15. Type of therapy
- _____ Pre-operative radiation
- _____ Chemotherapy
- Number of weeks _____
- _____ Post-operative radiation therapy
- Number of weeks _____
16. Description of surgery
- Location of colostomy _____
- Wears a bag yes no
- Type of rectal wound _____
17. Pre-operative teaching received _____
- _____
18. Post-operative teaching on colostomy care
- _____ Number of lessons
19. How long have you known your diagnosis
- Weeks _____ Months _____
20. Have you ever had surgery for colon cancer before?
- _____ Yes _____ No
21. Third party payer
- _____ Insurance _____ Medical _____ Medicare
22. Is a visiting nurse following the patient home? _____

23. Do you have any of the following illnesses at the present time?

(If "YES", ASK: "How much does it interfere with your activities, not at all, a little (some), or a great deal?" AND CHECK THE APPROPRIATE BOX.)

1		(1)	(2)	(3)
YES	ILLNESSES	NOT AT ALL	A LITTLE	A GREAT DEAL
a	Arthritis or rheumatism			
b	Glaucoma or cataracts			
c	Asthma			
d	Emphysema or chronic bronchitis			
e	Tuberculosis			
f	High blood pressure			
g	Heart trouble			
h	Circulation trouble in arms or legs			
i	Diabetes			
j	Ulcers (of digestive sys.)			
k	Other stomach or intestinal disorders			
l	Cancer or leukemia			
m	Anemia			
n	Effects of stroke			
o	Parkinson's Disease			
p	Epilepsy			
q	Thyroid or other glandular disorders			
r	Pressure sores, leg ulcers or burns			
s	Effects of fracture or broken bones			
t	Speech impediment or impairment			
u	Other disabilities [SPECIFY]:			

24. I have a list of common medicines that people take. Would you please tell me if you are or have been taking any of these either now or in the past month.

[CHECK "YES" FOR EACH MEDICINE TAKEN.]

(1)

YES

MEDICATIONS

- a Arthritis medication
- b Prescription pain killer (other than above)
- c High blood pressure medicine
- d Pills to make you lose water or salt (water pills)
- e Digitalis pills for the heart
- f Nitroglycerin tablets for chest pain
- g Blood thinner medicine (anticoagulants)
- h Drugs to improve circulation
- i Insulin injections for diabetes
- j Pills for diabetes
- k Seizure medications (like Dilantin)
- l Thyroid pills
- m Cortisone pills or injections
- n Antibiotics
- o Medicine for nerves or depression
- p Prescription sleeping pills (once a week or more)
- q Hormones, male or female (including birth control pills)
- r Other [SPECIFY]: _____

[FOR CLINICAL USE ONLY, SPECIFY ALL MEDICATIONS INCLUDING DOSE AND FREQUENCY SUBJECT IS TAKING]

Name of Medication	Dosage	Frequency
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

APPENDIX M

APPENDIX M**TABLE M-1
DESCRIPTION OF SAMPLE BY HOSPITAL**

HOSPITAL	SAMPLE NUMBER	PERCENT
Veterans Administration Medical Center	2	16.7%
University of California Los Angeles	2	16.7%
City of Hope Medical Center	6	50.0%
Glendale Adventist Medical Center	2	16.7%

**TABLE M-2
DESCRIPTION OF SAMPLE BY TYPE OF HOUSEHOLD**

TYPE OF HOUSEHOLD	SAMPLE NUMBER	PERCENT
Lives alone	0	0.0%
Lives with spouse	9	75.0%
Lives with friend	0	0.0%
Lives with children	1	8.3%
Lives with other family member	2	16.7%

**TABLE M-3
DESCRIPTION OF MEANS OF SUPPORT**

MEANS OF SUPPORT	SAMPLE NUMBER	PERCENT
Employed	4	33.3%
Unemployed	2	16.7%
Laid off	1	8.3%
Retired	4	33.3%
Disabled	1	8.3%

APPENDIX M (Continued)

TABLE M-4
DESCRIPTION OF SAMPLE BY LOCATION OF COLOSTOMY, WEARING BAG,
PRE-AND POST-OPERATIVE TEACHING, VISITING NURSE AND THIRD-
PARTY PAYOR

ITEM DESCRIPTION	SAMPLE NUMBER	PERCENT
<u>Location of Colostomy Bag</u>		
Left lower quadrant	7	58.3%
Right lower quadrant	4	33.3%
Unknown	1	8.3%
<u>Type of rectal wound</u>		
Open	2	16.7%
Closed	10	83.3%
<u>Pre-operative teaching --</u>		
<u>Number of sessions</u>		
1	1	8.3%
2	1	8.3%
3	7	58.3%
4	1	16.7%
Unknown	1	8.3%
<u>Visiting nurse</u>		
Yes	7	58.3%
No	4	33.3%
Unknown	1	8.3%
<u>Third Party Payor</u>		
Insurance	2	16.7%
Medi-Cal/Medicare	3	25.0%
Veteran	2	15.7%
None	5	41.7%

APPENDIX M (Continued)**TABLE M-5
DESCRIPTION OF SAMPLE BY TYPE OF MEDICINE BEING TAKEN**

MEDICATIONS	SAMPLE NUMBER	PERCENT
Arthritis medication		
Yes	1	8.3%
No	11	91.7%
Prescription pain killer (Other than above)		
Yes	5	41.7%
No	7	58.3%
High blood pressure medicine		
Yes	2	16.7%
No	10	83.3%
Pills to make you lose water or salt (water pills)		
Yes	1	8.3%
No	11	91.7%
Digitalis pills for the heart		
Yes	1	8.3%
No	11	91.7%
Nitroglycerin tablets for chest pain		
Yes	1	8.3%
No	11	91.7%

NONE OF THE SAMPLE WERE TAKING ANY OF THE FOLLOWING MEDICATIONS:

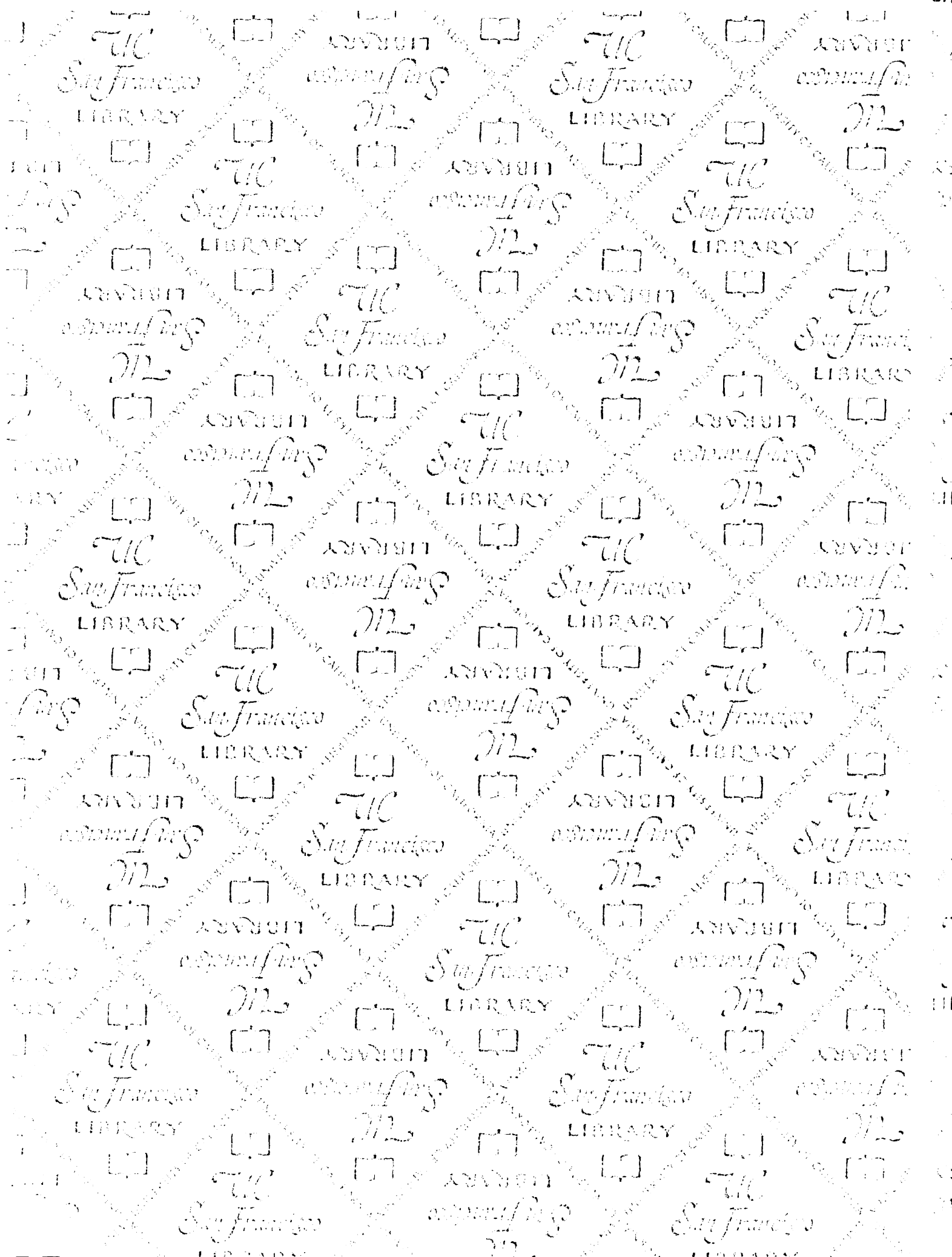
1. Blood thinner medicine (anticoagulants)
2. Drugs to improve circulation
3. Insulin for diabetes
4. Pills for diabetes
5. Seizure medications (like Dilantin)
6. Thyroid pills
7. Cortisone pills or injections
8. Antibiotics
9. Medicine for nerves or depression
10. Prescription sleeping pills (once a week or more)
11. Hormones, male or female (including birth control pills)

APPENDIX M (Continued)**TABLE M-5****DESCRIPTION OF SAMPLE BY OTHER TYPE OF ILLNESSES PRESENT IN PATIENT**

ILLNESS	SAMPLE NUMBER	PERCENT
Arthritis or rheumatism		
Not at all	9	75.0%
A little	3	25.0%
Glaucoma or cataracts		
Not at all	12	100.0%
Asthma		
Not at all	11	91.7%
A little	1	8.3%
Emphysema or chronic bronchitis		
Not at all	12	100.0%
Tuberculosis		
Not at all	11	91.7%
A little	1	8.3%
High blood pressure		
Not at all	9	75.0%
A little	2	16.7%
A great deal	1	8.3%
Heart trouble		
Not at all	9	75.0%
A little	3	25.0%
Circulation trouble in arms or legs		
Not at all	11	91.7%
A little	1	8.3%
Diabetes		
Not at all	11	91.7%
A little	1	8.3%
Ulcers (of digestive system)		
Not at all	11	91.7%
A great deal	1	8.3%

APPENDIX M (Continued)**TABLE M-5 (Continued)
DESCRIPTION OF SAMPLE BY OTHER TYPE OF ILLNESSES PRESENT IN
PATIENT**

ILLNESS	SAMPLE NUMBER	PERCENT
Other stomach or intestinal disorder		
Not at all	11	91.7%
A great deal	1	8.3%
Anemia		
Not at all	11	91.7%
A great deal	1	8.3%
Effects of stroke		
Not at all	11	91.7%
A great deal	1	8.3%
Parkinson's disease		
Not at all	12	100.0%
Epilepsy		
Not at all	12	100.0%
Thyroid or other glandular disorders		
Not at all	12	100.0%
Pressure sores, leg ulcers or burns		
Not at all	12	100.0%
Effects of fractures or broken bones		
Not at all	12	100.0%





FOR REFERENCE

NOT TO BE TAKEN FROM THE ROOM

CAT. NO. 22 012

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