MONTANA STATE UNIVERSITY

# Ostomy adjustment in the first year following surgery

by Kelle Maria Graves

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Nursing
Montana State University
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Abstract:
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A descriptive study design using a survey was used to explore the rural ostomate's adjustment in the first year following surgery.

J. Maklebust's (1985) Ostomy Adjustment Scale was mailed to 34 ostomates selected by Montana ET nurses. Twenty surveys were returned with data reported on seventeen. The ostomate's scores on each question were grouped into two time intervals.

Data revealed a sample population primarily male (13), Caucasian, over the age of 62 and retired from work. Time since surgery did not necessarily improve adjustment scores. The greater than 6 month group had 8 areas where their scores were lower than the 6 month or less post surgery group. The areas included caring for the ostomy independently, being able to talk about the ostomy easily, depression, clothing, public situations, traveling, physical and sexual activity. Only 2 participants found distance from health care services a problem.

Results of the study were not statistically significant, due to the small sample (n=17). The study could be expanded to include a larger region and number of ostomates. Implications include follow up of ostomates over a longer time period by ET nurses.

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A thesis submitted in partial fulfillment
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MONTANA STATE UNIVERSITY-BOZEMAN
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APPROVAL

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Kelle Maria Graves

This thesis has been read by each member of the thesis committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

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# ABSTRACT

Each year more than 100,000 people undergo ostomy surgery. The new ostomates must learn how to care for their ostomies, change bags, adapt their activities of daily living and re-establish relationships following surgery. The literature review revealed studies reporting data retrospectively. The studies identified common issues the ostomate must adapt to, such as changes in sexuality, relationships, and body image.

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# CHAPTER 1

# INTRODUCTION

## Purpose

This study assessed the ostomy patient's adjustment following surgery and hospitalization in a rural setting during the first postoperative year. The patient's adaptation to the presence and management of a stoma was explored by examining whether the patient's needs for emotional support and ostomy management skills were met. The patient's ability to assume care of the stoma and appliance, return to work or pre-surgical activities and continue relationships with family and friends was examined to define the patient's progress in adjusting to a new ostomy. The study provided insight into the needs of the ostomy patient after discharge from the hospital and as each new activity and interaction occurred in daily living. This insight will enhance the education and support provided by the Enterostomal Therapy nurse (ET nurse) to the ostomy patient, sometimes referred to in this study as an ostomate.

## Background and Significance of Study

Each year more than 100,000 people undergo ostomy surgery in which a gastrointestinal or urinary stoma is created (Klopp, 1990). Ostomies are created for a variety of reasons related to disease processes including malignant tumors, congenital anomalies, and inflammatory conditions. Colostomies and urostomies are most commonly a surgical intervention for cancerous lesions of the colon or bladder and are usually found in the elderly population. The majority of ileostomies are created for the treatment of inflammatory bowel diseases which occur more often in young adults. The underlying disease process that necessitates the formation of a stoma impacts the person's ability to adapt. An ileostomy to correct chronic diarrhea and abdominal pain may be easier to adapt to than a colostomy that results from asymptomatic rectal malignancy.

Whatever the etiology necessitating the formation of a stoma, the person with an ostomy must deal with a significant change in body image, the resulting incontinence, and the psychosocial impact this has on lifestyle. An ostomy affects relationships with spouse, family, and friends. Work and social situations, clothing and physical activities may be affected. The postoperative period is a time when a person with a new ostomy learns to care for the stoma. Issues such as how to change a pouch, what type of pouch to use, how to measure a stoma, how to empty

a pouch, how to adapt to the work place, bathing, sex, and exercising are just a few of the changes requiring adjustment by the ostomate. A cancer diagnosis requiring additional radiation or chemotherapy adds to the adjustment difficulties.

Rural culture also has an impact on a person's adjustment to an ostomy. Families are central to the rural culture. Sex-role traditionalism is predominate in the rural family where the women provide the health care (Bigbee, 1993). This can readily be seen when the husband has a stoma and the expectation is for the wife to be responsible for changing the ostomy appliance, obtaining supplies, and follow-up care.

A person with a new ostomy living in a rural environment faces challenges an urban counterpart may not. Isolation, both cultural and geographic, are other important factors in living in a rural area (Bigbee, 1993). Distance, together with transportation, economics, and weather, impact access to medical and nursing experts who care for ostomies on a routine basis.

Bigbee (1993) describes close community ties, the rural nurses as generalists, and professional isolation as characteristics of rural nursing practice. Community ties can provide a challenge when patient confidentiality is a concern. The rural nurse is required to function in a variety of areas often without back up and the ability to consult with nursing colleagues. Professional isolation may lead to limited exposure to

ostomy patients and the nurse may not have the knowledge and skills to deal with a new ostomate especially if stoma management is outside the norm.

Research studies conducted in the area of ostomy adjustment have been retrospective, asking the ostomate to remember back to a time early in the recovery period (Klopp, 1990) or studies using participants ranging from 6 months to 8 years postoperative (Eardley et al, 1976; Druss, O'Connor, Prudden, Stern, 1968). None have addressed the process of adjustment at set time intervals in the year following surgery or living with an ostomy in a rural area. In caring for a person with an ostomy during the first year post surgery there is a perceived turning point where the ostomate says "I can do this, it isn't so bad". In a rural setting, where it is normal for patients to live several hundred miles from the nearest ET nurse, it is difficult to assess how well a person is actually adapting to a new ostomy. Regular visits with an ET nurse is not the norm and patients often improvise or tolerate problems for which their urban counterparts would seek medical attention. This study describes the rural ostomate's adjustment at 4-month intervals during the first year following surgery.

## Problem Statement

Persons with ostomies in the rural setting lack the resources available to ostomates in the urban setting. Rural sites such as Montana

and Wyoming have fewer ET nurses providing ostomy care and education. Montana has seven ET nurses with six practicing in the larger cities. Support groups are available in three cities in Montana. Long distances and responsibilities at home and rural location of people may limit access to experts in the care of ostomies.

This research addressed how participants quantify their quality of life and readjustment at that particular point in time in the first year following surgery. The study provided insight into whether or not the new ostomate's needs were met. The participants were adults with a non-terminal condition and a newly formed ostomy.

## Research Questions

In addition to the problem statement, related research questions addressed are:

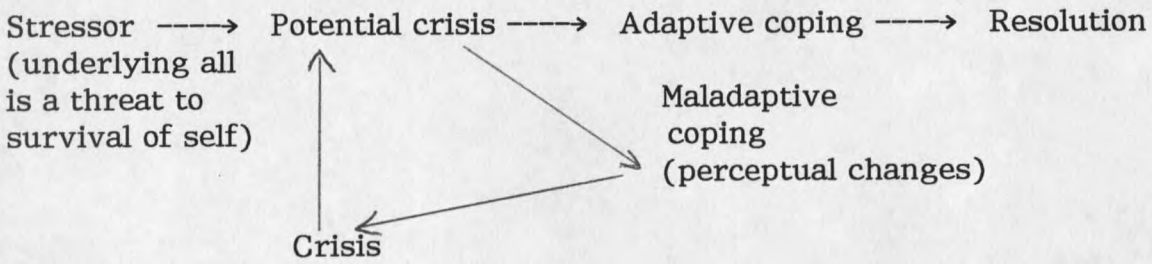
1. Is there a point in the first year post surgery where the ostomy patient fully integrates the ostomy into their life style?

2. Does the length of time post-operatively in the first year make a difference in adjustment and resocialization?

3. Does residing in a rural setting affect adjustment and resocialization of a person with an ostomy?

## Conceptual Framework

The conceptual framework for this study was Sultenfuss's (1982) crisis theory and management. This theory was also referred to by Kelman and Minkler (1989) and Hedrick (1987) as a method of describing a new ostomate's experience following surgery. The theory is diagrammed in Figure 1.




Variables:
1. Number and intensity of stressors
2. Past history, present perceptions
3. Resources - internal and external

Figure 1. Crisis Theory and Management

Sultenfuss (1982) defines a stressor as any actual/perceived loss or change that may threaten an individual's sense of balance. Surgery resulting in a permanent ostomy is a stressor that leads to a potential crisis. The postoperative period is a time where a patient must learn to cope with a change in body appearance (stoma), a change in body function (body wastes into a pouch), and potential changes in sexual function and

length of life. Whether a person copes successfully with these new changes depends upon three variables: (1) the number and intensity of stressors such as a stoma, cancer diagnosis, and impotence from the surgical procedure, (2) past history and experiences and present perceptions such as people with ostomies are always old and smelly, and (3) resources available to help them cope either internally or externally such as a supportive spouse. Adaptive coping occurs as a process. If a person becomes "stuck" in a stage, maladaptive coping can occur. Resolution is the final step. Sultenfuss (1982) defines resolution as a completion process where a loss or change is acknowledged and integrated into a person's life. The person may also see it as an opportunity to expand or experience living.

This crisis and management theory lends itself to the process an ostomy patient goes through upon hearing the initial news from the physician through the surgical procedure and the first look at their new body image with the first pouch change. Coping and adjustment begins immediately and continues throughout the hospitalization and discharge to home. Whether or not the person succeeds in adjusting to a new ostomy and integrating the changes is not always readily apparent in a patient living in a rural setting far from ET nurse follow up.

## Definitions

For the purpose of this study the following terms were used:

Adjustment: high score on the Ostomy Adjustment Scale (OAS)

ET Nurse: registered nurse with a Bachelor of Science in Nursing degree who is a graduate of an Enterostomal Therapy Nursing Education program accredited by the Wound, Ostomy, Incontinence Nurses Society.

Ostomy: a surgically created opening in the body.

Colostomy: surgical construction of a new opening on the abdomen for the large intestine.

Ileostomy: opening into the ileum.

Urostomy: any type of urinary diversion which results in a stoma.

Ileal anal pouch: surgical removal of colon and mucus lining of rectum, construction of an internal pouch from ileum, which is attached to rectum. A temporary ileostomy may be done.

Quality of Life: evidenced by a high score on the Ostomy Assessment Scale. The scores possible on the OAS range from a low of 8 to a high of 126.

Rural setting: according to the U.S Bureau of the Census incorporated or census-designated places of 2500 inhabitants or more is urban and all other places are rural. According to this definition, both Montana and Wyoming are considered rural for the purpose of this study.

## Assumptions

1. Ostomy clients can read and understand English.
2. Participant will be able to cognitively discriminate in answers.
3. All participants have had contact with an ET nurse.

## Limitations

1. Sample size is small due to low population in the geographic location chosen for the study.
2. Generalization to another population such as patients having ostomies in rural hospitals without ET nurses will not be possible.

# CHAPTER 2

## LITERATURE REVIEW

A review of the literature was done to explore the impact the creation of an ostomy has on a person's life. The creation of the first ostomy occurred in the 1700's, however, the study of its impact did not become prevalent until the 1950's and 1960's. The first research was conducted by the physicians performing the ostomy procedures and psychologists. Early research concerning ostomy adjustment was found in the psychiatric and surgical journals. While there continues to be reports of research in the psychiatric field, more research is being conducted and reported in journals connected with enterostomal therapy and oncology nursing.

The most commonly surveyed ostomy groups were those with colostomies, ileostomies, and urostomies. Adjustment to an ostomy has been studied in relation to quality of life, psychological impact, psychosocial interactions, body image, self-esteem, management skills, impact of gender, economic status, educational level, and sexuality issues. A person with a new ostomy is impacted by the surgical procedure, prognosis, relationships with significant others and their own ability to cope or adjust to a significant change in body appearance and function. Every aspect of a new ostomate's life is impacted by the presence of a

stoma; this is apparent in the overlapping discussion of issues relevant to the person with an ostomy. This literature review will discuss the general needs of a person adjusting to an ostomy, the psychosocial impact of ostomy surgery including body image and self-esteem, quality of life, and sexuality.

## General Needs of the Ostomate

Eardley et al. (1976) conducted a study to investigate the problems that arise during life with a permanent colostomy, with special emphasis on identifying those issues that offered a scope for practical solutions. The participants had a permanent colostomy for a minimum of 6 months. The study participants (n=76) included 40 men and 36 women ranging in age from 30 to 85 years. Thirty five percent had their colostomy for less than a year, 45% between 1-3 years and 20% for greater than 3 years. For 72 participants, the major reason for the colostomy was cancer. The study was conducted by interview in the participant's home and covered the hospital experience, early adjustment, and current adjustment. The interviews revealed 27% would have liked more information and reassurance about the surgery. Twenty nine percent felt the management instructions were inadequate and expressed a concern about coping alone with a permanent ostomy. Seventeen percent had not reached a proficiency in appliance care by the time of discharge. During the early adjustment

period, 41% identified difficulties with management, usually with ill-fitting and unreliable appliances. Twenty one percent noted physical problems such as weakness, incontinence or abscesses. Fifty nine percent of the participants felt depressed in the first few weeks following surgery with concerns about the prospect of living with a permanent colostomy and worry about the possibility of resuming a normal life. Current adjustment was divided into three categories: management, activities, and reaction to colostomy. Sixty three percent of the participants had some problem related to management. Two thirds of the participants had some type of problem with their original appliance with one third changing to a new system. Dietary restrictions or modifications were noted in 50% of the participants with 25% having severely restricted their diets. Activities affected included employment, social life, and sexual function. Two thirds of the participants mentioned that they had no restrictions in their activity and the remainder noted minor restrictions such as lifting. However, many of the participants were over retirement age and were not working prior to surgery. Social life was not affected in 60% of the participants, but 24% were restricted due to "psychological" reasons. Eighteen percent refused to stay away from home due to difficulties managing the colostomy. Fifty seven percent stated their colostomy made no difference in their sex life. For those who were affected, problems were related to physiologic changes, fear of harming oneself and embarrassment. Half of the

participants suffered from depression in varying degrees. Eardley et al. concluded that a patient with an ostomy needs to demonstrate proficiency in self care prior to discharge and have adequate professional follow up available after discharge. The study is retrospective, asking participants to remember back anywhere from 6 months to 3 years.

Ewing, G. (1989) conducted a study using Orem's self care model of nursing preparation of stoma patients. The study consisted of an observer who watched patient teaching during pouch changes by the nurses and patient. Multiple pouch changes were monitored for 12 hospitalized patients with special attention to preparation of patient, removal of appliance, skin care, selection of new appliance, preparation of appliance, application, and provision of developmental environment. Ewing (1989) reached the conclusion that the patients were receiving considerable nursing assistance in management of their ostomy and did not show the new self-care skills necessary for care after discharge. A reluctance on the part of the nurses to let go and allow the patient to assume care was noted. The study population is small, n=12, but provides insight into patient teaching and its potential impact on adjustment to a new ostomy.

Coe and Kluka (1990) investigated and compared the concerns of the patient and spouse in relation to ostomy surgery for treatment of cancer. Crisis theory formed the conceptual framework for examination of the course of events experienced by the individual and spouse when faced with

a cancer diagnosis and ostomy surgery. Two phases of study were conducted. During Phase 1 of the study, a content analysis identified 48 client-expressed concerns and 24 client-perceived helpful behaviors. Phase 2 of the study involved twenty additional couples who separately ranked the concerns identified during Phase 1 using Q-sort methodology. Data analysis revealed that the four primary concerns of both patient and spouse were fear of cancer spreading, the need to have further treatments, fear of death, and having cancer. Patients also identified the "desire to be involved in the learning process", while the spouses ranked "knowing how to offer encouragement" a priority. Topics of least concern include "keeping the surgery a secret", "fear of transferring the cancer to others", "feeling embarrassed about the surgery" and knowing "when and how to tell their children". The report of data is limited to four topics and does not address ostomy adjustment.

Deeny and McCrea (1991) noted that most of the literature related to the needs of the stoma patient was presented according to the physician or nurse perspective. Researchers identified problem areas prior to approaching the patient. Using a qualitative study approach, Deeny and McCrea allowed the patients to identify their own needs. A theoretical basis for the study was drawn from Bergmann's theory which identified three components of human needs: biophysical needs, psychological needs, and sociocultural needs. The researchers used open-ended interviews

lasting between 45 minutes and 5 hours. Questions were developed prior to the interviews but the interviewer was encouraged to use active listening skills and formulate questions as the interview progressed. A pilot study utilizing this format was conducted to evaluate the interview technique and its ability to provide qualitative data. The participants (n=6) were asked what their needs were and how these needs were fulfilled by the nursing care. Anxieties about life with an ostomy related to diet, clothing, managing the appliance and sexual activities were identified. The need to express fears about the ostomy and surgery and the lack of opportunity to do so was also reported as a psychological need. Sociocultural needs included the need to have relationships with other individuals including family and peers and the need to resume social roles and sexual activities. The findings indicated the ostomates psychological and sociocultural needs went unmet. The study population was small (n=6) but identifies needs that are not being met.

## Psychosocial Impact

### Adjustment related to activities of daily living

Druss et al. (1968) studied how patients react to ostomy procedures in terms of their day to day, physical and emotional functioning in order to provide information of practical use to individuals caring for these patients. Study participation was limited to patients over the age of 21

years who had a colectomy between 1969 and 1976. The questionnaire was prepared by the Office of Vocational Rehabilitation with additional questions related to sexuality. The questions addressed the pre-surgical period, immediate post surgical period, and the overall long-term adjustment since surgery. The study sample (n=41) consisted of 41% men and 59% women with a mean age of 35, who had suffered from ulcerative colitis for 7 years prior to surgery. Forty one percent of the population required at least one additional surgery post colectomy. All but one stated that they now had an excellent or very good state of health, saying in addition that having an ileostomy was greatly preferred over living with their previous severe form of colitis. Participation in social activities deteriorated following surgery for 4 participants, 3 men stated work situations worsened, 3 men and 1 woman stated that sexual relations were less satisfactory. Forty six percent said that the ileostomy was a problem in their current life. Specifically these problems related to skin surrounding the stoma, fear of unpleasant odor in public, special adjustments to clothing by the women, accidents, inconvenience of emptying the pouch in public. Interpersonal relations were seen as an important issue. The patients saw their ileostomy and their own acceptance or rejection influenced by relationships with key figures in their life such as spouse, fellow workers, and superiors. Sexual performance problems were also related in terms of expected reaction of their partners.

Forty one percent stated they had emotional problems pre- and post-colectomy. The authors noted that although a good outcome was represented at a functional level, this did not carry through in terms of intrapsychic well being. The study was limited to ileostomy patients who were asked to remember back several months or years to answer a questionnaire.

Psychological impact

Pryse-Phillips (1971) in a study of patients (n=20) with a colostomy or ileostomy for greater than 18 months examined the psychologic effects of ostomy surgery. Using an interview technique the researcher administered four tests: Depression Rating Scale, Eysenck Personality Inventory, 16 Personality Factor Questionnaire, and Scale of Obsessional Symptomatology. No psychiatric symptoms or only trivial symptoms were evident in fourteen patients while 6 were moderately or severely incapacitated. Incapacitation was not related to the physical presence of the stoma, but to the morbid fear that some property of the colostomy, such as odor, would lead to detection by others and result in shunning, mockery, or criticism. The same 6 participants were significantly more depressed and showed symptoms or behaviors such as excessive attention to the stoma, protracted washing and cleanliness routines, and severe withdrawal from social activities. The study population was small (n=20) and the data does not reflect a rural population.

Orbach and Tallent's (1965) focused their study on identification and description of the processes initiated by radical surgery and how patients with a colostomy come to terms with its existence. Forty eight patients participated in the interview section of the study with 31 also receiving the Rorschach Test. Attributes of the population included a mean age of 60, 5 to 10 years post surgery, predominantly Jewish and having been born in Europe. Two thirds had an elementary school education. Orbach and Tallent (1965) described the impact of surgery as a violation or an assault on the body intactness which had not lessened over the 10 years since surgery. In addition, the reduction of function and relinquishment of roles required a radical revision of how the person perceived his relationships with himself and to other people. The sense of being on a leash, tied to a bathroom, affects mobility and indirectly autonomy. Changes in body concept were related to moving the evacuation orifice from rear to front. In addition the taboos against touching the anal area without wads of paper transferred a sense of dirtiness to the stoma. The Rorschach Tests revealed a syndrome that is imposed upon or coexists with the basic personality. All participants revealed some degree of impairment of psychological nature resulting in a facade to cover subjective feelings of depression, anxiety, sense of inadequacy and feelings of lost personal integrity. The sample population in this study was limited to essentially

Jewish, European men which does not reflect a rural Montana population or culture.

Oberst & Scott (1988) using crisis theory described the magnitude and temporal pattern of crisis development experienced by post surgery cancer patients and their spouses during a 9-week period beginning prior to discharge from the hospital. Study sample consisted of 40 patient-spouse dyads (n=80) recently diagnosed and surgically treated for bowel or urinary cancer with a good prognosis. Half of the participants had a permanent ostomy (n=20). Instruments used in addition to the semi-structured interview process included: Brief Symptom Index, State-Trait Anxiety Inventory and the Vulnerability Scale. Interviews were conducted predischarge, 10, 30, 60, 90, and 180 days post discharge. Few differences were identified between the patients and their spouses in the intensity of distress experiences. Findings suggest that the crisis of initial cancer treatment, even when the diagnosis is good, is not resolved until 3 to 6 months post discharge rather than 6 to 8 weeks predicted in acute crisis theory. Distress was considerably higher after being home for 10 days, usually related to physical symptoms which were unexpected or more severe than anticipated. The ostomy group took longer to return to pre-illness function levels and experienced more psychological distress. The study was not specific to ostomy patients (n=20) and does not specify why the ostomy group experienced more stress.

Long term adaptation in colostomy and ileostomy patients was the focus of a study by Keltikangas-Jarvinen, Loven, Moller, (1984). The purpose of the study was twofold: to determine the contribution of psychic factors such as depression, body image disturbances, anxiety, ego strength, defensiveness, denial, regression, hypochondria, and sense of reality in long-term psychosocial adaptation and identify if there is a difference in adjustment between colostomy and ileostomy patients. The participants, 34 colostomy and 32 ileostomy patients, were tested by a psychologist using Heidelberg Colostomy Questionnaire, Beck's Depression Inventory, Block's Ego Resiliency Scale, and the Rorschach Inkblot Test. Findings revealed that emotional support of a marital partner was important in the adjustment of the ileostomy patients while support from the surgeon decreased preoperative anxiety and postoperative depression in the colostomy patients. Personality factors such as neurotic and hypochondriacal symptoms, defensiveness and lack of adaptability impacted working capabilities resulting in 23% of the ileostomy patients retiring from work while 28% of the colostomy group retired due to an older age. Denial, depression and a lack of psychic energy were listed as the reason for decreased participation in social activities by the ileostomy group. Sexual problems were noted in both groups, ileostomy patients finding the change in appearance the greatest obstacle for sexual satisfaction while colostomy patient's problems related to results of the surgical procedure, and

decreased libido and sexual interest. Colostomy patients scored higher on the depression scales while the ileostomy patients scored higher in obsessive-compulsivity. Colostomy patients were also more worried about change in appearance, passing of gas and odor. In comparing the data, the researchers found ileostomy patients adapted better than the colostomy patients in every aspect of the study. The difference may be due to the difference in disease course and preoperative personality.

Body Image and Self-Esteem

Kelman & Minkler (1989) utilized Sultenfuss's (1982) four stages of grieving or adaptation to examine quality of life and self-esteem in relation to the variables associated with ostomy management. A questionnaire including the tools: Quality of Life Index and Rosenberg's Self Esteem Scale were mailed to participants (n=50). Data demonstrated that there is a relationship between quality of life and self-esteem among individuals with ostomies (correlation of -0.5070 between self-esteem and quality of life scores). One implication of the study noted by the author was the need for more ET nurses in smaller community hospitals and community health settings. Only 0.04% of the subjects viewed the community health nurse as being helpful in their management of the ostomy.

Smith (1989) interviewed 128 patients undergoing radical cystectomy at four different intervals: One to two weeks preoperative, 6 weeks, 3 and 6 months postoperative. Patient adjustment was evaluated in terms of

return to presurgical activities and their response to questions related to self-image such as whether the surgery changed the way they thought about themselves or changed the way their partners, coworkers and friends treated them. Two levels of adjustment were established, level one indicating a lower level of adjustment. A higher percentage of women (88.5%) compared to men (66.7%) were in the level 2 with the housewife group demonstrating best adjustment followed by professionals, white collar and then blue collar workers. A high percentage of those who responded yes to the question about being treated differently by friends, sexual partners or coworkers were in the group with a lower level of adjustment. This study is limited to patients with ileal conduits.

Klopp's (1990) research examined the relationship between body image and self-concept in persons with stomas and if the length of time since surgery impacted the relationship. Sensory phenomena's impact on body image and self-concept were also examined. The study was based on a model developed by Klopp looking at stoma formation and the resulting sequela on behavioral manifestations. The study population (n=152) was drawn from a convenience sample located in or near an urban area with a stoma one month to 10 years post surgery. Four tools were used: Body Cathexis Scale, Self-Cathexis Scale, Beck Depression Inventory, and Body Phenomenon Index. The Body Phenomenon Index, developed by the researcher to investigate specific sensory perceptions among persons with

stomas and the degree of their concern about how others perceive the same sensory phenomena. Results demonstrated that as the concern over stoma related sensory phenomena such as odor, sound, appearance, and feel increases, the person's satisfaction with the body and self decrease. This was true of individuals with fecal stomas having a poorer body image than those with urinary stomas. Depression was noted in 70% of the study population. One third of the participants were unaware of the type of stoma they had and 5% did not know why they had a stoma. The study population was urban and anywhere from one month to 10 years post surgery which would not adequately represent the rural population.

## Sexuality

A person's sexuality is affected by ostomy surgery as mentioned in research described earlier in this review. Sexuality is impacted by physiological changes occurring in relation to a surgical procedure or by a psychological response to the presence of a stoma. Gloeckner & Starling (1982) explored the influence of ostomy surgery on an individual's sexual self-image or his/her perception of sexual functioning. Forty (n=40) patients, including 24 men and 16 women, with a permanent colostomy, ileostomy, or ileal conduit were interviewed. Questions covered during the interview included changes in sexual performance, changes in sexual attractiveness including appliance problems and reactions of partners, information received on sexuality, and recommendations for education of

future ostomy patients. Changes in sexual performance were noted by 29% of the men who now had permanent impotence, 50% who had less frequent intercourse since surgery and 12% of the ileostomates who had increased frequency in sexual intercourse. Dyspareunia was the greatest problem in the first year postoperative among the majority of the women with 21% reporting a difference in their perception of orgasm after surgery. Over 50% of the participants expressed a decreased feeling of sexual attractiveness in the first year after surgery. The authors noted that few of the patients had been given information concerning preparation for sexual activity such as pouch covers. Fifty eight percent were given information concerning sexuality and possibility of impotence, and at no time were feelings about sexuality discussed. The study reflects the need for sexuality counseling.

Rolstad, Wilson, Rothenberger (1983) explored the long term sexual concerns in 50 well-rehabilitated ileostomy patients. The participants were able to care independently for their stomas, had returned to normal preoperative activities and had resumed previous interpersonal relationships. A 14-item questionnaire was sent to the participants asking specific sexual concerns related to the stoma, which individuals were important to sexual adaptation of the patient and the techniques used to solve problems encountered during sexual activity. Data revealed that 46% said yes, the stoma made sexual intercourse psychologically more difficult,

46% said it did not. Seventy two percent cited appliance problems as a physical hindrance to sexual activity followed by 16% of the participants' concerns with the stoma and 4% with odor. Sixty percent of the women felt sexually less desirable or attractive since their surgery compared to 52% of the men. Seven percent of the women stated their spouses felt the same compared to 31% of the men. Thirty six percent of the patients talked to their spouses when they needed advice about sexuality, 28% talked to no one and 6% talked to their physician or ET nurse. The authors were surprised to find significant problems related to sexuality in a group they felt to be well adjusted. Most of the concerns were related to unresolved altered body-image issues.

Quality of Life

Padilla & Grant (1985) developed the Quality of Life Index (QLI) which was tested in two studies. The first study tested the tool and provided for reliability and validity. The tool was found to provide a multidimensional operational definition of quality of life. Dimensions included in the definition of quality of life were psychological and physical well being, body image concerns, response to diagnosis/treatment and social concerns. The tool was then revised as to content for phase 2 study. Items reflecting interpersonal and body image aspects of self-worth were added to the instrument. Colostomy patients were included in the population for the second study (n=135) and rated their quality of life one

week after discharge. They scored second to the lowest score following a non patient group and an inpatient group. The most important dimension of quality of life was psychological well being, followed by physical well being, body image concerns, response to diagnosis/treatment, and social concerns. While the instrument addresses body image concerns and quality of life, it is not designed specific to the ostomy patient.

Pemberton, Phillips, Ready, Zinsmeister, Beahrs (1989) compared the quality of life after a conventional Brooke ileostomy with the newer ileal anal pouch procedure. A questionnaire was mailed to 406 ileostomy patients and 298 ileal anal pouch patients. The instrument was designed to ascertain the impact of the surgery and resulting ileostomy or pouch on the patient's life style. Questions addressed the perception of general health, diet, social habits, occupation, daily activities and stoma or pouch related questions when appropriate. Data revealed the Brooke ileostomy patients had a higher re-operation rate at 22% compared to 11% for pouch patients. Both reported 5-6 trips to the bathroom to empty appliances or anal pouch. Quality of life questions reflected that both groups appeared to be satisfied with their life styles with 60% of ileostomy and 62% of pouch patients saying that their attitude had improved. Issues affecting quality of life of ileostomy patients included persistent unhealed perineal wounds and sexual limitation. Thirty percent of the Brooke ileostomy patients, compared to 13% of those with an ileal anal pouch, identified sexual limitations. The

reason for sexual dysfunction could be divided into those caused by the surgical procedure and those caused by the presence of the stoma. Sixty percent of the ileostomy patients were aware of the new procedure but desired no change in their ileostomy. Pemberton et al. examined quality of life in 7 areas of daily activities and found that those with an ileal anal pouch had improved performance in each category.

Awad, El-Gohary, Skilton, Elder (1993) studied the quality of life and the presence or absence of psychological morbidity in 82 patients using a questionnaire in addition to the General Health Questionnaire (GHQ30). Questions related to the stoma, bag emptying and changing, peristomal skin problems, dietary restrictions, leisure activity, holidays and travel, sex life, assessment of satisfaction and if they were "happy" with the ileostomy. A final question was included to gain understanding of the patient's view of the ileal anal pouch procedure. The GHQ30 was included to assess psychiatric morbidity and is sensitive to detecting forms of psychiatric disorders that may be relevant to the patient's medical condition. Results of the study showed that 93% were "happy" and generally coping well with the stoma and those who had encountered restrictions found the restrictions fewer than those present before surgery. Peristomal skin problems had occurred in 74% of the patients and 26% to 40% had restricted diets in order to avoid excessive odor or to decrease ileostomy effluent. Forty six percent had some degree of

morbidity with respect to sexual activity. Psychiatric morbidity occurred in 5% of the participants. Almost 20% of the participants reported improvement in a variety of life style activities which could be explained by the general improvement of physical condition following elimination of inflammatory disease.

Maklebust (1985) studied adjustment following ostomy surgery using a retrospective, descriptive study design. The population was comprised of permanent ostomates over 18 years of age with either an ileostomy, colostomy, or urostomy of 6 months to less than 5 years duration. The Ostomy Adjustment Scale (OAS) was developed and tested prior to being mailed to 150 members of an urban United Ostomy Association chapter (UOA). The ileostomy group had the highest mean score on the OAS followed by the colostomy and urostomy groups. Ostomates visited by a UOA visitor scored significantly higher on the OAS regardless of type of ostomy. This study was limited to an easily obtainable urban population who also happened to be members of an ostomy chapter making it difficult to generalize the data to other ostomy populations. In addition this study was also retrospective.

Hedrick's (1987) study was to determine the ET nurse's impact on the ostomy patient's social readjustment and rehabilitation. Forty ostomates participated in the study, 20 had interacted with an ET nurse and 20 did not. Maklebust's Ostomy Adjustment Scale was mailed to participants

between 1 and 3 months postoperative. Those participants having an ET nurse scored higher on the OAS. The study sample was small (n=40).

## Summary

The studies reviewed provide a picture of the ostomy patient living for the most part in an urban setting. The data provided is retrospective in nature. Identification of the different issues an ostomate must work through are presented, however, the rural ostomate's adjustment has not been explored. This study is a beginning attempt to fill the gap in knowledge concerning the rural ostomate and process of adjustment during the first year after surgery.

# CHAPTER 3

# METHODS

## Population/Sample

The sample was accessed through ET nurses practicing at different sites in Montana. The study population lives in rural Montana and northern Wyoming. Residents living in northern Wyoming are included in the study since they obtain medical care from a regional medical center in Montana. Inclusion criteria included people greater than eighteen years of age who had either a colostomy, ileostomy, or an ileal conduit. The ostomate's surgery occurred within the last 12 months prior to data collection. Exclusion criteria included ostomates who were unable to read or write English, were physically or mentally unable to care for themselves or considered terminal at the time of surgery. Proposed subject population for this study was a sample of 30.

## Design

A descriptive study design was chosen to explore the rural ostomate's adjustment. Descriptive studies are designed to gain more information about characteristics within a particular field of study and to provide a picture of situations as they naturally happen (Burns & Grove, 1987).

## Data Collection

Montana ET nurses were contacted and asked to participate in data collection (Appendix A). The ET nurses were asked to review their client statistics for persons with ostomy surgery done in the past year. Questionnaire packets were sent to the ET nurse to label with the participants' mailing address and then mailed. The packet contained a letter of introduction and consent form, the questionnaire and a self-addressed stamped envelope. The ostomates returned the completed packet by mail directly to the researcher. The names of the subjects were not known by the researcher since only group data were reported. Subject confidentiality was maintained since the ET nurses did not know which of their clients returned the questionnaires.

Each ET nurse received a packet with a copy of the questionnaire, cover letter, and human subjects approval form. Any information for hospital approval to participate in the study was provided upon request. The ET nurses were requested to keep a list of those clients who received a stamped packet. The list was to prevent sending more than one packet and to facilitate mailing a reminder post card.

Participants were asked to return the questionnaire within two weeks. A post card was sent one week after the packets were mailed to remind the participant to fill out and return the questionnaire.

## Instrument

The Ostomy Adjustment Scale (OAS) was designed by JoAnn Maklebust (1985) to study the adjustment of ostomy patients. The OAS was chosen because the content reflects the assessment criteria used for the rehabilitation of ostomy patients given by Wound, Ostomy, Continence Nurses Society (WOCN). The ET nurses participating in the study are WOCN certified (completed a WOCN certified education program and certification exam). Permission to use and adapt the instrument was obtained from the author (Appendix B). The instrument consists of two sections: a demographic data with ostomy history section and a section concerning readjustment (Appendix B).

The demographic section contains closed-ended questions with unordered response choices as well as partially closed ended questions. The adjustment section contains 18 items having a Likert scale with a range of answers from strongly agree (1) to strongly disagree (7). Half of the items were worded positively and the other half were worded negatively.

The demographic information and ostomy history section provided data concerning the age of the subject, the date of surgery, the reason for surgery and support systems. The second section provided data concerning adjustment following ostomy surgery as perceived by the participant. Adjustment following ostomy surgery was defined by the

ostomate's return to presurgical activities of daily living, independent care of the stoma, and resumption of relationships and presurgical social activities.

Maklebust's development of the instrument started with a review of the literature. Eighteen items to measure adjustment were identified from other ostomy surveys. The items also reflected the assessment criteria for the rehabilitation of ostomy patients defined by the Wound Ostomy, Continence Nurses Society (formerly the International Association of Enterostomal Therapists) and the American Nurses Association. In scoring the instrument, Maklebust (1985) split the questions. For questions 1, 4, 5, 6, 7, 8, 11, 12, and 17 a higher score reflected better adjustment. For questions 2, 3, 9, 10, 13, 14, 15, 16, and 18 a lower score denoted better adjustment. To obtain a final total, each set of scores were totaled separately, with the mean score of each set identified. One set was transposed or given a reverse value to match the other to reach the final total. Possible scores could range from 18 to 136. The highest scores represented a positive adjustment.

Content validity was established after a thorough review of literature. In addition, five specialists in ET nursing reviewed the tool to verify that the instrument content adequately represented the variables being studied.

Reliability had been pre-established by the test-retest method. Twenty three ostomates from the United Ostomy Association completed the questionnaire. A retest was conducted four weeks later. Results of the two tests correlated with a Pearson coefficient of 0.94.

The instrument was first used in Maklebust's (1985) original study which examined the relationships between type of ostomy, adjustment, and the impact of United Ostomy Association trained ostomy visitor. The study was done as a retrospective, descriptive study which asked the subjects to remember back to six months after surgery. The participants (n=118) had either a colostomy, ileostomy, or urostomy.

The instrument was used again by Judith Hedrick (1987) in studying the effects of ET nursing intervention on adjustment following ostomy surgery. The tool was completed by forty subjects. Twenty subjects received ET nurse intervention and the other 20 did not. The tool was given two to three months postoperative.

## Data Analysis

Completed questionnaires were sent to the Office of Applied Research Studies of Montana State University-Bozeman for data entry and statistical analysis. Data were categorized according to three groupings: Surgery to four months, four to eight months and eight to twelve months post surgery. Descriptive statistics were used to summarize demographic data

and statistical correlations compared the groups according to age, gender, and urban versus rural setting.

## Human Subjects

Subject Populations: Participants were men and women over the age eighteen who had either a colostomy, ileostomy, or ileal conduit of one year duration or less. Subjects were under the care of an ET nurse who provided postoperative teaching. Participation in the study was strictly voluntary.

Potential Risks: There were no physical risks from participating in the study. There may have been some psychological discomfort involved in answering questions about relationships and feelings. When used in previous studies, the questionnaire offered an opportunity to express emotions which participants found helpful. The participants could withdraw from the study at any time prior to returning the survey.

Potential Benefit: There were no direct benefits to the participants. The opportunity to reflect on life experiences and the chance to "be heard" may have been of benefit to the participant. The participant was able to obtain information about the results of the study from their ET nurse or the ostomy newsletter.

Consent Procedures: Survey questionnaires contained a cover letter explaining the study and stating that returning the questionnaire implied

consent to participate in the study (Appendix A). The cover letter included the researcher's address and telephone number and the address and telephone number of the committee chairpersons.

Protection of Subjects: The ET nurses participating in the study maintained a list of potential participants to send the packets. The researcher received only the completed questionnaire which did not indicate the name of the participant. The data was then coded to remove confidential information. Participants' names and identifying information were not used. All data was accessed only by the principal investigator and director and/or designated person of the Office of Applied Research Studies at Montana State University-Bozeman. Following data analysis, the completed questionnaires were kept in a locked and secure place at Montana State University campus in Bozeman and will remain there for five years. All data was presented as group data without reference to individual participants.

Risk/Benefit Ratio: Psychological or emotional discomfort was a potential risk when asking an ostomate to recall painful events. The benefit of this study is the potential gain in knowledge concerning ostomy adjustment in the rural setting and ultimately improving quality of nursing care.

Human Subject Review: The study was approved by the Montana State University-Bozeman College of Nursing Human Subjects Review Committee prior to the start of data collection.

# CHAPTER 4

# RESULTS

The purpose of this study was to assess the ostomy patient's adjustment following surgery and hospitalization in a rural setting during the first postoperative year. The participant's adjustment to a new ostomy and the time since surgery were explored in addition to the distance from ostomy resources. The results are presented in the following order: (1) Description of Sample, (2) Questions (3) Summary.

## Description of Sample

A total of five ET nurses agreed to participate in the study but only four were able to find subjects to meet the criteria. Thirty seven survey packets were sent out and 20 returned. After reviewing the surveys for completeness 17 were included in the data analysis. See Table 1 for Demographics.

Table 1. Demographics

| | | Count | Percent |
|---|---|---|---|
| **Gender** | Male | 13 | 76.5 |
| | Female | 4 | 23.5 |
| **Age** | 44 | 1 | 5.9 |
| | 45 | 1 | 5.9 |
| | 50 | 2 | 11.9 |
| | 59 | 1 | 5.9 |
| | 62 | 1 | 5.9 |
| | 66 | 1 | 5.9 |
| | 67 | 1 | 5.9 |
| | 68 | 1 | 5.9 |
| | 71 | 1 | 5.9 |
| | 73 | 1 | 5.9 |
| | 74 | 1 | 5.9 |
| | 75 | 3 | 17.6 |
| | 77 | 2 | 11.8 |
| **Race** | White | 17 | 100.0 |
| **Education** | Elementary | 4 | 23.5 |
| | Junior High School | 1 | 5.9 |
| | High School | 5 | 29.4 |
| | Beyond High School | 7 | 41.2 |
| **Marital Status** | Married | 9 | 52.9 |
| | Divorced | 4 | 23.5 |
| | Never Married | 1 | 5.9 |
| | Widowed | 3 | 17.6 |
| **Employed** | Yes | 5 | 29.4 |
| | No | 12 | 70.6 |
| **Type of Ostomy** | Colostomy | 7 | 41.2 |
| | Ileostomy | 4 | 23.5 |
| | Urostomy | 6 | 35.3 |
| **Time Since Ostomy Surgery** | < 2 months | 1 | 5.9 |
| | 2–4 months | 5 | 29.4 |
| | 4–6 months | 2 | 11.8 |
| | 6–8 months | 1 | 5.9 |
| | 9–12 months | 8 | 47.1 |

The subjects were caucasian, 13 were male with permanent ostomies. Ages ranged from 44 to 77 years of age. Eleven were over the age of 62. Educational background varied with four completing elementary school, one finishing junior high, five completing high school and the majority (7) completing part or all of college. Marital status also varied, nine were married, four were divorced, and three were widowed. The majority of the subjects were no longer employed (12). It was also noted that 12 of the subjects were 62 years of age or older qualifying many for retirement. The type of ostomies included seven colostomies, four ileostomies, and six urostomies.

Ostomy surgery was done for a variety of reason. Cancer was the underlying disease process resulting in ostomy surgery for 12 of the participants. Surgery for inflammatory bowel disease resulted in four ostomies.

Family support was reported by all the participants. Eleven of the participants also received support from a United Ostomy Association visitor. Sixteen participants reported that their surgery was explained so they could understand.

The population of the participants' home communities ranged from 300 to 85,000. Four were from communities with populations of 42,000 or greater. Four participants did not know the population of their home town. See Table 2 for distribution of population.

Table 2. Population Home Community

| Population | Frequency | Population | Frequency |
|---|---|---|---|
| 300 | 1 | 7,000 | 2 |
| 360 | 1 | 42,000 | 1 |
| 700 | 1 | 50,000 | 1 |
| 2,400 | 1 | 60,000 | 1 |
| 2,500 | 1 | 85,000 | 1 |
| 3,000 | 1 | Unknown | 4 |
| 3,300 | 1 | | |

## Time Intervals

Two month time intervals from surgery were originally established for data collection. The ostomates were spread out over the time intervals with the majority (47.1%) in the 9-12 month interval. The small number of ostomates in each time interval (Table 1) led to the decision to run the data on two intervals. The first interval included eight ostomates in the period from surgery to six months and nine ostomates who were greater than six months post surgery.

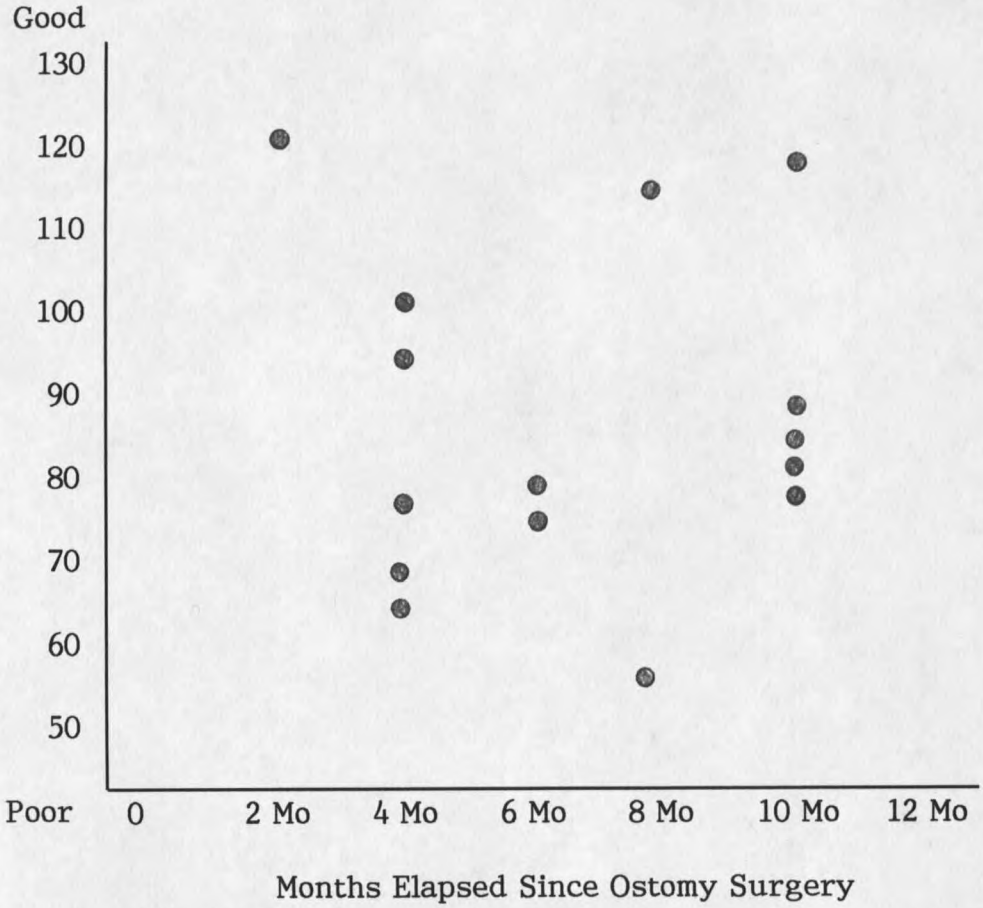
## Questions

The survey tool included 18 questions based on different aspects of ostomy care. The responses to the questions were based on a Likert scale with seven possible answers ranging from strongly agree to strongly disagree. Each question could be scored from 1 to 7 points. The higher the total score, the greater the adjustment. The total scores ranged from 63 to 120, with 126 being the highest score possible (Table 3). Table 4 shows the scores graphed over a one year period. Each question was analyzed using ANOVA.

Table 3. Distribution of Total Scores on Ostomy Adjustment Survey Tool

| Value | Frequency | Percent | Valid Percent | Cum Percent |
|---|---|---|---|---|
| 63.00 | 1 | 5.9 | 5.9 | 5.9 |
| 65.00 | 1 | 5.9 | 5.9 | 11.8 |
| 72.00 | 1 | 5.9 | 5.9 | 17.6 |
| 73.00 | 1 | 5.9 | 5.9 | 23.5 |
| 74.00 | 1 | 5.9 | 5.9 | 29.4 |
| 76.00 | 1 | 5.9 | 5.9 | 35.3 |
| 79.00 | 2 | 11.8 | 11.8 | 47.1 |
| 81.00 | 1 | 5.9 | 5.9 | 52.9 |
| 83.00 | 3 | 17.6 | 17.6 | 70.6 |
| 91.00 | 1 | 5.9 | 5.9 | 76.5 |
| 98.00 | 1 | 5.9 | 5.9 | 82.4 |
| 111.00 | 1 | 5.9 | 5.9 | 88.2 |
| 113.00 | 1 | 5.9 | 5.9 | 94.1 |
| 120.00 | 1 | 5.9 | 5.9 | 100.0 |
| Total | 17 | 100.0 | 100.0 | |

Table 4. Adjustment Scores Utilizing the Ostomy Adjustment Scale (Maklebust, 1985)




Following is a compilation of the data collected utilizing the Ostomy Adjustment Survey. A total of 18 questions were asked and the responses were summarized on the Ostomy Adjustment Survey Data shown on Table 5.

Table 5. Ostomy Adjustment Survey Data

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|---|---|---|---|---|---|---|---|---|---|
| | Future is hopeless due to ostomy | Able to care for ostomy by self | Can easily talk to family/ friends about ostomy | Feel helpless when I look at my stoma | Ostomy takes too much time. Limits normal daily activities | Feel very angry that ostomy happened to me | Prevents satisfactory relationships with others | Fear ostomy has odor that will offend people | Look at stoma w/o feeling depressed |
| Strongly agree | | 1 | 1 | 1 | 1 | 3 | | 1 | 3 |
| Moderately agree | 2 | | 2 | | 1 | | 1 | 1 | 1 |
| Slightly agree | | 2 | 2 | | 4 | 3 | 1 | 3 | |
| Uncertain | 3 | 1 | | 3 | | 3 | 1 | 1 | 2 |
| Slightly disagree | | | | 1 | 1 | 1 | 3 | | 3 |
| Moderately disagree | 4 | 4 | 4 | 7 | 5 | 3 | 4 | 3 | 3 |
| Strongly disagree | 8 | 9 | 8 | 5 | 5 | 4 | 7 | 8 | 5 |
| ≤ 6 mos Post Surgery | | | | | | | | | |
| Mean | 5.6250 | 5.7500 | 5.3750 | 5.3750 | 4.750 | 4.2500 | 5.0000 | 4.6250 | 4.2500 |
| SD | 1.768 | 1.488 | 2.446 | 1.996 | 2.375 | 2.435 | 1.927 | 2.446 | 2.605 |
| SE Mean | .625 | .526 | .865 | .706 | .840 | .861 | .681 | .865 | .921 |
| ≥ 6 mos Post Surgery | | | | | | | | | |
| Mean | 5.6667 | 5.7778 | 5.7778 | 5.7778 | 5.2222 | 4.5556 | 6.3333 | 5.8889 | 5.2222 |
| SD | 16.871 | 2.224 | 1.641 | 1.202 | 1.787 | 2.068 | .707 | 1.691 | 1.922 |
| SE Mean | .624 | .741 | .547 | .401 | .596 | .689 | .263 | .564 | .641 |
| Mean Difference – | –.0417 | –.0278 | –.4028 | –.4028 | –.4722 | –.3056 | –.1.3333 | –1.2639 | –.9722 |
| F = | .262 | .997 | 1.732 | .983 | 1.808 | .278 | 5.918 | 3.256 | 2.533 |
| P = | .616 | .334 | .208 | .337 | .199 | .605 | .028 | .091 | .132 |

Table 5 (Continued) Ostomy Adjustment Survey Data

| | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 |
|---|---|---|---|---|---|---|---|---|---|
| | Dress in same kind of clothes as before surgery | Avoid public situations more than before surgery | Ostomy is a physical disability | Traveling away from home is not a big problem | At least as physically active as before surgery | At least as socially active as before surgery | At least as sexually active as before surgery | Sexual relationship is worsened because of ostomy | Would give me pleasure to visit new ostomates to offer encouragement |
| Strongly agree | 2 | | 2 | 1 | 1 | 2 | 10 | 9 | 3 |
| Moderately agree | 2 | 3 | 4 | 2 | 3 | 2 | 1 | | 1 |
| Slightly agree | 2 | 4 | 3 | 2 | 2 | 2 | 1 | 1 | |
| Uncertain | 2 | 2 | 3 | 2 | 1 | 1 | 2 | 2 | 4 |
| Slightly disagree | 1 | 2 | 2 | 1 | 2 | 2 | | | |
| Moderately disagree | 2 | 1 | 1 | 6 | 4 | 4 | | 1 | 3 |
| Strongly disagree | 6 | 5 | 2 | 3 | 4 | 4 | 3 | 4 | 5 |
| ≤ 6 mos Post Surgery Mean | 4.3750 | 4.7500 | 3.3750 | 4.3750 | 4.3750 | 4.7500 | 2.7500 | 3.5000 | 5.0000 |
| SD | 2.264 | 2.188 | 2.066 | 2.200 | 2.387 | 2.121 | 2.188 | 2.507 | 2.000 |
| SE Mean | .800 | .773 | .730 | .778 | .844 | .750 | .773 | .886 | .707 |
| ≥ 6 mos Post Surgery Mean | 4.8889 | 4.3333 | 3.7778 | 5.1111 | 4.8889 | 4.4444 | 2.4444 | 2.8889 | 4.3333 |
| SD | 2.421 | 1.871 | 1.856 | 1.764 | 1.900 | 2.351 | 2.603 | 2.848 | 2.550 |
| SE Mean | .807 | .624 | .619 | .588 | .633 | .784 | .868 | .949 | .850 |
| Mean Difference – | –.5139 | –.4167 | –.4028 | –.7361 | –.5139 | .3056 | .3056 | .6111 | .6667 |
| F = | .279 | .312 | .037 | 1.023 | 2.042 | .080 | .182 | .863 | 1.304 |
| P = | .605 | .585 | .850 | .328 | .174 | .781 | .676 | .368 | .271 |

The first question asked the ostomates if they felt the future was hopeless because of their ostomy. Two of the ostomates moderately agreed that the future was hopeless and three were uncertain of the future. The remaining 12 participants disagreed with the question with eight strongly disagreeing. The mean score for the less than 6 months and greater than 6 months were similar at 5.6250 and 5.6667. The mean difference was -.0417 with an F value of .262 and a p value of .616.

The majority of the participants (13) disagreed with being able to care for their ostomy themselves. The remaining participants were either uncertain (1) or agreed to being able to care for themselves. The mean scores were similar for those less than 6 months 5.7500 and 5.7778 for those greater than 6 months post surgery with a mean difference of -.0278, $F = .997$, $p = .334$.

The third question asked the participants if they could easily talk about their ostomy. Twelve participants either moderately or strongly disagreed with being able to talk easily about their ostomy. The remaining five agreed to being able to talk about their ostomy. The ostomates who were six months or less post surgery had a mean score of 5.3750 and those greater than six months scored 5.7778. The mean difference in scores was -.4028 with $F = 1.732$, $p = .208$.

One person strongly agreed that the future was hopeless while 12 either moderately or strongly disagreed, three were uncertain and one slightly disagreed. The mean score was 5.3750 for those six months or less post surgery and 5.7778 for those greater than six months from surgery. The mean difference was -.4028 with an F value of .983 and a p value of .337.

The fifth question asked the ostomate whether their ostomy took so much time that it limited normal daily activities. Ten moderately or strongly disagreed with the ostomy taking too much time. One slightly disagreed with the statement. The remaining participants either strongly agreed (1), moderately agreed (1) or slightly agreed (4) with their ostomy interfering with normal daily activities. Those ostomates six months or less post surgery had a mean score of 4.750 and those greater had a mean score of 5.2222 with a mean difference of -.4722, F = .808, p = .199.

The responses to the question about feeling very angry that the ostomy had happened were spread across the scale. Three strongly agreed and three slightly agreed with feeling angry about the ostomy while three ostomates were uncertain. Of those disagreeing with feeling angry four strongly disagreed, three moderately disagreed and one slightly disagreed. The mean score for those six months or less post surgery was 4.2500

and those greater than six months was 4.5556. The mean difference was -.3056, F = .278, p = .605.

The seventh question asked participants whether their ostomy prevented them from having satisfactory relationships with others. The majority (14) disagreed with the question while two either moderately or slightly agreed that the ostomy prevented satisfactory relationships. One participant was uncertain. The means score for those six months or less post surgery was 5.0000 and those greater than six months was 6.3333. The mean difference was -1.3333, F = 5.918, p = .028.

The majority (11) of the ostomates were not concerned about odor from their ostomy offending people. The remaining six participants were either strongly (1), moderately (1) or slightly (3) afraid of offending others with odor from their ostomy. One participant was uncertain. The mean score for those participants six months or less from surgery was 4.6250 and 5.8889 for those greater than six months post surgery. The mean difference -1.2639, F = 3.256, p = .091.

The ninth question asked the ostomate if they could look at their stoma without feeling depressed. Three participants strongly agreed and one moderately agreed that they could look at their stoma without feeling depressed. The remaining were uncertain (2), slightly disagreed (3), moderately disagreed (3), or five strongly disagreed with the statement

and did feel some degree of depression when looking at the stoma. The mean score of the ostomates six months or less post surgery was 4.2500 and 5.2222 for those greater than six months. The mean difference was -.9722, F = 2.533, p = .132.

The responses to the question about being able to dress in the same clothes worn prior to surgery were varied. Six of the participants strongly disagreed with being able to wear the same clothes, two moderately disagreed and one slightly disagreed. Two of the ostomates agreed to each of the remaining categories. The ostomates six months or less post surgery had a mean score of 4.3750 and those greater than six months 4.8889. The mean difference was -.5139, F = .279, p = .605.

Seven participants moderately or slightly agreed with the question about avoiding public situations more postoperatively than prior to their ostomy surgery. Two were uncertain or slightly disagreed with the question and six ostomates either strongly or moderately disagreed with avoiding public situations. Six months or less mean score was 4.7500 and greater than six months post surgery was 4.3333 with a mean difference of -.4167, F = .312, p = .585

The twelfth question asked the participants if they felt that their ostomy was a physical disability. Nine of the ostomates either strongly, moderately, or slightly agreed with the statement that their ostomy was

a physical disability. The remaining participants were uncertain (3), slightly (2), moderately (1), or strongly (2) disagreed. Those ostomates six months or less post surgery had a score of 3.3750 and those greater than six months 3.7778. The mean difference was -.4028, F = .037, p = .850.

Ten participants disagreed with the question that traveling away from home was not a problem. The remaining ostomates were either uncertain (2) or expressed varying degrees of agreement that traveling was not a problem. The mean score for those six months or less post surgery was 4.3750 and 5.1111 for those greater than six months. The mean difference was -.7361, F = 1.023, p = .328.

The fourteenth question asked the participants if they were at least as physically active as they were prior to surgery. Ten disagreed with eight of these moderately or strongly disagreeing. The remaining participants strongly agreed (1), moderately agreed (3), or slightly agreed (2), with being physically active and one was uncertain. The mean score of those six months or less post surgery was 4.3750 and 4.8889 for those greater than six months. The mean difference was -.5139, F = 2.042, p = .174.

Eight participants disagreed that they were at least as socially active as before surgery. Two of the ostomates slightly disagreed and one

was uncertain. Two each strongly, moderately, or slightly agreed that they were socially as active as prior to surgery. Those ostomates six months or less mean score was 4.7500 and those greater than six months was 4.4444. The mean difference was .3056, F = .080, p = .781.

The sixteenth question asked the participants if they were as sexually active as before their ostomy surgery. Ten participants strongly agreed, one each moderately or slightly agreed with being as sexually active. Two ostomates were uncertain and five moderately or strongly disagreed with the question. The mean score for those six months or less post surgery was 2.7500 and 2.4444 for those greater than six months. The mean difference was .3056, F = .182, p = .676.

The next question asked if the sexual relationship had worsened since surgery. Nine strongly agreed that it had and one slightly agreed. Two were uncertain and five either strongly or moderately disagreed with the statement. The mean score for those six months or less post surgery 3.5000 and 2.8889 for those over six months. The mean difference was .6111, F = .863, p = .368.

The final question asked the participants if they would visit with a new ostomate in the hospital to offer encouragement. Eight moderately or strongly disagreed and four were uncertain. The remaining four strongly or moderately agreed with visiting a new ostomate. Six months or less mean

score was 5.000 and 4.3333 for those greater than six months. The mean difference was .6667, $F = -1.304$, $p = .271$.

## Summary

The study population was small (n=30) with only 17 surveys returned, thus providing little statistical significance. The time interval post surgery had little impact on the person's adaptation to the new ostomy. The population or distance from medical care had little impact on the participants with only two reporting it as a problem and one of those wrote that the problem was transporting ostomy equipment in the car, as the heat tended to melt the appliances.

# CHAPTER 5

## DISCUSSION

The data looked at adjustment at each ostomate's particular point in time after ostomy surgery. The scores were graphed on Table 3. The ostomy adjustment scores do not necessarily improve with time following surgery. The four highest scores were at 2, 4, 8 and 10 month intervals. The lowest scores were at 4, 6, and 8 months. Therefore the time since surgery made little difference in adjustment for this population and there was no evidence of a particular point in time when the ostomy is incorporated into the ostomate's lifestyle.

Two other published studies utilized the Ostomy Adjustment Scale. Comparisons were difficult because of the different focus and direction of the research. Maklebust's (1985) study population was retrospective 6 months to 5 years post surgery and reported total scores per ostomy grouping rather than time intervals. Hedrick's (1987) study population was 2 to 3 months postoperative. No scores were reported so a comparison was not made.

Sultenfuss' crisis theory (1982) describes the process of adaptive coping and resolution dependent on variables such as the number and intensity of stressors, present perceptions and internal and external resources. Variables found in the demographics and survey data included new cancer diagnosis, impaired sexual relationship, dependence on others for ostomy care, social interactions and physical activity. Emotions such as hopelessness and depression were also examined. Access to resources, whether it was ostomy supplies or medical care, was also examined. Smaller populated towns with fewer resources and greater distance from a health care facility were perceived as a problem in only two surveys.

The Ostomy Adjustment Scale had 18 questions phrased either positively or negatively. The higher the score on questions 1, 4, 5, 6, 7, 8, 11, 12, and 17 the better the adjustment. The lower the score on questions 2, 3, 9, 10, 13, 14, 15, 16, and 18 the better the adjustment. The adjustment scores actually decreased in eight of the questions for those participants in the greater than 6 month group which could indicate stressors affecting the adjustment and a potential for maladaptive coping.

When comparing the mean scores for the group in the first 6 months to those greater than 6 months, 8 questions were identified. The greater than 6 month group identified caring for the ostomy independently, being able to easily talk about the ostomy with friends and family, looking at the

stoma without depression, dressing in same kind of presurgery clothing, public situations, traveling, physical activity and sexual relationships as problem areas. Time and experience with the ostomy should have increased the ostomates self confidence and eventual adjustment.

The demographics of the study population may have had an impact on the individual responses to the survey questions. The population is primarily male, over the age of 62, married and retired. The tendency for the rural male to have his spouse provide the medical care and in this situation, the ostomy care, would impact the response to the ostomy self care question. The older, retired population has less of an incentive to go out into public and fewer reasons to be socially active.

Surgeries such as radical cystectomies and abdominal perineal resections combined with adjunctive therapies such as radiation will often result in impotence in the male population and an altered response in the female population. The physiological changes would have had a negative impact on participants' responses to questions about sexual relationships and physical activity. Physical changes in body appearance such as protruding abdomen, stoma and appliance could have impacted clothing styles.

Cancer treatments and the emotions generated by the diagnosis of cancer are stressors that could delay or interfere with the individual's

ability to cope. Chemotherapy and radiation are started within a month of surgery and last 6 months to a year. The ostomates in this survey may have been delayed in dealing with the social aspects of their ostomy and return to presurgery physical well being.

The ostomy related problems noted in this research were consistent with those mentioned in the literature review. Depression, problems with sexuality, body image and fear of odor were common reactions to ostomy surgery.

In summary, the data has demonstrated that time is not the great healer. Stressors continue to interfere with adjustment months after the surgery. The ET nurse needs to be able to identify the stressors, assist the ostomate in adaptive coping until they reach resolution and incorporate the ostomy into their life style.

## Limitations

The study was limited by the size of its sample. The results cannot be generalized since the population of the study was 17 and consisted of only caucasians. Male participants significantly outnumbered female participants (13 to 4) which also limited the generalizability of the study. The survey questions were limited in the fact that only seven categories for answers were provided and the categories did not discriminate feelings

relative to the answers. The population of the community in which the participants lived was not a good indicator of distance from medical care.

## Implications

### Research

Continued research in this area would expand the knowledge base for ET nurses working in a rural environment. Expanding the participant pool to include data from other ostomates living in a rural environment such as those accessed through ET nurses living in the northwest including Washington, Idaho, Oregon, and Alaska would strengthen the statistical significance of the study.

Research looking at the responses of Native Americans and other ethnic groups and comparing the data to that of caucasians would provide cultural information that could be used in patient education. The addition of an interview component would provide more in-depth data. Research using the Ostomy Adjustment Scale with participants who were not exposed to an ET nurse would be valuable since there are significantly fewer ET nurses in the rural hospitals where some ostomies are being created.

Education

The ostomate living in the rural environment is often lost to follow up especially if stoma management has not been a problem. Annual stoma assessments are recommended by the Wound, Ostomy, Continence Nurse Society. A traveling stoma clinic visiting rural hospitals on a yearly basis would provide for the stoma assessments and also provide updated information on equipment and an opportunity to educate ostomates and assess for any psychosocial issues.

Utilization of the Ostomy Adjustment Survey as a tool to determine if new ostomates are having any problems incorporating the stoma into their life style would enhance outpatient postoperative teaching sessions. The tool could be used as a guide for discussion. Often the outpatient sessions are used to solve appliance problems and diet instruction. The data from this study identifies the need to change or enhance the focus of discussion on psychosocial issues.

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# APPENDICES

# APPENDIX A

# CONSENTS

The Detroit Medical Center

Wayne State University
DMC Harper Hospital

November 15, 1994

Kelle Graves, RNC, CETN
3400 Canyon Drive 2F
Billings, MT, 59102

Dear Kelle,

You have my permission to use the "Ostomy Adjustment Scale" that I developed for my study titled "United Ostomy Association Visits and Adjustment Following Ostomy Surgery". I am interested in your project. You may have read the report of a study by Judith Hedrick that looked at the relationship between ostomy adjustment and ET nurse care. Her work was published in the November-December, 1987 issue of The Journal of Enterostomal Therapy and is also included in a medical-surgical textbook published by Mosby.

Dorothy Doughty and Debbie Broadwell of Emory University also are using the tool to examine the relationship between learning theory and ostomy adjustment. Terry Lowry from Louisiana looked at the relationship between ostomy adjustment and social support. Judith Griffin examined the relationship between body image of the ostomate and the ET Nurse visit. Please keep me informed of the progress on your study. I wish you success in your graduate work at Montana State University.

Sincerely,

JoAnn Maklebust

JoAnn Maklebust, MSN, RN, CS, CNP
Clinical Nurse Specialist
Harper Hospital
Detroit Medical Center
3990 John R
Detroit, MI 48201

*ET Nursing Services*

Pat O'Brien, RN, BSN, CETN

P.O. Box 143
Bozeman, MT 59771

Telephone (406) 586-5314
Mobile Phone (406) 580-5314

February 8, 1995

Dear Kelle,

I am writing this letter of consent to be a participant for your data collection project for ostomy patients. Please let me know if you need anything else for your research proposal. I am looking forward to the results.

Sincerely,

Pat

Pat O'Brien, RN, CETN

January 5, 1995

Dear Kelle,

I consent to participate in your research project "Ostomy Adjustment in the first Year following Surgery."

The results should be beneficial in revamping our discharge teaching.

Hope you had a happy holiday season.

Jeanne Knecht
Columbus Hospital

St. Patrick Hospital

April 22, 1995

Dear Kelle,

Thank you for the invitation to participate in your graduate study. There are some wonderful ostomates in the Missoula that I am sure would like to hear from you.

I discussed your study of Ostomy Adjustment with the physician director of St. Patrick Hospital Investigational Review Board and he would like a formal request from you to place on file but believes that it is fine for us to participate.

I'm excited for you and your undertaking. Will be most anxious to see the data from our area!

Best Wishes,

Edine

Edine Loran RN CETN

Sponsored by the Sisters of Providence 500 W. Broadway, P.O. Box 4587, Missoula, MT 59806 (406) 543-7271

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Saint Vincent Hospital & Health Center

May 2, 1995

Kelle M. Graves, RN, BSN, CETN
2nd Floor Annex Building
Deaconess Medical Center
P O Box 37000
Billings MT 59107

Dear Ms. Graves:

Expedited review and approval were given to the questionnaire/study, #95.14 Ostomy Adjustment in the First Year After Surgery for your research paper.

As you know the confidentiality of the participant is very important, and since the responses to this questionnaire will not include any names, code numbers, etc., the study can be reviewed through the expedited procedure.

If the study is not completed within 12 months, it will be subject to a periodic review. If it closes prior to that time, please advise the IRB by letter and include a final report of the results.

Sincerely,

INTER-INSTITUTIONAL REVIEW BOARD

James A. Patten, Chairman

• (406) 245-8528 •
• 1925 Grand Avenue, Suite 110 • Billings, Montana 59102 •

St. Patrick Hospital

EXPEDITED APPROVAL: May 11, 1995
APPROVED: June 6, 1995
PERIODIC REVIEW DUE: June 1996

June 6, 1995

Kelle Graves RNC BSN CETN
3400 Canyon Drive 2F
Billings, MT 59102

Dear Ms. Graves:

Research Entitled: OSTOMY ADJUSTMENT IN THE FIRST YEAR AFTER SURGERY QUESTIONAIRE.

Your research project and consent form have been reviewed and approved by the full Joint Investigational Review Board on June 6, 1995. This approval is effective for one year. The following conditions will apply to this project:

1. All patients being entered on this project must sign the current Approved Consent Form. You are responsible for maintaining all consent forms in appropriate medical charts and in your personal records as investigator.
2. The project will be subject to continuing review. A report will be required on completion of the study or on the next periodic review date as noted above in the upper right hand corner.
3. Emergent problems, unexpected side effects, serious adverse reactions and deaths, whether or not study related are to be reported within five days. Procedural changes or amendments will be reported to the IRB and no changes may be implemented without IRB approval except to eliminate apparent immediate hazards.
4. Periodic site visits may be made by the IRB. You are therefore, requested to provide the information required should your project be reviewed.
5. If your project has been significantly altered as a result of the IRB review and recommendations, it is your responsibility to notify the study sponsor of the changes.

Sincerely,

J.E. Gouaux, M.D., Chairman
Joint Investigational Review Board

JEG/lg
pc: Marcia Gragert, PhD, RN

MONTANA STATE UNIVERSITY
BOZEMAN

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**Missoula Campus**
UM North Corbin Hall
Missoula, MT 59812
Phone (406) 243-6515
Fax (406) 243-5745

April 13, 1995

TO: Kelle Graves

FR: Marty Rhea, Interim Chair
College of Nursing Human Subjects Committee

RE: Human Subjects Proposal: Ostomy Adjustment in the First Year After Surgery

I have reviewed your revisions to the consent form and other documents submitted for consideration by the Human Subjects Committee. The changes are responsive to the essential concerns of the reviewers. Therefore, final approval is granted.

You may now proceed with data collection. Good luck!

Please feel free to contact me should you have any questions or concerns regarding this matter.

cc: Dr. Marcia Gragert, Thesis Chairperson

## CONSENT TO PARTICIPATE

Dear Participant,

My name is Kelle Graves, I am a graduate student currently enrolled at Montana State University School of Nursing. Enclosed is a survey about adjustment to an ostomy. I would greatly appreciate it if you would take the time to fill it out, however, before you do, let me explain a little about the research study.

As an ET nurse, working with ostomy patients, I want to know more about how the person with an ostomy adjusts to life after the hospital. I have asked your ET nurse, as well as other ET nurses in the state, to send you this questionnaire. The information will provide us with insight into what happens after ostomy patients return to their own homes and life and how the process of adjustment and return to a presurgical quality of life takes place. The information gained from the study will assist us in adapting our teaching and follow-up plans.

**CONFIDENTIAL** Your responses to the questionnaire will be strictly confidential. Your name is known only to your ET nurse, who is mailing the questionnaire to you. The questionnaire will be returned to me in a self addressed stamped envelope, without your name, your responses will remain confidential. If you choose not to participate in the study there will be no consequences. Return of your questionnaire is your consent to participate in the study. I will share only group data (no individual responses) with your ET nurse at the end of the study.

It is important that you fill out and return the questionnaire within 2 weeks. If you have any questions please contact my research chairperson Marcia Gragert or myself. Thank you for your time and cooperation.

**Kelle Graves, RN, BSN, CETN**
3400 Canyon Drive 2 F
Billings, Montana 59102
406-657-4379 (work)

**Marcia Gragert, PhD, RN**
MSU College of Nursing
2800 11th Avenue Suite 4
Great Falls, Montana 59405
406-455-5619 (work)

# APPENDIX B

# INSTRUMENT

## OSTOMY ADJUSTMENT SURVEY

I have read and understand the description of this study and my rights as a subject. I further understand that the return of this questionnaire constitutes my informed consent to participate.

### SECTION ONE

Please do not write your name on this form. It is important that you answer each item as thoughtfully and frankly as possible. Check (✓) or fill in the appropriate blank spaces for each of the following items.

1. What is your sex?
   _____Male _____Female

2. What is your age? _____Years (Please write in)

3. What is your race?
   _____White _____Native American
   _____African American _____Other (Please write in)

4. What is the highest level of education completed?
   _____Elementary School _____Junior High School
   _____High School _____Beyond High School
   Describe:_____

5. What is your marital status?
   _____Married _____Separated
   _____Divorced _____Widowed
   _____Never married

6. Are you currently employed?
   _____Yes _____No

7. What type of ostomy do you have?
   _____Colostomy _____Urostomy
   _____Ileostomy _____I don't know

8. How long ago was your ostomy surgery?
   _____Less than 2 months ago _____2-4 months ago
   _____4-6 months ago _____6-8 months ago
   _____8 months to 1 year ago

9. Why was you ostomy surgery necessary?
_____Ulcerative Colitis _____Crohn's Disease
_____Diverticulitis _____Cancer
_____I don't know _____Other (Please write in)_____

10. Is your ostomy permanent?
_____Yes
_____No
_____I don't know

11. Was your ostomy surgery explained to you so that you understood it?
_____Yes
_____No

12. Did an enterostomal therapy nurse participate in your care or teaching?
_____Yes
_____No

13. Was your family a great source of support for you when you had your ostomy surgery?
_____Yes
_____No

14. While you were in the hospital for your ostomy surgery did you receive a United Ostomy Association Visitor?
_____Yes
_____No

15. What is the population of your home community?
_____

16. Is the distance from ostomy resources a problem for you?
_____Yes
_____No

What are the problems?_____
_____
_____
_____
_____
_____
_____
_____
_____

## SECTION TWO

Listed below are 18 statements which represent feelings that people with ostomies sometimes have. Based upon the feelings you have *right now*, rate how much you agree with each statement. ***Circle one number*** on each line to indicate whether you STRONGLY AGREE with the statements, MODERATELY AGREE with it, SLIGHTLY AGREE, are UNCERTAIN, SLIGHTLY DISAGREE, MODERATELY DISAGREE, or STRONGLY DISAGREE. There are no right or wrong answers. We just want to know how you feel now after your ostomy surgery.

| | Strongly Agree | Moderately Agree | Slightly Agree | Uncertain | Slightly Disagree | Moderately Disagree | Strongly Disagree |
|---|---|---|---|---|---|---|---|
| 1. I feel that the future is hopeless because of my ostomy. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. I am able to take care of my ostomy by myself. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. I can easily talk about my ostomy to my family and friends. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4. I feel very helpless when I look at my stoma. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. My ostomy takes to much time that is has limited my normal daily activities. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 6. I feel very angry that this ostomy has happened to me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 7. My ostomy prevents me from having satisfactory relationships with others. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 8. I fear that my ostomy has an odor that will offend people. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 9. I can look at my stoma without feeling depressed. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| | Strongly Agree | Moderately Agree | Slightly Agree | Uncertain | Slightly Disagree | Moderately Disagree | Strongly Disagree |
|---|---|---|---|---|---|---|---|
| 10. I can dress in the same kind of clothes that I wore before my ostomy surgery. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 11. I avoid situations where I would be out in public more then I did before I had my ostomy surgery. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 12. I feel that my ostomy is a physical disability. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 13. Traveling away from home is not a big problem for me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 14. I am at least as physically active as I was before I had my ostomy surgery. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 15. I am at least as socially active as I was before I had my ostomy surgery. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 16. I am at least as sexually active as I was before I had my ostomy surgery. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 17. My sexual relationship has worsened because of my ostomy. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 18. It would give me pleasure to help a new ostomate by visiting him or her in the hospital to offer encouragement. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

***Thank you for your time and cooperation!***

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