

DEVELOPMENT AND TESTING OF THE OSTOMY CONCERN

(OC) SCALE

by

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A Thesis

**Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of**

Master of Nursing

**School of Nursing, University of Manitoba
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A Thesis submitted to the Faculty of Graduate Studies of the University of Manitoba in
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DEVELOPMENT AND TESTING OF THE OSTOMY CONCERN (OC) SCALE

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Abstract

The integration of nursing theory, research and practise is prompted when the development of an instrument to measure clinical nursing phenomena in practice settings has qualitative beginnings and is tested through research. A three phase investigation was undertaken; the overall purpose was to identify the concerns experienced by clients who require ostomy surgery due to cancer and to compare the concerns with those of the spouse. Crisis theory was applied as the conceptual framework for the study. The first phase generated a list of 48 client and spouse expressed concerns following content analysis of 40 taped interviews. The second phase used a Q sort methodology to determine priority concerns and to compare the responses among the couples. Factor and cluster analyses revealed that the majority of clients (70%) identified priorities different from those indicated by the spouses. The findings also demonstrated that any one concern may be a priority concern at any given time. The third phase, and the focus of this investigation, was to develop and test an instrument, the OC Scale, using the qualitatively generated items of the first two phases. Pilot testing was completed to assess clarity, apparent internal consistency and content validity as well as to review possible response descriptors. Assessments of internal consistency, stability of the instrument over time and internal validity of the scale were completed during subsequent testing efforts. Internal consistency estimates, measured by Cronbach's standardized alpha coefficients were .92 at both test times 1 and 2. A Spearman's correlation coefficient of .73 was achieved in testing stability over time. Internal validity was assessed using cluster analysis. Two time-related groupings among the responses were produced; the first cluster were classified as internalization concerns related to the immediate postoperative period. The second cluster of items labelled social re-entry concerns related to later phases of the postoperative period. It is hoped that the OC Scale will assist nursing by identifying priority concerns and by prompting an individualized assessment of each member of the client couple. Once further tested, the OC Scale is intended for use by nurses in conjunction with a resource guide developed by the researcher.

Acknowledgements

The researcher wishes to acknowledge the assistance of Drs. Linda Kristjanson, Karen Chalmers, Dexter Harvey and Jeff Sloan for their timely expertise and direction in completing this study. The ongoing support and encouragement of my fellow graduate students is also gratefully acknowledged; in particular it has been my friend, Ann Lemieux who has offered so much reassurance. I would also like to recognize Maureen Coe who was a co-investigator during Phases I and II of this research; our combined efforts as novice researchers has stimulated and challenged subsequent work. The support and flexibility of the VON Winnipeg Branch has also been instrumental in the completion of this program.

Most importantly, I wish to acknowledge the assistance and support of my family and friends. To my parents, Grant and Alice, and sister, Carolyn for their unconditional love and support, I thank you. To my son Christopher who has inspired my work and been patient even at difficult times, and to my husband Joe who has maintained his support and encouragement and whose sense of humor has sustained me at critical moments, I am deeply grateful. My deepest appreciation is reflected by dedicating this work to those who helped to make it a reality.

A priority task for
clinical research is the
development of tools to
measure phenomenon of
interest to nursing ...

(Imle & Atwood, 1988, p.23)

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THE DEVELOPMENT AND TESTING OF THE OSTOMY CONCERN
(OC) SCALE

CHAPTER 1

STATEMENT OF THE PROBLEM

Introduction

Ostomy surgery is often performed in response to a variety of clinical conditions, the most common of which is cancer (Hurny & Holland, 1985). The diagnosis of cancer and the simultaneous need for ostomy surgery confronts the client and spouse resulting in a multitude of psychological responses (Freidenbergs, Gordon, Hibbard & Diller, 1980; Watson, 1983; Wilson, 1981). A crisis situation could be precipitated by either the diagnosis or the need for ostomy surgery (Infante, 1982). The individual is faced with the need to cope with the physical assault of surgery and change in bodily function and appearance (Dlin, 1978). The spouse must also cope with the changes caused by the surgery and adjust to maintain the functioning of the family unit (Holland & Frai, 1973; Lewis, 1983; Welch, 1981). Literature indicates that how they as individuals and as a couple cope with the experience is related to a number of factors. The needs created by fear, anxiety, role and lifestyle changes, body function and image alterations, all can be anticipated (Craven & Sharp, 1972).

How we as health professionals assist these couples during this time can play a critical role in their adjustment; maladaptation may occur if needs are not met during the experience (Gloeckner, 1983; Watson, 1983). For example, Gloeckner (1983) found that subjects who received counselling intervention demonstrated positive alterations in self-concept and self-esteem as compared with subjects who were not counselled. Before meaningful intervention can occur, it is necessary to identify the concerns experienced by each member of the client couple at various times during the illness process.

The literature reports that the spouse is of primary importance in the successful rehabilitation of the ostomate (Dlin, 1978; Dyk & Sutherland, 1956; Gloeckner & Starling, 1982). Dlin (1978) supports the earlier work of Dyk & Sutherland (1956) in stating that the ostomate's spouse must be involved in the pre- and postoperative periods because of the critical role the spouse plays in terms of the patient's adaptation. In a study to obtain information regarding additional variables affecting sexual adaptation after permanent ostomy surgery, Gloeckner and Starling (1982) found that 33 percent of the female patients were mainly concerned about the reaction of a sexual partner. Kobza (1983) has specifically studied the needs of the spouse when his/her partner requires ostomy surgery. Until then, much had been written regarding the needs of the ostomy patient; however,

there was a lack of literature dealing with the needs of the family. Since the spouse in particular had been identified as the key figure in the ostomy patient's adaptation, a descriptive study was undertaken by Kobza (1983) to determine the needs of a particular family member. She identified the predominant needs of the spouse as the need for information, follow-up and support. Kobza (1983) also suggested increased recognition of spouses' needs in the rehabilitation process. To date, there remains a paucity of research regarding how the concerns compare among ostomy clients and spouses. There has been an assumption in the literature that spouses and ostomy patients have the same concerns. However, empirical testing of this relationship has not been documented. Therefore, further study comparing these two groups is needed.

Additionally, as in many aspects of nursing care, clinically tested instruments are lacking which help caregivers plan and individualize care. Hopwood and Maguire (1988) support the need for further development and testing of instruments needed to assess this client group. These authors reviewed literature concerning difficulties ostomy and cancer patients experience related to changes in body image and stated that there is a need for ways of identifying patients at risk, such as the use of self-report questionnaires. A review of pertinent literature by this investigator revealed the existence of one instrument, the Quality of Life Index (QLI) for colostomy patients (Padilla & Grant, 1985).

However, this instrument is restricted to use with colostomy patients and during later phases of rehabilitation. The current investigation seeks to test a more recently developed instrument, the Ostomy Concern (OC) Scale which is intended for use with patients who may require a colostomy, ileostomy or urostomy due to cancer and their spouses. Further, the OC Scale is designed to identify concerns during the immediate postoperative period (6 -10 days after surgery).

Purpose of the Study

A three phase investigation was planned to develop an instrument to measure the concerns of clients who have had ostomy surgery due to cancer and to compare the concerns with those experienced by their spouses. A qualitative approach was used in Phase I to compile a list of concerns experienced by patients and spouses regarding ostomy surgery due to cancer. Phase II was undertaken to prioritize the concerns identified in Phase I and then to identify the most salient items. The purpose of the third phase of the research reported here, was to develop and test an instrument based on the concerns experienced by this client group. The tool was tested for reliability and validity with a sample of patients and their spouses.

Background to the Problem

More than 70,000 persons undergo ostomy surgery annually in Canada and the United States; and in 1989, it was estimated that at least 750,000 ostomates were living in North America (Kelman & Minkler, 1989, p.4). Management of an ostomy can be an overwhelming experience. The impact that ostomy surgery may have on an individual's quality of life and self-esteem has been the focus of recent research (Boyd et al, 1987; Kelman & Minkler, 1989; Watson, 1983; Williams & Johnston, 1983). The findings suggest that the creation of an abdominal stoma is a traumatic event in a psychophysiologic context. The path from this traumatic occurrence to an adaptive state requires resources within the person and his/her external environment. Kelman & Minkler (1989) studied quality of life and self esteem among individuals with ostomies (N=50) and found that how an individual recovers and adapts following this surgery impacts the long term quality of life and self esteem of the individual. Watson (1983) contends that the physical mutilation, loss of control over urinary or fecal elimination, need to master complex ostomy care skills and the probability of sexual dysfunction make tremendous demands on the overall capabilities of the individuals involved.

This hypothesis is supported by research completed by Smith and Babaaian (1989) who studied the adjustment of 128 patients over a two year period following urostomy surgery.

The adjustment of these patients was significantly influenced by a number of factors including gender ($p=0.03$), how the sexual partner responded ($p=0.001$), whether or not the patient perceived a change in self image ($p<0.001$), level of preoperative activity ($p=0.04$), response of friends ($p=0.001$), those involved in the appliance changes ($p=0.001$) and whether or not chemotherapy was administered ($p=0.03$). Although there is agreement in the literature that these couples face a wide array of fears and anxieties regarding role, body image and lifestyle changes, further investigation is necessary to determine priority issues for spouses and patients. Lack of knowledge about how the concerns of the spouse might compare to those of the client makes it difficult to establish the most effective means of assisting ostomy clients and their spouses to resume their lifestyles and independence. The development and validation of a clinical assessment tool is a critical link in providing more appropriate and individualized care.

Research Questions

To investigate the proposed problem, two central research questions were considered:

1. How reliable is the Ostomy Concern (OC) Scale in identifying the concerns of the client group under investigation?
2. To what extent can the Ostomy Concern (OC) Scale be considered a valid instrument in identifying the concerns experienced by this client group?

If results supported the reliability and validity of the OC Scale, two additional sub-questions were then to be addressed:

3. What are the concerns of the ostomate and spouse in the immediate postoperative period (approximately one week following ostomy surgery)?
4. How do the concerns identified by ostomates on the OC Scale compare to the concerns identified by spouses?

Significance of the Study

Positive adjustment and rehabilitation may be facilitated by the timely intervention of health care personnel (Gloeckner, 1983; Watson, 1983). If nurses are to assist these couples during the period of adaptation following ostomy surgery, an individualized assessment to identify specific concerns must be considered the initial task. The challenge of this third phase is to produce a valid and reliable clinical assessment tool based on the qualitatively generated concepts of the first two phases. Given the number of

individuals affected by ostomy surgery, including patients and spouses, attention to the adjustment and rehabilitation of these individuals is essential. Without a valid and reliable means of assessing needs, care may be based on trial and error. Therefore, a more systematic and efficient means of assessing concerns of patients and spouses would facilitate effective nursing care.

The development of an assessment tool and the completion of initial testing procedures responds to the current challenge facing many nurse researchers of establishing the means to measure phenomenon of interest to nursing (Imle & Atwood, 1988). This research will contribute to the empirical evidence that is needed to direct nursing care and to evaluate its outcomes.

Summary

This chapter has outlined the need for further study regarding the concerns experienced by persons who require ostomy surgery due to cancer. In particular, there is a need to compare the concerns of those persons having the surgery with the concerns experienced by their spouses. Individualized assessment of the concerns experienced by each member of the client couple must be considered an initial task before effective interventions can be planned. Timely

intervention by health care professionals can facilitate the client couples' positive adjustment following ostomy surgery.

The purpose of this phase of the research was to develop and test the Ostomy Concern (OC) Scale for reliability and validity. The instrument is based on the qualitatively generated concepts from two prior research phases that elicited and refined the concerns experienced by client couples when ostomy surgery is required because of cancer. Specific research questions have been identified that are relevant to the problem statement. The significance of the study for clinical nursing and nursing research was discussed.

Chapter II

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Introduction

Chapter II includes a critical review of pertinent research findings in relation to a defined and relevant conceptual framework, crisis theory, which has been used as the conceptual framework to guide the research. As well, the chapter has focused on an examination of the more specific literature that describes the process encountered by patients and spouses when ostomy surgery is required due to cancer. This review clarifies the findings of previous studies in this area, identifies the need for further investigation and substantiates the significance and relevance of the current study.

Crisis Theory

Crisis theory is frequently referred to in nursing practise because it describes a process that applies to a variety of clinical situations. This segment of the literature review explores crisis theory, substantiates the need to adapt this theory for nursing's use and outlines a

conceptual framework that is a modification of crisis theory for use in nursing. The modified framework provides the context to report the remaining pertinent findings within the literature review.

The two Chinese characters that represent "crisis" signify danger and opportunity (Aguilera & Messick, 1978). A person in crisis feels helpless; unable to take the action needed to resolve the problem independently. According to Parad & Caplan (1965) ... "a crisis is a state of disequilibrium overpowering the individual's homeostatic mechanisms" (p.56). Crisis intervention has been defined as the immediate help that may be extended to assist a person in crisis to reestablish equilibrium (Aguilera & Messick, 1978).

Although Caplan is commonly cited in relation to the development of crisis theory, it is more accurate to report that the theory has been based on a broad range of theories in human behaviour including those of Freud, Hartmann, Rado, Erikson, Lindemann and Caplan (Aguilera & Messick, 1978). The theory, therefore, integrates writings from developmental psychology and sociology. Its roots are fundamental to present-day mental health intervention techniques.

Sigmund Freud was the first to identify that ... "every act of human behaviour has its cause or source in the history and experience of the individual" (Bellak & Small, 1965, p.6). Hartmann, an early ego analyst, postulated that Freud's theories could prove valid for normal as well as pathological

behaviour (Loewenstein, 1966). He stressed that an individual's ability to adapt in early childhood as well as his ability to adapt to his environment in later life had to be given consideration. A more refined conceptualization was presented by Rado, who positively correlated human behaviour with principles of motivation and adaptation (Salzman, 1962). Erikson (1963) outlined eight stages of psychosocial development each involving specific developmental tasks. His theories provided the basis for later work in the areas of maturational and situational crises.

In 1956, Lindemann developed the foundation for crisis theory in what he termed... "a conceptual frame of reference" for investigating emotional crises (cited in Murphy & Fawcett, 1983, p.49). Lindemann and other psychiatrists had not been satisfied with the treatment modalities for mental disorders because they emphasized therapy only after illness had developed and often resulted in institutionalization. To seek alternative approaches, their attention was redirected to social scientists and public health workers. This interdisciplinary focus is significant since emphasis was to be averted to the maintenance of mental health and the prevention of mental illness.

Lindemann's study of the bereavement responses of survivors and families of victims of the Coconut Grove Nightclub fire in Boston (Lindemann, 1944) is generally accepted as the beginning of crisis theory (Darbonne, 1968).

His two landmark observations included 1) psychopathological sequelae to bereavement were less likely to develop when the individual completed an identifiable course of grief resolution, and 2) that professional and community caretakers could intervene in this process (Murphy & Fawcett, 1983). He further hypothesized that these findings could be generalized to other hazards of psychological well-being. These ideas directed clinical practise by Lindemann and his colleagues in a community based mental health program established in 1948.

Caplan, also a psychiatrist, began investigating potentially crisis-producing situations in the 1950s after joining Lindemann at this facility. Caplan examined the diagnosis of tuberculosis in a family member (Parad & Caplan, 1965) and the reactions of parents to the birth of a premature infant (Caplan, Mason & Kaplan, 1965). His efforts focused on the development of empirical generalizations about crisis theory.

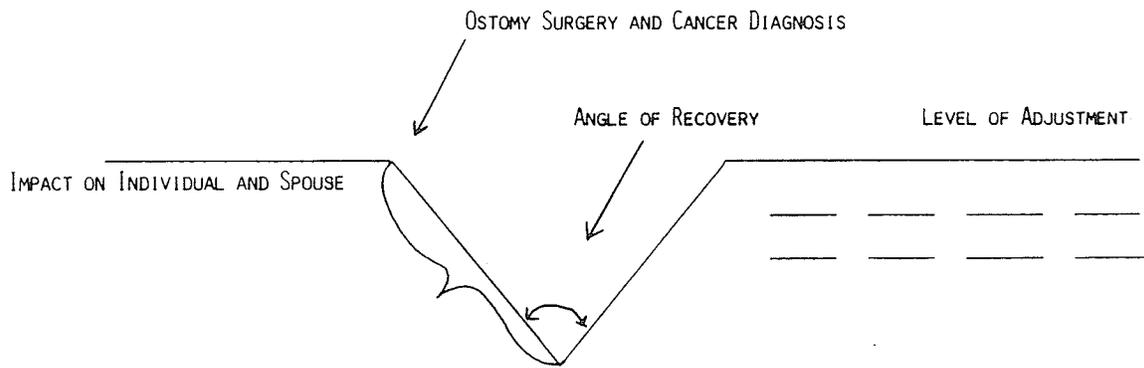
Concurrently, there existed heightened consumer demand for an increase in preventive mental health programs. Caplan's 1964 book Principles of Preventive Psychiatry included his version of crisis theory and claims that emphasized intervention could not only prevent illness but promote mental health. His approach described crisis as a time limited phenomenon and that during the disequilibrium phase the individual was more susceptible to the influence of others than during periods of stability (Caplan, 1964). Since

then, the crisis theory framework has been used by a variety of disciplines. A summary of crisis theory as it was developed by its originators is presented in Appendix I and Figure I.

In this form, several issues must be addressed before the theory could be considered relevant for use by nurses:

- 1) the original theory is intended to address psychological elements, intervention and psychopathology; biological elements have not been included;
- 2) the theory stresses the event must be perceived by the individual as being hazardous. What direction is offered in cases where a client is not viewed as being capable of such a perception?;
- 3) the angle of recovery is a critical element; extensive testing is required to determine in which instances the angle is best directed. For instance, a less acute angle may result in a more positive long term adjustment in response to some hazardous events (e.g., loss of a spouse);
- 4) the theory's time frame suggests resolution within six weeks; this time frame may not be the most appropriate in

Figure 1. Crisis Theory



ADAPTED FROM HILL R. GENERIC FEATURES OF FAMILIES UNDER STRESS, IN: PARAD HJ ED, CRISIS INTERVENTION-SELECTED READINGS, NEW YORK: ELSEVIER PRESS 1965:32 - 52.

all instances, further testing is necessary in a variety of situations;

5) the theory describes the assistance of the professional when an individual is in crisis; more recognition of the impact of "significant others" is necessary to fully reflect nursing's perspective. Additionally, the role of the professional where family plays an integral role must be given consideration;

6) the potential for growth seems unlikely in all situations, whereas, a lack of growth may not necessarily result in maladaptation. The theory does not account for a continued level of functioning consistent with levels previous to the hazardous event;

7) the theory outlines three stages of crisis - subsequent interpretations by Infante (1982), for example, stresses nursing's role in Stage I and III, but cautions priority involvement by nursing in Stage II. She suggests this to be solely a medical domain since this stage is considered to be critical regarding outcome. Extensive testing and consideration is necessary prior to such an exclusion of nursing's potential;

8) the theory calls for intervention once a crisis has been determined (i.e., there is disequilibrium). Consideration and emphasis must be given to the pre-crisis stage in terms of nursing assessment and intervention in various circumstances;

9) empirical testing would be required at all levels to assess the validity and applicability of the theory from a nursing perspective.

Conversely, there are elements of crisis theory which prompt its adaptation for use by nursing:

1) it is a client-centred approach as opposed to a problem-centred approach - repeatedly, the theory stresses the individual's perception of the event and the need for mutual goal setting;

2) it is amenable to empirical testing using, for example, the following variables once operationalized: the quality of the intervention, the nature of the hazard or the past experience of the individual in relation to outcome of the crisis. Such research would be a valuable source in directing future practise; and

3) the phenomenon described within the theory seems plausible to nurses (Geissler, 1984).

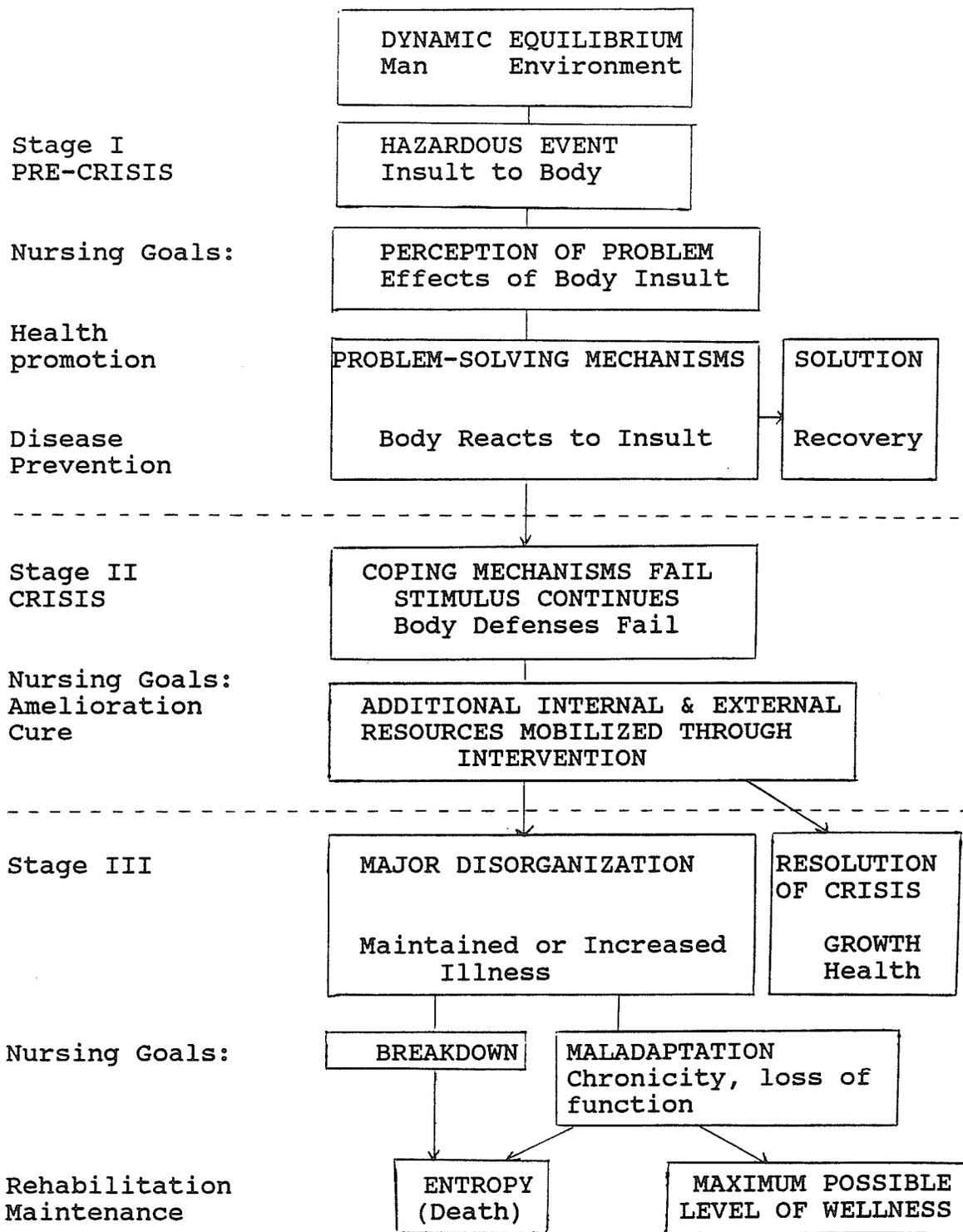
Therefore, it is the opinion of this writer, that although crisis theory has meaningful parameters to guide nursing interventions, a modification of this framework may better address the scope and priorities of current practise. The crisis theory conceptual framework outlined in the next portion of this chapter responds to the shortcomings previously identified regarding crisis theory in its original form.

Crisis Theory Conceptual Framework

The crisis theory conceptual framework, based on crisis theory, was developed in 1968, by the faculty of the University of Connecticut, School of Nursing for use in revising their nursing curriculum (Appendix II and Figure II). It outlines an attempt by nursing to adapt a borrowed theory from a related discipline to achieve a framework useful to nursing. Suggestions are included about how one might refine crisis theory to increase its applicability for nursing and more specifically, to provide the theoretical underpinnings for the current study.

The original crisis theory has not incorporated physical elements, and as such, has limited use to nursing. The faculty reasoned that a biophysical stimulus could also provoke a psychosocial response and that a similar process may be described when biophysical responses are observed. As Murphy and Fawcett (1983) suggest..."it became possible to talk of physiological as well as psychological disequilibrium and resolution of upsets in the steady state" (p.53). The biophysical responses to hazardous events were added by the faculty to the flow chart depicted in Figure II by their use of lower case captions under capitalized headings. Murphy and Fawcett (1983) summarize this change as the difference between ..."the formulation of the crisis theory which was based on inductive modes versus the

Figure 2 - CRISIS THEORY MODEL*



* Prepared by the faculty of The University of Connecticut School of Nursing, 1968.

development of the conceptual framework based on a deductive approach" (p.54).

Aguilera and Messick (1978) state that the term, crisis, implies both danger and opportunity; that a person in crisis is at a turning point. Perhaps this is the most fundamental rationale for the applicability of the crisis theory conceptual framework for this study. Since nursing strives to assist its clients in electing adaptive responses within situations identified as requiring change, it seems reasonable to suggest this framework describes a point where such assistance might be directed.

Since the crisis event is dependent on the perception of an occurrence by the individual (Geissler, 1984), the theory supports the need for nursing to assess the significance of the event to the individual. Any precipitating event which may be large or small could be considered an antecedent. A crisis precipitating event is likely to threaten physiological and/or psychological homeostasis. Two events, including a diagnosis of cancer or the need for ostomy surgery have each been cited as crisis-precipitating events (Infante, 1982). Crisis theory directs caregivers to consider the individual's perception of the event and factors which may influence or contribute to this perception (e.g., reaction of the spouse). For nurses, knowledge of these perceptions can help individualize assessments and interventions.

The next segment of the literature review reports recurring themes that emerge when client couples cope with ostomy surgery because of cancer. The final portion of the literature review focuses on an application of the crisis theory conceptual framework to the most pertinent aspects of this process.

Related Literature

A review of pertinent literature from the past four decades reveals the following emergent and recurring themes: impact of a cancer diagnosis, implications of ostomy surgery, rehabilitation challenges and the significance of the spouse's role. A summation of the findings relevant to these themes as well as the associated nursing interventions is provided. Many of the citations are included to emphasize how findings have led to similar conclusions over time; (i.e., the literature has continued to report a multitude of physical and psychological sequelae that must be considered in caring for these client couples). The literature review yielded the existence of one instrument which is designed to assess aspects related to quality of life following ostomy surgery.

Impact of a Cancer Diagnosis

The underlying condition predisposing an individual to ostomy formation can either be a chronic, symptomatic or an unexpected, nonsymptomatic situation. There is a marked contrast in expectation and understanding about the need for the surgery, depending on which situation is indicative.

In the first scenario, the client's diagnosis necessitating ostomy surgery is likely to be an inflammatory bowel disease, a chronic incompassitating condition that restricts one's lifestyle. The patient is generally 25-40 years of age and is likely to have known for some time that ostomy surgery is a possibility. These clients have also frequently had the opportunity to review the impact of the surgery by reading relevant teaching booklets and perhaps meet with others who have had ostomy surgery in the past. In such cases, when surgical intervention is employed to resolve the problem, the ostomy is viewed as curative (Dietz, 1969). There is a relief of symptoms and the patient's sense of well-being is frequently improved.

In sharp contrast, when cancer is the reason for surgery, there is often a lack of overt symptoms. It is difficult for the individual to understand the need for a radical procedure when he/she feels well. The patient is generally over sixty years of age and likely requires the surgery immediately after hearing the cancer diagnosis. Cancer frequently connotes pain, disfigurement, debilitation

and long term treatment. Therefore, the concerns of the patient and spouse regarding the need for ostomy surgery are greatly confounded by the age of the patient and the diagnosis itself (Hurny & Holland, 1985; Welch, 1981). Inherent in a diagnosis of cancer is fear; fear of pain, fear of mutilation, fear of recurrence and fear of death. Sarles (1980) cites fears experienced by the individual as a result of a cancer diagnosis to include fear of pain, death, the unknown, disfiguration, disability, disruption of family relationships and financial stress.

A diagnosis of cancer is associated with increased levels of psychosocial distress for both the individual and family members (Freidenbergs et al., 1980; Lewis, 1983; Welch, 1981). Giacquinta (1977) notes that the diagnosis of cancer for any family member is experienced as a personal tragedy and an assault on the entire family system. Krumm (1982) identifies these effects as well and notes that uncertainty of the disease outcome influences patient and family behavioural responses.

Thus, it is felt that adaptation to an ostomy created because of cancer is more complex than the adaptation to an ostomy created for another reason (Katona, 1967; Prudden, 1971; Rush, 1976). Part of the issue is dealing with the feelings, reactions and physical trauma necessitated by this diagnosis and surgery. Therefore, the literature was reviewed

to elicit the central issues described by patient and spouse about the crisis and strain of ostomy surgery.

Impact of Ostomy Surgery

Surgery is often employed in the treatment of cancer. With the increase in medical knowledge and advances in surgical techniques, the treatment of cancer by the surgical creation of an ostomy is becoming more prevalent. The survival of these patients has increased, even as recently as within the past decade (Rheame & Gooding, 1991). In the case of colon-rectal and urinary bladder cancer, this surgery may result in the formation of an ostomy, a surgically created opening on the abdomen for the elimination of body wastes. This is often referred to as diversionary surgery and produces visible changes in bodily function and appearance.

An ostomy presents a patient with unique and profound psychological problems not encountered in other types of surgery (Winkelstein & Lyons, 1971). Fear, denial, grief and a sense of loss are common emotional reactions to an ostomy (Gill, Hogan, Rowbotham & Schuster, 1972). Technical skills required to manage the ostomy must be learned by the patient often at the same time he/she is struggling to adapt to an altered body image (Watson, Wood, Wechsler & Christensen, 1976). Thus, to attain the highest level of personal rehabilitation, individuals undergoing such surgical changes

need to learn not only the technical skills of care, but also how to cope with their emotional responses.

Although anxieties, fears and attempts to seek help are common themes among patients experiencing stress as the result of illness or injury, Jackson (1976) contends that the needs of the patient undergoing surgical creation of an ostomy are intensified due to the unique fears associated with the possibility of odour and soiling. It has been noted by Orbach (1957) that many patients develop ritualistic tendencies while doing their ostomy care to rid themselves of the contamination of excreta. Cleanliness becomes the uppermost thought in the minds of these people. With improvements in appliances available for management of ostomies today, perhaps some of this behaviour is less common. However, it is the experience of this investigator, that many people still focus on the care of their appliance to a degree that their level of social activity is greatly reduced in comparison to their level of social activity prior to surgery.

Gallagher (1972) described the establishment of an ostomy as creating both physiologic and psychosocial needs. Lenneburg (1971) described the ostomate's needs as the 1) physical aspects which include management, self care, diet and skin care, 2) psychological aspects such as emotional reactions and social adjustments, and 3) practical aspects which include the availability of equipment and techniques. Hurny and Holland (1985) have summarized common psychosocial

problems among ostomy patients based on similar physical, emotional and interpersonal aspects.

Ostomy surgery is classified as a mutilating surgery both in terms of the physical appearance and the emotional response of the patients (Winkelstein & Lyons, 1971). Meyer (1970) points out that every person harbours a distinct sense of physical self which is profoundly affected by such procedures, and that, just as an amputee is suddenly placed in the position of learning to walk again, the ostomy patient is placed in a similar position because of the necessity to relearn the management and control of excretions. Winkelstein and Lyons (1971) concur with this opinion adding that in our society which places such strong emphasis on early childhood training in complete bowel and bladder control, the sudden deprivation of control is an insult to one's self-esteem.

Psychosocially, the person must deal with changes in lifestyle necessary to cope with the change in body function. The need for change may illicit responses including anger, fear, denial or a sense of loss. Furst (1978) describes surgical fears and anxieties as falling into three major categories; the nature and locale of the illness itself, the surgical procedure and anticipated long range consequences of the operation.

Orbach and Tallent (1965) interviewed 48 patients with colostomies performed for malignant and non-malignant diseases. These researchers found that even after a period of

five to ten years, most patients still believed their body's intactness had been disrupted and its functioning seriously compromised. These patients expressed feelings of depression, altered perception of their bodies and lowered self-esteem.

One of the major implications of ostomy surgery includes the change in body image (Dlin, Perlman & Ringold, 1969; Rush, 1976) Body image includes not only what a person thinks about one's appearance, but also his/her perceptions of function, sensation and mobility (Hopwood & Maguire, 1988; McCloskey, 1976). Thus, the ostomy patient must not only contend with a change in appearance, but also with an alteration in function, a loss of sensation due to the absence of a rectum or urinary bladder and the fear of restricted mobility due to possible management problems causing embarrassment of leakage and odour. Anxiety and depression can be widespread reactions, as well as withdrawal from social life and absence from work, which are common occurrences among male and female ostomates (Boyd et al, 1990; Druss, O'Connor & Stein, 1969; Hurny & Holland, 1985).

Decreases in work status were more recently investigated by Nordstum, Nyman and Theorell (1990) who studied the extent to which an ileal conduit urinary diversion influenced a patient's capacity to work. A majority of patients (68%, N=47) in this study experienced a decrease in hours worked following surgery. In particular, those patients who required

surgery due to cancer, as opposed to incontinence, were more likely to reduce their number of hours worked.

Depression was significantly more prevalent in patients who were treated by abdominal perineal resection for low rectal cancer in a study by Williams and Johnston (1983). Assessment of these patients (N=38) was conducted by questionnaire one year after surgery. Each patient was incontinent and 28 (66 per cent) had leaks from their appliances (12 frequently and 13 occasionally).

Mount (1980) states that the impact of a change in body image is particularly devastating when there is a loss of sexual and/or excretory function. Warneke (1981) also identified changes in body image, concern with the sexual relationship and changes in familial roles as psychological concerns for the individual undergoing an abdominal perineal resection.

Ostomy surgery, thus results in an altered self-image and may also directly alter sexual function. Although there is no definite consensus of opinion regarding impotency after ostomy surgery, it is estimated that 50-75 percent of men undergoing radical surgery for colon-rectal cancer and nearly 100 percent of men undergoing radical surgery for bladder cancer will exhibit some degree of impotency. The extent of impotency will vary from individual to individual (Bergman, Nilsson & Peterson, 1985).

Functional difficulties may also arise due to fear of rejection by the sexual partner, fear of possible odours or leakage and fear of injury or pain (Chadwick & Stower, 1990; Winkelstein & Lyons, 1971; Williams & Slack, 1980). Mullens (1976) categorizes sexual impairment into five areas:

1. Change in body image and impaired self-esteem,
2. Fears about the ostomy or appliance interfering during coitus,
3. Concerns about conception, pregnancy and parturition in women,
4. Perineal wound and scar problems, especially in women,
5. Impotence or failure to ejaculate in men.

In a study determining psychologic response to a permanent colostomy, Druss et al (1969) questioned 36 patients who had undergone ostomy surgery due to rectal cancer. Regarding sexual function one year after surgery, 64 percent of the men stated they had the same amount of sexual desire as they did prior to surgery while 32 percent stated they experienced less sexual desire than they did prior to surgery. In terms of sexual activity, 41 percent were less active than they were during the preoperative period. Of the women questioned, 35 percent described having the same sexual desire, 28 percent less desire and 21 percent described having pain or a lack of sensation during intercourse.

Dyk and Sutherland (1956), in a classic study, reported more dramatic changes in sexual relations after ostomy

surgery. Of the 22 men interviewed in their study, three reported little or no change in sexual relations. Seven men had marked impairment while 12 were totally impotent following ostomy surgery. Of the 15 women interviewed in this study, ten had been sexually active prior to surgery. Of these ten women, three discontinued intercourse after surgery; seven continued to have intercourse after surgery, but all stated it was with reduced interest and less frequency. Since their study, completed nearly four decades ago, there has been no consensus reported in the literature as to the type or degree of sexual difficulty that women may experience following ostomy surgery. It is known, however, that difficulties related to lubrication, scarring and change in body image are possible concerns (Bergman, 1985).

Therefore, the literature and empirical work suggest that needs created by ostomy surgery are physical, psycho-social and sexual in nature and that these concerns have been consistently reported since the 1950s. More recently, work has been pursued related to the adaptation necessary as a result of these concerns. Adaptation to changes brought about by this procedure is a long process beginning at the time the need and reason for surgery become known to the patient and the spouse (Watson, 1983). Therefore, the literature that describes the adaptation process following ostomy surgery due to cancer is reported in the following section of the literature review.

Rehabilitation Challenges

As stated, the rehabilitation needs of the patient undergoing ostomy surgery are both physical and psychological in nature. Nagi (1969) defines disability ... "as a pattern of behaviour that evolves when impairments impose limitations on the individual's capacities and levels of functioning" (p.12). Although an ostomy is created as a solution to an underlying problem, the ostomy itself can be viewed as a disability since it produces changes in a person's excretory function, psychological self-concept and sexual relations. These changes can be limiting in nature and produce a need for individual adaptation if a rehabilitative process is to take place.

Watson (1976) has proposed a model of coping behaviour of the spinal cord injured person as a tool to evaluate adaptive responses of a person with an ostomy. The four stages of the model are: 1) shock, 2) defensive retreat, 3) acknowledgement, and 4) adaptation. The patient is believed to progress through these phases. A more complete description of the stages in Watson's model is included since it closely resembles, and therefore adds support to, the selection of the crisis theory framework proposed as the basis for this study.

The shock phase commences with the announcement of the diagnosis and the need for surgical intervention. The patient experiences fear and apprehension about the future and can be significantly immobilized emotionally and physically. Time is

required for the patient to assimilate what is happening to him/her. This phase begins in the preoperative period.

The defensive retreat phase is characterized by wishful thinking, denial and emotional distance from people. Behaviour may correspond to the grief response with intense preoccupation with the image of the lost object. This phase is usually seen immediately following surgery but may be prolonged into later stages.

The acknowledgement phase is the time in which the patient begins to accept the confrontation of reality. Attempts are made to resolve the sense of loss, and responses such as guilt, somatic distress, anorexia, fatigue and anger may be present.

The adaptive phase indicates a person is moving on to a realistic level of independence. Although this complete phase occurs six to twelve months after surgery, evidence of adaptation should be seen in the patient's responses to the ostomy prior to discharge from the hospital.

The patient's interpretation of his/her situation is an important variable in the adaptation process. When assessing the psychosexual response to ileostomy and colostomy, Dlin and Perlman (1969) found that before surgery and in the early post surgical period, the primary concern of the patient is survival and success of the surgery. This finding is congruent with this investigator's clinical impressions.

Later, attitude changes concerning personal vanity, problems relating to spouse, family and friends and a loss of self-esteem can occur. For some, hope and confidence begin to replace these feelings as convalescence occurs. They strive for the fullest life possible after surgery. For others the feelings of loss, grief, and depression are not so easily resolved and comprehensive rehabilitation for these individuals is hindered (Watson et al., 1976). The patient's response to one's situation after ostomy surgery reflects one's personal views of life and self premorbidity (Dlin, 1969; Prudden, 1971; Rush, 1976; Watson, 1976).

More recently, a nursing research group at Memorial Sloan-Kettering Cancer Centre studied forty patients and their significant others at one or two days prior to discharge, and at ten, thirty and sixty days after discharge (Oberst, 1983). Of these adult patients who were newly diagnosed with cancer of the large bowel or genitourinary system, half required a stoma at the time of the resection surgery. Data about problems encountered were obtained and standardized measures of distress, the State-Trait Anxiety Index (STAI), Brief Symptom Index (BSI) and Vulnerability Scale were completed.

The STAI is comprised of two 20 item self report scales. The A-State scale, used as a crisis measure in this study, had demonstrated construct and discriminant validity; reliability coefficients in the range of .83 to .92 have been reported (Oberst & Scott, 1988).

The BSI is a 53-item self report form designed to reflect psychological symptom patterns of psychiatrically and medically ill populations. The BSI is a short form of the SCL-90-R which has been extensively tested and its internal consistency, test-retest reliability and concurrent validity are well established: correlations between the SCL-90 and the BSI are high ($r=.90$) for all of the subscales (Derogatis, Rickels & Rock, 1977).

The Vulnerability Scale is a 13-item observer rating of affective behaviour. In a subsequent study by Oberst and Scott (1988), alpha coefficients for the total scale ranged from .84 to .93 in multiple testings with patients and from .84 to .92 when used with spouses.

Preliminary results suggested that the group of patients with an ostomy, as compared to the group that did not require ostomy surgery, demonstrated a different pattern of distress and adaptation in time. Prior to discharge and for the first sixty days, the ostomy patients focused almost exclusively on the stoma and its management. The psychological reaction to the cancer and the possible threat to life did not surface until approximately two months post surgery. The group who did not require surgery had anxiety levels peak at approximately ten days following surgery; whereas, the ostomy patients' anxiety levels remained elevated for at least sixty days postoperatively. The spouses of the ostomy patients experienced even more distress and anxiety than the patient.

The spouses's ability to cope effectively declined and even two months after hospital discharge had anxiety levels that were well above those recorded for hospitalized psychiatric inpatients (Oberst, 1983).

The reactions of significant others to the resulting stoma is thus recognized as a key component in the rehabilitation of the ostomy patient. Dyk and Sutherland (1956), Prudden (1971), Rush (1976) and Winkelstein and Lyons (1971) all attribute a major portion of the patient's adaptation to the influence of significant others. Druss (1968) and Dericks (1974) have shown that patients who adapt to their situation most rapidly are the patients who are strongly supported by those persons who are most important to them.

Of equal importance, however, is the identification of concerns experienced by the spousal member of the pair. Health care providers must include attempts to meet the needs of the spouse as well as those of the client. The next portion of the literature review focuses on the role of the spouse in the rehabilitative process. Nursing measures that have been reported to facilitate a positive adjustment are then described.

Significance of Spousal Role

The significance of the spouse in the successful

adjustment of the ostomate is well documented in the literature. Sutherland, Orbach, Dyk and Bard (1952) reported that whenever there was poor rapport between husband and wife prior to surgery, tensions increased and new areas of conflict were created. Conversely, when rapport was good before surgery, it continued following the surgery. Dyk and Sutherland (1956), Gloeckner and Starling (1982) and Gloeckner (1983) reported the spouse to be the key to the individual's success or failure in adapting to this disability. Prudden (1971) also reported that those who adjusted best had been strongly supported by persons most important to them. Grubb and Blake (1976) reported that the individual is hypersensitive to the conscious and unconscious reactions of persons around the patient and that family or spouse reaction is a major factor in the patient's response.

The family member closest to the individual shares the strain of illness with the patient (Holland & Frai, 1973). Illness may be a serious threat to the dynamic equilibrium of the relationship between a husband and wife (Dyk & Sutherland, 1956). The level of anxiety experienced by the family will influence their adaptation. Role changes within the family are reported by several writers to be a major stressor when illness occurs (D'afflitti, 1975; Klein, 1967; Lewis, 1983). Interestingly, Klein (1967) notes that the tension exhibited by some spouses was greater than the "patient" member of the pair.

Kobza (1983) has most specifically addressed the needs of the ostomate's spouse. Semi-structured interviews were conducted with twenty spouses whose mates had required ostomy surgery at least one month prior. The interviews were guided by a review of the literature pertaining to the needs of spouses in other chronic conditions. Kobza (1983) adapted her questions to clients requiring ostomy surgery. The predominant needs identified were needs for: information, emotional support and follow up when dealing with lifestyle changes. She contends it is critical that the personal needs of the spouse also be met. As Oberst (1983) stated in the conclusions of her preliminary paper..."learning to live with cancer (and a stoma) is clearly no easy task. Learning to live with someone else's cancer (and stoma) may be even more difficult, precisely because no one recognizes just how hard it really is" (p.23).

Although the spouse has frequently been noted as the most significant person in the ostomate's rehabilitation, there has been little done prior to Kobza's work to determine these needs. Considering the critical influence a spouse may have in the successful rehabilitation of the client, it seems reasonable to suggest that by addressing the concerns of the spouse, the health professional is also indirectly influencing the client member of the pair.

Nursing Interventions To Assist Rehabilitation

A review of the literature related to interventions for this client group indicates that crises such as these present opportunities for nursing. The following component of the review describes nursing interventions aimed at this experience.

Giacquinta (1977) has outlined therapeutic nursing approaches based on five phases she believes are encountered when families face the crisis of cancer. The phases include impact, functional disruption, a search for meaning, informing others, and engaging emotions. Giacquinta (1977) has adapted these phases and outlined nursing interventions based on Kubler-Ross's (1969) proposed five stages through which the dying person proceeds emotionally. The similarity of Kubler-Ross's stages and those outlined within crisis theory add further support to the appropriateness of these approaches in caring for this client group,

Furst (1978) emphasized the need for skillful counselling when the individual is faced with a change in definition of self. Freidenbergs et al (1980) suggested three basic types of psychological intervention for cancer patients: education, counselling and environmental manipulation (i.e., consulting with other health care personnel).

In describing the impact of chronic illness on the

spouse, Farkas (1980) identified the social worker or other health care personnel's role in assisting the spouse to understand the reaction of the partner to illness, to reopen and clarify communication between the two, to assist the spouse in planning care and to help the spouse maintain a balance between serving the partner and respecting their own needs. The spouse needs the opportunity to express feelings that might otherwise seem unacceptable. Wassner (1982) summarizes the benefits of counselling the individual and family before and after surgery to reduce fear and promote thoughts about the pending change in body image and possible short and long term effects on their lifestyle.

Lamb and Woods (1981) identify that nurses may promote sexual health by fostering open communication, providing anticipatory guidance, validating normalcy, educating, and counselling. In a descriptive article intended for health care professionals, these authors offer direction for intervention based on relevant literature and clinical expertise in gynaecologic oncology. When Gloeckner (1983) studied the reaction of the spouse and partner upon reassuming sexual activity following ostomy surgery, she concluded that health professionals can help ensure optimal sexual rehabilitation by giving special attention to individuals and their spouses because it is the attitudes of the latter that are the most crucial in the adjustment process.

The timing of these rehabilitation interventions is an

important consideration. The counselling and teaching aspects of nursing are required throughout the phases of rehabilitation (Wilpizeski, 1981). Watson's (1983) study was intended to determine whether short term supportive counselling instituted during the postoperative period of hospitalization would favourably alter self concept, particularly the component of self esteem in individuals who had undergone ostomy surgery for cancer. A pre- and post test experimental control group design with random assignment of subjects to treatment and control groups was used in the study (N=31). The Tennessee Self Concept Scale (TSCS) and the Rosenberg Self Esteem (RSE) inventory were used as measures of self concept/self esteem. Watson (1983) reports that the TSCS provided a total P-score which was used as a global estimate of self-concept. Two week test-retest reliability coefficients of the total P-score and RSE were .92 and .85, respectively. The subjects who received counselling during the postoperative period demonstrated significant positive alterations in self concept and esteem ($F=9.29$; $p<0.01$), ($F=9.55$; $p<0.01$).

Therefore, when a couple enters a process catalyzed by the need for ostomy surgery, there are biophysical, psychosexual, and rehabilitation elements to be considered. Nursing may play a critical role in facilitating a positive adjustment at opportune moments throughout this process. Of prime importance is the health care provider's ability to

predict and identify the means to most effectively intervene on behalf of the client and the spouse. The use of a reliable and valid assessment tool, designed and tested for use with this specific client group may assist in this endeavour. The literature review revealed the availability of one instrument, the Quality of Life Index (QLI), developed and tested to assess quality of life in colostomy patients who have had surgery due to cancer in the long term phases of adaptation (Padilla & Grant, 1985). Alternatively, the OC Scale has been designed for use by patients with various abdominal stomas (i.e., colostomy, ileostomy and urostomy) required as a result of cancer, their spouses, and is intended for use in the immediate postoperative period.

Ostomy Concern Scale

A three phase investigation was undertaken; the overall purpose was to identify the concerns experienced by patients who require ostomy surgery due to cancer and to compare the concerns with those of their spouses. The first phase generated a list of 48 client and spouse expressed concerns. The second phase asked couples to prioritize the 48 items according to their particular experience. A more specific summary of these phases is included to demonstrate the qualitative means of obtaining the instrument items and to report initial comparisons of concerns.

Phase I - Compilation of Concerns

The purpose of Phase I was to compile a list of concerns experienced by clients who have required ostomy surgery due to cancer as well as those experienced by their spouses. Semi-structured interviews, guided by the previous research of Kobza (1983) who outlined three areas of informational need by these couples, were conducted with twenty client couples. The interviews were completed with the client and spouse separately. Content analysis of tape recorded interviews yielded 48 client and spouse-expressed concerns (Coe & Kluka, 1988).

The co-investigators independently coded the content; the categories that emerged were similar in nature. Subsequent support of the categories has since been provided by Oberst & Scott (1988) who identified eleven similar categories in their analysis of discharged postsurgical cancer patients and their spouses. Wingate and Lackey (1989) also identified physical and informational needs as those most dominant in a study of the needs of noninstitutionalized cancer patients.

The list of forty-eight concerns was compared with a cumulative list of concerns requested from twelve enterostomal nursing experts from across Canada to determine the completeness of the data. No additional concerns were identified by this panel, further supporting the investigators' decision that a point of saturation had been reached during analysis of the qualitative data. Twenty-four

client/spouse-expressed helpful behaviours were also yielded during this phase.

Phase II - Establishing Priority Concerns

The second phase of the study used a Q sort methodology to determine priority concerns and to compare the responses among the couples. Twenty additional couples ranked the forty-eight concerns identified in Phase I (Appendix IV, Coe & Kluka, 1988). Factor and cluster analysis were used to examine the data obtained. Although four priority disease related concerns were identified, the findings also demonstrated that each concern was a priority concern for at least one client or spouse (Coe & Kluka, 1990). The majority of clients, or 70 percent of those who participated, identified priorities different from those indicated by their spouse.

It is critical to recall that each of the 48 client and spouse expressed concerns identified in Phase I received priority rating by a second group of couples in Phase II. Therefore, each of the 48 items were retained for use in the OC Scale. The third phase of the investigation, reported here included assessments of reliability and validity of the instrument.

Summary

It has been stated that empirical testing is required to assess the validity and applicability of a theory prior to its application to a phenomenon of interest to nursing. In Chapter II, the conceptual framework was re-examined to determine the degree of consistency between the framework and the empirical findings reported in the literature.

A critique of the conceptual framework indicated that the crisis theory conceptual framework provided a perspective on the events which occur when an individual or spouse is faced with the need for ostomy surgery due to cancer. The literature documents that the impact of either a cancer diagnosis or the need for ostomy surgery can be a traumatic, crisis precipitating event for either member of the client couple. Increased levels of psychosocial distress have been reported for both the individual or the spouse.

The impact of the surgery is confounded by the diagnosis; more so than with other disease entities. The critical element of this framework, based on crisis theory, is that the degree of impact and resulting period of disorganization is dependent on the perception of the occurrence(s) by those experiencing it. The literature describes the period of disorganization as including a multitude of anxieties and fears related to physical, psychosocial and sexual sequelae that may be precipitated by the diagnosis and/or the surgery.

Challenges concerning aspects of body image, role, and lifestyle changes confront the individual and the spouse. A key factor that has been reported to influence the angle of recovery, (i.e., whether it is to be more or less acute), is the role of the spouse in the adaptation process. Equally important is the consideration that spouses' needs must be individually assessed and strategies planned to meet their particular needs.

Crisis theory indicates that the past experiences and previous levels of support received during the experience effect the crisis outcome in a positive or negative direction. The availability of a reliable and valid assessment tool to detect the most critical concerns of individuals who have experienced ostomy surgery due to cancer and their spouses, would allow caregivers to address these concerns and promote positive adaptation. Without the use of such an instrument, intervention may be based on trial-and-error approaches to care or on routine programs which may be inappropriately delivered to everyone. A more systematic method of assessing concerns of individual patients and spouses is therefore necessary. A summary of the developmental phases of the OC Scale has been outlined.

CHAPTER III

METHODOLOGY

Introduction

A three phase investigation was planned with the overall objective of identifying the concerns of clients who have had ostomy surgery due to cancer compared to the concerns experienced by their spouses. The objectives and outcomes of Phases I and II have been reported in Chapter II. The purpose of the third phase, and the focus of this study, was to develop and test an instrument, the OC Scale, designed to assess the concerns experienced by this client group. The methodology applied in the third phase of the research is reported. A list of definitions specific to the study are noted in Appendix III.

The OC Scale is intended to identify couples experiencing a high degree of concern and provide information about how their concerns compare. If nursing is to assist couples during the period of adaptation following this surgery then an individualized assessment to identify specific concerns must be considered the initial task. The challenge of this third phase was to produce a tool based on the qualitatively generated concepts of the first two phases that

could be assessed for validity and reliability. A major challenge to the nurse researcher who is developing instruments ... "is the evaluation of whether the meaning inherent in qualitatively generated concepts has been retained in scales constructed for a quantitative instrument" (Imle & Atwood, 1988, p.23).

Pilot testing procedures are both a critical and logical first step to assess a scale's clarity, apparent internal consistency and content validity. Imle & Atwood (1988) have described pilot testing procedures to estimate these dimensions in the Transition to Parenthood Concern Scale. The methodology for pilot testing the OC Scale outlined in Chapter III was based on their design. Additionally, the pilot test included an assessment of the most appropriate descriptors to use as responses to the Likert-type format of the OC Scale. The means of obtaining this information from panel members during the pilot test are described.

Subsequent testing was undertaken to assess the tool for reliability and validity. The sample, selection criteria, instrumentation, data collection and analysis procedures are outlined for both the pilot and subsequent testing methods. Ethical considerations and study limitations are also discussed.

Phase III - Pilot test

Introduction

The pilot testing phase was designed to respond to one of the central research questions of the study: "To what extent can the Ostomy Concern (OC) Scale be considered a valid instrument in identifying the concerns by this client group?" To address this query more specifically, four sub-questions were posed:

1. To what extent are the items in the OC Scale clear?
2. To what extent do the items in the scale evidence apparent internal consistency?
3. To what extent do the items in the OC Scale evidence content validity?
4. What response options are most meaningful to subjects who respond to the OC Scale?

Imle & Atwood (1988) remind that the sequence of rating procedures is an important consideration. Clarity of items for example, must be assured prior to subsequent ratings since they are dependant on this aspect in order to be accurate in the remaining procedures. Internal consistency needs to be assessed prior to content validity since the panel, once aware of the content, would be unable to make content-free estimates. The design applied in this investigation, was an adaptation of a concept assessment procedure first

recommended and later operationalized by Atwood (1975; 1978). Field and Morse (1985) suggest strategies to assess qualitative data for reliability and validity. One of these is to have key informants review the findings to ascertain that the researcher and informants view the data in a consistent way. Imle & Atwood (1988) support this approach in that it..."ensures that other observers besides the researcher can agree about the internal cohesion of each category" (p.25). This approach for pilot testing an instrument was followed in this investigation.

Members of an expert panel were asked to respond to a question regarding the most appropriate descriptors they considered meaningful as response options for the OC Scale. Review of pertinent literature, the results of the previous phases, and the clinical expertise of the investigator yielded conflicting information about whether the scale best reflects the frequency or the intensity of the concerns experienced by this group. Therefore, the investigator completed the pilot testing by asking the expert panel for advice with this decision.

Sample and Selection Criteria

The panel of key informants for this study was selected using the same selection criteria employed in the first two research phases. Panel members were: postoperative ostomy patients or spouses, the patient had a diagnosis of cancer

known to both of them, able to read and understand English and geographically accessible for contact. This is consistent with the recommendations by Aamodt (1983) that the pilot testing procedure should have the same type of informants who provided the initial data.

For the purpose of the pilot testing, a minimum of four members for the panel was selected by approaching the Winnipeg Ostomy Association (WOA) Executive. Lynn (1986) identified the minimum number of experts that must agree to endorse an item or instrument and establish content validity beyond the .05 level of significance. She recommended that for a panel of 4, all 4 must agree, whereas, 5 of 6 panel members must agree to achieve this level of significance. The WOA executive reflects a knowledgeable, appropriate and willing group of experts, inclusive of clients and spouses. It is considered essential by Imle & Atwood (1988) to have the same panel complete the various components of the pilot so that the researcher knows discrepancies are not a result of differences between panels.

Instruments, Data Collection and Analysis Procedures

An explanation of the study and more specifically the pilot testing procedures (Appendix IV), was given by the investigator during a regular meeting of the WOA Executive. The investigator arranged to use the executive's meeting room following the meeting. The location of the meeting room was

both convenient and private. Those members of the WOA Executive who met the selection criteria and who were interested in participating in the study were asked to remain following the meeting. These subjects were asked to then read a disclaimer which they kept (Appendix V).

The investigator requested that the group briefly review the contents of the OC Scale. The group was then asked for direction regarding the response option descriptors to be used within the OC Scale by means of responding to the questions shown in Appendix VI.

Clarity of Items

Clarity of items was the first component assessed. Each component consisted of instructions for the raters, the list of numbered scale items and a response sheet (Appendix VIII). The instructions specified how the raters were to evaluate each set of items. The first rating procedure used to assess clarity had two parts: clarity of scale items and clarity of scale directions. Raters received identical instructions. Participants were asked to complete the materials in the order presented. Space for comments was included and discussion with the researcher about these was encouraged following completion of the rating procedure. The scale directions were also reviewed regarding format, clarity and reading level and the group's decision regarding scale descriptors was incorporated. The raters were asked to note any unclear

statements. All scale items were rated in terms of clarity. This pilot testing approach uses percentage agreement among raters. Imle & Atwood (1988) justify this method because the purpose is to test..."a scale for psychometric attributes rather than explaining outcomes in terms of another variable," (p.32). A major criticism of percent agreement is that the likelihood of chance agreement between two raters increases as the number of occurrences of an event is increased. However, the strategy outlined in this study is such that there is only one occurrence of an event per item (Imle & Atwood, 1988), making this method acceptable. Imle & Atwood (1988) suggest a 70 percent agreement rate a priori for clarity of items and instructions. This is consistent with Lynn's (1986) recommendation that the number of panel members who must agree to establish content validity beyond the .05 level of significance to be 4 of 4 (100 percent agreement rate) or 5 of 6 (83 percent agreement rate).

Apparent Internal Consistency

The second component of the pilot rating procedure assessed the apparent internal consistency of the scale, the extent to which all items of the scale seemed to measure the same variable. Using the same set of instructions, the rating activity consisted of answering two questions; "Do these items generally belong together?" and "Does each item belong in the set?" (Appendix IX). The a priori criterion for an item or

subscale to be retained in the scale set by Imle & Atwood (1988) was 70 percent agreement among raters per item.

Content Validity

The third procedure of the pilot test assessed content validity. Content validation estimates how well and how adequately items reflect the meaning of the conceptual domain without redundancy. Using identical instructions for each list of items, the rating activity included completion of four questions; "In general, does the label and definition of the scale fit the whole set of items? Does the item fit the label and definition? Is this item unique (not repetitious)? Are there concerns left off the list you think should be there?" (Appendix X). The a priori criteria for acceptance suggested by Imle & Atwood (1988) is 80 percent agreement for the first two questions and 85 percent agreement on uniqueness for the third question.

Summary

The methods used to obtain direction from an expert panel regarding the most appropriate response option descriptors were described. The methodology for assessing the scale's clarity, apparent internal consistency and content validity was outlined. Criteria used to estimate these psychometric properties were provided with supporting rationale.

Phase III - Subsequent Testing

Introduction

Subsequent testing of the OC Scale involved assessments of the internal consistency and the stability of the instrument over time. The methods used for this testing phase are reported here.

Sample and Selection Criteria

Twenty couples participated in the study. This sample size represents approximately seven percent of clients in Manitoba who undergo ostomy surgery for cancer each year. Selection criteria were the same as the initial two phases and pilot test: postoperative ostomy patients and spouses, a patient diagnosis of cancer known to both members of the couple, subjects able to read and understand English and geographically accessible for contact.

Recruitment Procedure

Approval for access to conduct research in the following institutions was requested; Bethesda Hospital, Brandon General Hospital, Carman Hospital, Concordia Community Hospital, Grace General Hospital, Health Sciences Center, Misericordia General Hospital, Portage la Prairie Hospital, Selkirk and District Hospital, Seven Oaks Hospital, St. Boniface General Hospital and the Victoria Hospital (Appendix

XI). Once consent from the institution was obtained, the respective enterostomal (ET) nurse consultants were asked to identify potential couples who met the selection criteria and to give them a written copy of the study introduction as prepared by the principal investigator (Appendix XII). Potential clients included those who had undergone ostomy surgery within the past week (i.e., current subgroup) (N=11) or those who required surgery within the past year and were asked to participate by recalling his/her experience during the first week following the operation (i.e., recall subgroup) (N=9). Couples interested in participating in the study identified themselves to the ET nurse who provided the investigator with a list of potential subjects. The investigator then contacted interested couples and arranged to meet with them either in hospital or at their home. The explanation of the study was reviewed with the couple and a written disclaimer was read by each member of the couple (Appendix XIII). Subjects were given an opportunity to ask questions regarding the study and their participation.

Instrumentation

OC Scale

The OC Scale consists of the original 48 items reported in the first phase of the investigation (Appendix XIV). The items, listed in random order, have been formatted into a five

point Likert-type scale. Although a Likert scaling format usually includes both positively and negatively worded items to avoid response-set bias, the items of the OC Scale do not reflect this approach. Rather, the items are listed as reported in the transcribed interviews of Phase I. Based on past clinical expertise of the investigator and research expertise with this population, it was anticipated that participants would be motivated to honestly reveal their concerns. Also, keeping the items as originally reported was judged to be more straight forward and would create less confusion for subjects completing the instrument.

Demographic Data Sheet

During the initial contact with the participants, the principal investigator completed the demographic data sheet using information obtained through discussion with subjects (Appendix XV). Data concerning age, gender, client or spouse member of the pair, type and date of surgery, knowledge of the patient diagnosis known to each member of the couple, the occupation of the patient and the care setting. These data were required to examine whether demographic variables suggested in the literature review or the ability to recall the experience might explain differences among concerns identified (Gloeckner, 1983; Holland & Frai, 1973; Kobza, 1983; Nordstum, Nyman & Theorell 1990; Oberst, 1983; Winkelstein & Lyons, 1971).

Data Collection Protocol

Following an explanation of the study and disclaimer, the investigator administered the OC Scale to each member of the couple separately. The investigator provided verbal instructions regarding completion of the instrument. Average length of time to complete the instrument was 30 minutes.

A test-retest procedure was completed approximately 24 hours later. This was implemented by the investigator leaving an envelope containing a second copy of the instrument with each participant during the initial contact. The participants were asked to complete the second copy of the instrument, allowing approximately a 24 hour interval. The completed retest data for the couple was collected by the investigator. A decision was made to not administer the retest instrument in person due to time and economic constraints and the fact that the tool itself did not necessitate further interpretation. All of the retest instruments (100 percent) were completed.

Data Analysis Procedures

Subsequent testing of the OC Scale was undertaken to investigate the research question:

How reliable is the OC Scale in identifying the concerns of the client group under investigation?

The reliability of an instrument concerns the "...extent of the repeatability or consistency of measurements" (Zeller & Carmines, 1980, p.75). Therefore, the subsequent testing

and analysis of the OC Scale examined the internal consistency and stability of the instrument over time.

Data analysis occurred in three phases. Descriptive statistics were used to measure central tendency, dispersion and frequencies among the demographic variables and scale responses.

A second phase of the analysis estimated the internal consistency of the scale; the extent to which all items on a scale measure the same variable. Internal consistency reliability is based on the average correlation among items within a test and the overall number of items. Coefficient alpha, developed by Cronbach (1951), is considered a basic formula for determining internal consistency reliability (Zeller & Carmines, 1980). Cronbach's alpha varies between .00 and 1.00, taking on these extremes when the item intercorrelations are equal to zero and unity, respectively (Zeller & Carmines, 1980). Nunnally (1967) recommends that a Cronbach's alpha should be greater than .70 for immature scales when testing for internal consistency reliability and that inter-item correlations should be between .30 and .70. The item-to-total correlations were also obtained and correlations between .40 and .60 were set as the acceptable criterion (Nunnally, 1978).

The third step in the data analysis estimated stability of the instrument over time. A Spearman's correlation coefficient was calculated to test the relationship between

scale scores at time 1 and 2. Given the small sample size, normal distribution could not be assumed; therefore, use of this non-parametric correlation coefficient was appropriate. A coefficient of greater than or equal to .80, significant at the $p < .05$ level, was used as the minimum criterion to test stability of the instrument over time (Carmines & Zeller, 1979).

If the criteria for internal consistency and the stability of the instrument over time were met, analysis related to two additional questions was planned:

1. What are the concerns of the ostomate and spouse during the immediate postoperative period (approximately one week following ostomy surgery)?
2. How do the concerns identified by ostomates compare with the concerns identified by spouses?

Cluster analysis was used to examine groupings of identified concerns for the total group and each subgroup (i.e., ostomates and spouses, current and recall).

A Kendall's coefficient of concordance ($p < .05$) was calculated for the overall sample and for each subgroup to determine the extent of agreement among respondents about the concern.

Finally, the identified concerns were to be dichotomized into high and low categories based on the results of the frequency distribution. A Fisher's exact test was to be used to test for differences in concerns between groups

according to demographic variables (e.g., gender, age) and status (e.g., current versus recall subgroups). This statistic was recommended in view of the sample size.

Ethical Considerations

The study followed the ethical standards of the Canadian Nursing Association (1983) and was approved by the Ethical Review Committee of the School of Nursing at the University of Manitoba. Written permission was obtained from each hospital to access subjects. Participation of subjects was voluntary. Subjects were assured they could withdraw from the study at any time and that participation in the study would in no way influence the care received.

Potential participants for this study received an explanation about the research and were invited to participate. A written disclaimer was given to subjects to read prior to their participation. Confidentiality of responses were maintained by the researcher. Responses were recorded without any association of the participant's name. Demographic data, collected by the investigator, corresponded to the responses made on the scale by means of a numerical code only. Information pertaining to a particular hospital or nursing unit was alphabetically coded. All codes and completed instruments were kept in separate, locked files.

The data obtained during this phase was for the sole purpose of testing and revising the OC Scale prior to its use in the clinical setting. All reports related to the study refer to a summary of the pooled responses. At no time will it be possible to identify individual subjects, surgery dates or hospital locations. The risk to subjects was minimal. It involved the sharing of details about their concerns following surgery with another person and the time required to complete the instruments. In order to reduce potential anxiety of the subjects, the investigator was sensitive to each individual's needs and approached each subject in a non-threatening manner. The investigator was an enterostomal (E.T.) nurse who had specialized in the care of people (and families) who have required, or may require, ostomy surgery and therefore is familiar with approaches considered to be sensitive when interacting with this client group. However, if enterostomal nursing expertise was required, the client(s) were referred to the enterostomal nurse who was coordinating the care. This need was identified on two occasions and referrals were completed by the investigator.

Limitations

Due to the limited sample size, this study would require replication before generalizations to a larger population may be made. Volunteer subjects may have been selective in the

information they wished to share, therefore, their responses may not be a complete representation of the concerns expressed by the total population. Finally, the responses of those participants who have been asked to recall the concerns they experienced one week after surgery may be affected by their ability to accurately remember priority concerns.

Since the study focused on the immediate postoperative period (approximately one week following surgery), comparative studies would need to be completed to determine how an individual's concerns may change over time.

A further limitation of this study involved the focus on clients who have had ostomy surgery due to cancer. The results, therefore, should not be considered for those whose surgery was required due to other disease entities.

Although it is beyond the scope of this study, ideally, future research would build on these findings by addressing issues of concurrent and predictive validity of the OC Scale. At present there are no specific tools that are suitable to use for a criterion validity assessment. Therefore, the outcome of this study was limited to assessments of item clarity, apparent internal consistency, content validity, internal consistency, stability over time and internal validity. Given the state of the art in this clinical area, this careful tool development and testing represents a constructive and useful contribution to understanding the needs of ostomates and their spouses.

Summary

The items of the OC Scale were obtained using qualitative methods. The methodology outlined for this phase of the larger investigation was selected because it allowed the researcher to quantify the findings into a scale while preserving the original value of the item content. Clarity of items, apparent internal consistency and content validity were pilot tested with a panel of experts. This panel also guided the researcher in terms of the most appropriate descriptors to be applied within the OC Scale. Subsequent testing procedures assessed internal consistency, stability of the instrument over time and internal validity of the scale. Ethical considerations and study limitations have been described. The scale has the potential to assist in the care of current and future couples who face adaptation following ostomy surgery for cancer.

Chapter IV

DATA ANALYSIS

Introduction

The focus of this study was to develop and test an instrument, the OC Scale. Pilot testing procedures were undertaken to assess the scale's clarity, apparent internal consistency and content validity. The pilot test also included an assessment of the scale's most appropriate response option descriptors to be used for the Likert-type format. Subsequent testing procedures were intended to assess the tool for reliability and validity. The outcomes of the pilot and subsequent testing phases are reported in this chapter.

Phase III - Pilot test - Data Analysis

Introduction

Following the protocol outlined in the previous chapter, a panel of key informants was selected. Six panel members, who met the selection criteria, participated in the pilot test. Five of six panel members agreed that the most appropriate descriptors to be used as responses to the Likert-type format of the OC Scale involved those depicting frequency of the concern (i.e., Never Important, Seldom Important,

Occasionally Important, Frequently Important, Always Important), as opposed to the degree of concern (i.e., Very Unimportant, Unimportant, Important, Fairly Important, Very Important). The sixth panel member had difficulty deciding which of the two sets of descriptors was best, but was agreeable to the consensus of the group. Since the panel was not able to guide the investigator in terms of further alternatives, the descriptors depicting frequency of concern were used during the remainder of the pilot and subsequent testing procedures.

Clarity of Items

Clarity of the scale's items and directions were the the first two components of the pilot rating procedure (Appendix VIII). Although space was allotted for comments it was not used by the subjects. The raters had little difficulty assessing the clarity of the scale items. One female participant thought the word "wardrobe" should be used in item 12, rather than "clothing" because to her this concern meant changing the clothing one was currently wearing as opposed to changes within one's wardrobe. The cumulative responses during the pilot test resulted in an 83 percent agreement rate for all items. This level of agreement met the preset criteria to establish clarity of the scale items and directions (>80%) at the .05 level of significance.

Apparent Internal Consistency

The second component of the pilot rating procedure assessed the apparent internal consistency of the scale; the extent to which all items of the scale measure the same construct (Appendix IX). Two questions were completed; first to determine if the items in general seemed to belong together, and second to verify whether each item belonged within the set. In each case, panel members supported the inclusion of the items, indicating 100 percent agreement for each of the questions. Apparent internal consistency was thus established at the .05 level of significance.

Content Validity

Content validity was the third rating procedure of the pilot testing phase (Appendix X). Content validation assesses how well and how adequately items reflect the meaning of the conceptual domain and how well they avoid redundancy. The panel members all indicated that the label and definition of the scale fit the entire item set. As well, they agreed that each item fit the label and definition. Comments confirmed that they believed each of the forty-eight concerns were realistic and could be priority issues for someone having had an ostomy due to cancer or for his/her spouse. None of the items were considered to be repetitious. Content validity of the OC Scale was supported at the .05 level of significance. No further concerns were added to the list by

the participants; additions to the number of scale items were therefore not required.

Summary

Results of the pilot testing phase indicated that the previously determined criteria for clarity, apparent internal consistency and content validity were met. The OC Scale, therefore, was not revised prior to the subsequent testing procedures.

Phase III - Subsequent Testing - Data Analysis

Introduction

Subsequent testing of the OC Scale was conducted to assess internal consistency, stability of the instrument over time and internal validity of the scale. Analysis of the data proceeded in three major areas as outlined in the previous chapter.

Demographic Statistics

The following is a summary of the demographic characteristics of the sample (Table 1). All clients had undergone ostomy surgery within the previous year for bowel or urinary cancer. Eleven of the twenty clients required surgery within two weeks prior to contact by the investigator; actual range of postoperative contact for this subgroup was 7 to 11

days. Fifteen of the twenty clients were male. The majority of the clients (16 of 20) and spouses (18 of the 20) were at least sixty-five years of age. Colostomies were needed for eleven clients. The remaining eight clients required urostomies. All of the current clients and all but two of the current spouses were contacted in hospital.

Table 1. Demographic Characteristics of Participants by Subgroup

	<u>CURRENT</u>		<u>RECALL</u>	
	Client	Spouse	Client	Spouse
<u>Demographic Characteristics</u>				
<u>Gender :</u>				
males	7	4	8	1
females	4	7	1	8
<u>Age:</u>				
under 65	2	1	2	1
over 65	9	10	7	8
<u>Stoma Type:</u>				
colostomy	8	-	3	-
urostomy	3	-	6	-
<u>Location:</u>				
hospital	11	9	-	-
home	-	2	9	9

Frequency Distribution

The total possible range for the OC Scale is 48 to 240. The actual range used by the subjects was 54-194. The participant who responded with the lowest ranking of the items, or score (54), was a female client who had surgery nine days prior to contact by the investigator. At the time of the contact she indicated she would have ranked the items higher if she..."had not just received a considerable amount of teaching by her enterostomal nurse" (verbal communication with investigator). The participant who responded with the highest score (194) was a man recalling the experience. The spouses who recalled their concerns recorded the highest mean ranking of the items (test 1: \bar{X} =136 s.d.=34.83 and test 2: \bar{X} =148 s.d.=19.64). The range of responses obtained at test time 1 and 2 are listed in Table 2 by subgroup (i.e., clients, spouses, current and recall). Using star plots, Figures 3 and 4 illustrate the item rankings for the entire group at time 1 and 2.

Table 2. Mean, Standard Deviations and Ranges of Responses to OC Scale by Subgroup at times 1 and 2.

SUBGROUP	Time 1			Time 2		
	\bar{X}	(Range)	s.d.	\bar{X}	(Range)	s.d.
CURRENT CLIENT	119	(57-165)	37.0	121	(59-159)	34.1
RECALL CLIENT	137	(91-191)	30.8	130	(90-156)	26.6
CURRENT SPOUSE	121	(77-167)	32.3	120	(58-166)	39.3
RECALL SPOUSE	137	(56-176)	34.9	148	(116-170)	19.7

Figure 3. Star Plot - Concerns by Mean - Entire Group
(N=40) - Test 1

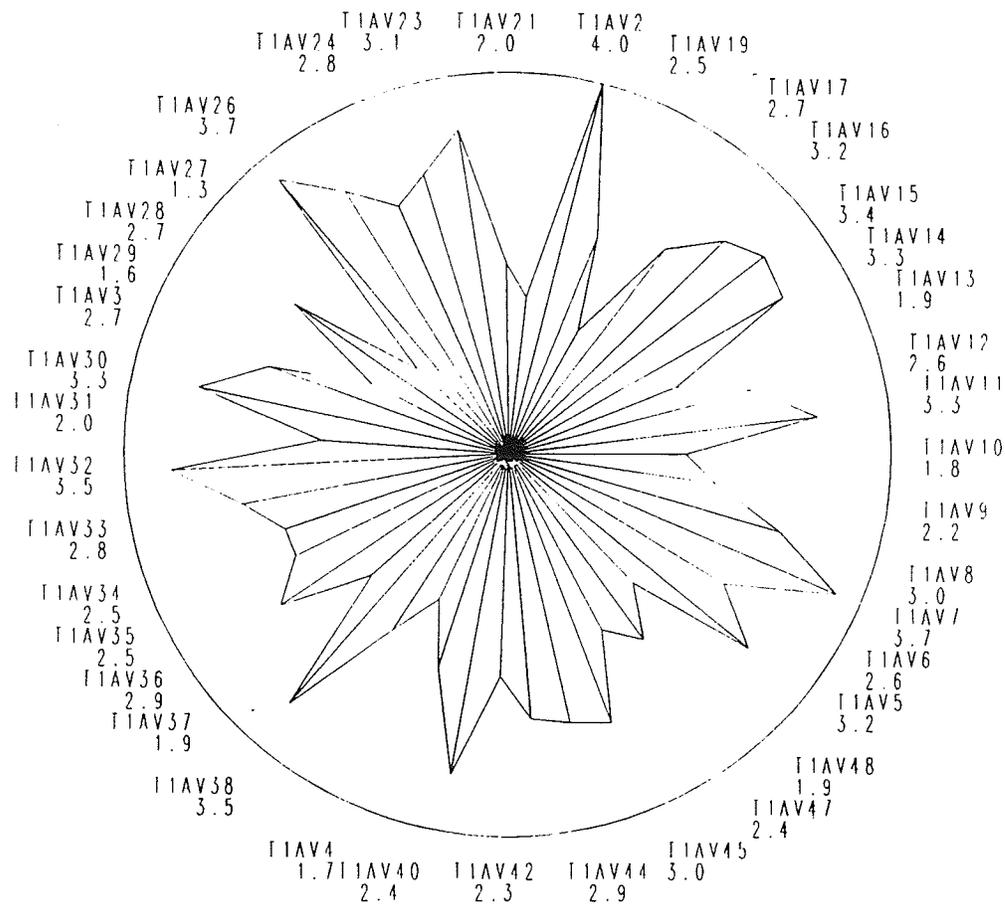
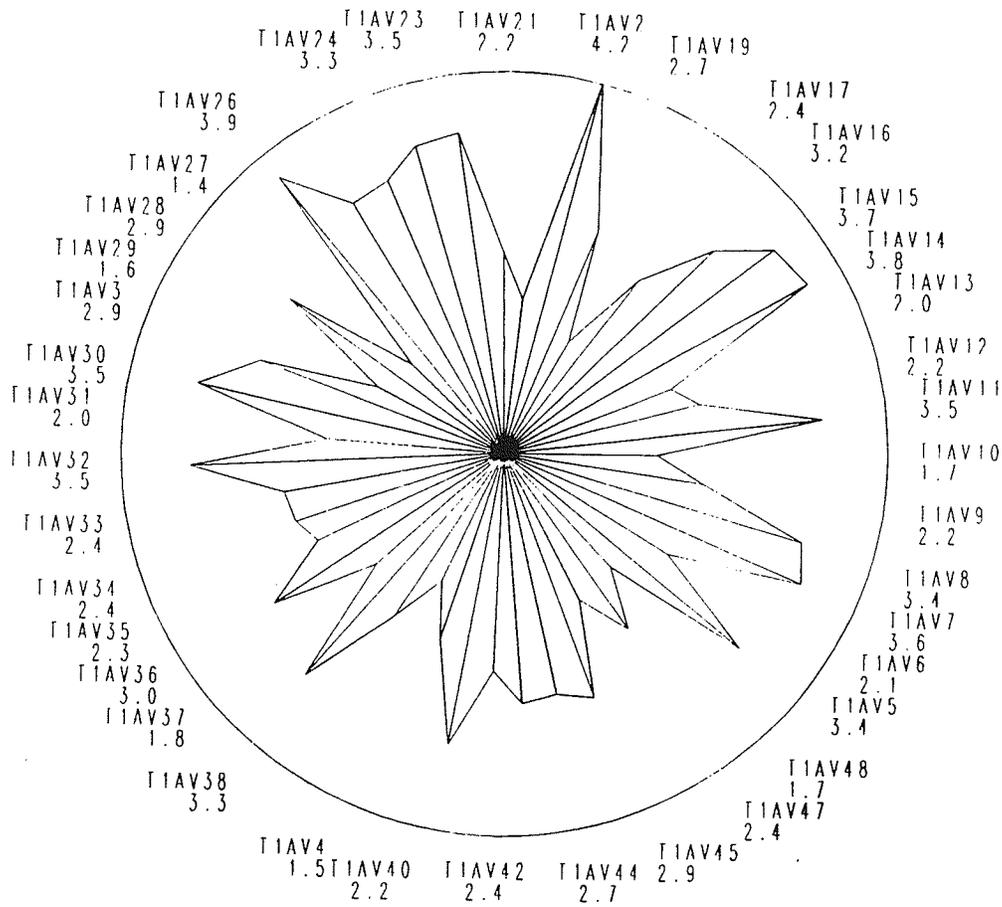


Figure 4. Star Plot - Concerns by Mean - Entire Group (N= 40) - Test 2



The responses are listed by mean in rank order in Table 3. All items received a range of responses from "one" (never important) to "five" (always important) with the exception of item 26. This item states... "Since my (spouse's) operation, I am concerned about fearing I will transfer the cancer to others". The highest ranking for this item was "three" (sometimes important). This item had zero variability in the reliability analysis. In view of these findings, it was therefore judged to be a poor item and was deleted from further analysis.

A response of "n/a" yielded a ranking of zero and therefore did not contribute to the overall score. The frequency for use of this response was one percent of all responses for the entire group (N=40).

The rankings of the concerns by all subgroups can be compared by reviewing Figures 5 to 8. In view of the overall similarity of the responses among subgroups, the data were then collapsed into two subgroups to check for differences between all of the clients in the sample responses versus those of all spouses. A Fisher's exact test was to have been used to test for differences in concerns between these subgroups; however, the identified concerns could not meaningfully be dichotomized into high and low categories because of the uniform distribution of the scores. A decision was then made to tabulate Wilcoxin scores to test for significant differences among the two subgroups.

Table 3. Rank Ordering of Concerns by Mean for Entire Group (N=40) From "Always Important" to "Never Important"

ITEM	X	(s.d.)	CONCERN
01	4.0	(1.5)	Being involved in learning about the stoma
25	3.7	(1.6)	Fearing the cancer may spread
06	3.7	(1.5)	Needing more information
29	3.3	(1.8)	Having cancer
37	3.5	(1.6)	Needing to have further treatments
14	3.4	(1.6)	Dealing with pain
21	3.4	(1.6)	Believing the pouch will stick without leaking
31	3.5	(1.5)	Learning how to care for the stoma
40	3.4	(1.6)	Knowing about the sanitary aspects
04	3.2	(1.7)	Emptying and cleaning the pouch
10	3.3	(1.6)	Not understanding medical terms
13	3.3	(1.6)	Knowing how to offer encouragement
22	3.0	(1.9)	Fearing death
24	3.2	(1.7)	Having odor apparent
15	3.2	(1.6)	Wondering how it will affect my usual activities (sports, hobbies, etc.)
44	3.0	(1.8)	Wondering what I can eat
07	3.0	(1.7)	Looking at the stoma for the first time
43	2.9	(1.8)	Worrying about my spouse's reaction
35	2.9	(1.7)	Looking after myself in others' homes
08	2.2	(1.3)	Feeling alone
42	2.8	(1.7)	Having to change the pouch the first time
02	2.7	(1.7)	Touching the stoma
16	2.7	(1.7)	Wondering if I've been told the truth
23	2.8	(1.6)	Not feeling well enough to bother with the ostomy care
27	2.7	(1.7)	Being able to have a bath or shower
32	2.8	(1.5)	Having a tube in my nose
48	2.6	(1.6)	Wondering how I will cope in the days to come
05	2.6	(1.5)	Suffering by our family because of me
18	2.5	(1.6)	Trying to sleep while wearing a pouch
33	2.5	(1.6)	Having to take extra supplies when going out
34	2.5	(1.6)	Passing gas
11	2.6	(1.4)	Having to wear a pouch that's noticeable

Table 3. Rank Ordering of Concerns by Mean (continued)

ITEM	X	(s.d.)	CONCERN
41	2.3	(1.7)	Paying for the medical supplies
46	2.4	(1.6)	Worrying I should have gone to the doctor earlier
39	2.4	(1.4)	Accepting that it is a permanent change
38	2.2	(1.5)	Wondering about the stoma appearance
45	2.0	(1.5)	Not feeling like a whole person
20	2.0	(1.4)	Deciding who to tell
47	1.9	(1.5)	Knowing when and how to tell family members
30	2.0	(1.3)	Changing the appearance of my body
36	1.9	(1.3)	Keeping the surgery a secret
09	1.8	(1.3)	Worrying about my return to work
03	1.7	(1.3)	Being able to resume sex
12	1.9	(1.1)	Changing my wardrobe
19	1.7	(1.0)	Wondering how family members will accept the ostomy
28	1.6	(1.1)	Wondering if the pouch will interfere while having sex
17	1.5	(1.0)	Feeling embarrassed about the surgery
26	1.3	(.08)	Fearing I will transfer the cancer to others

Figure 5. Star Plot - Concerns by Mean - Clients
(N=20) - Test 1

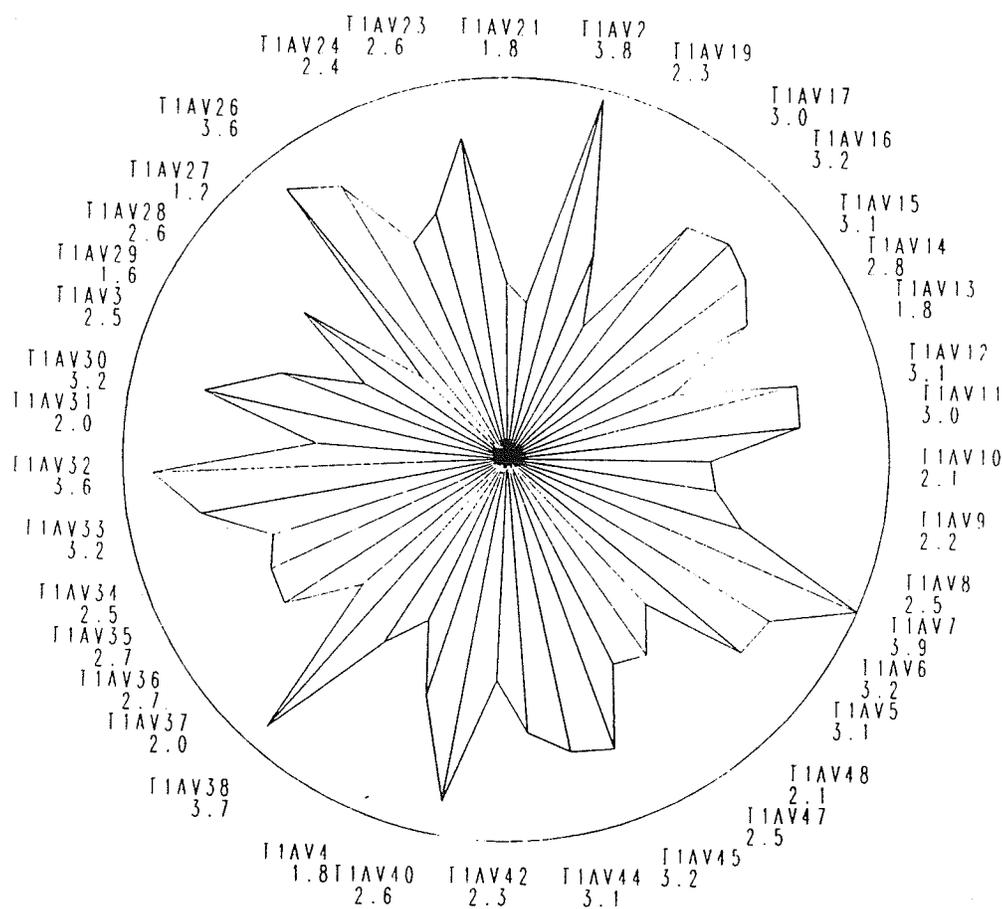


Figure 6. Star Plot- Concerns by Mean - Clients
(N= 20) - Test 2

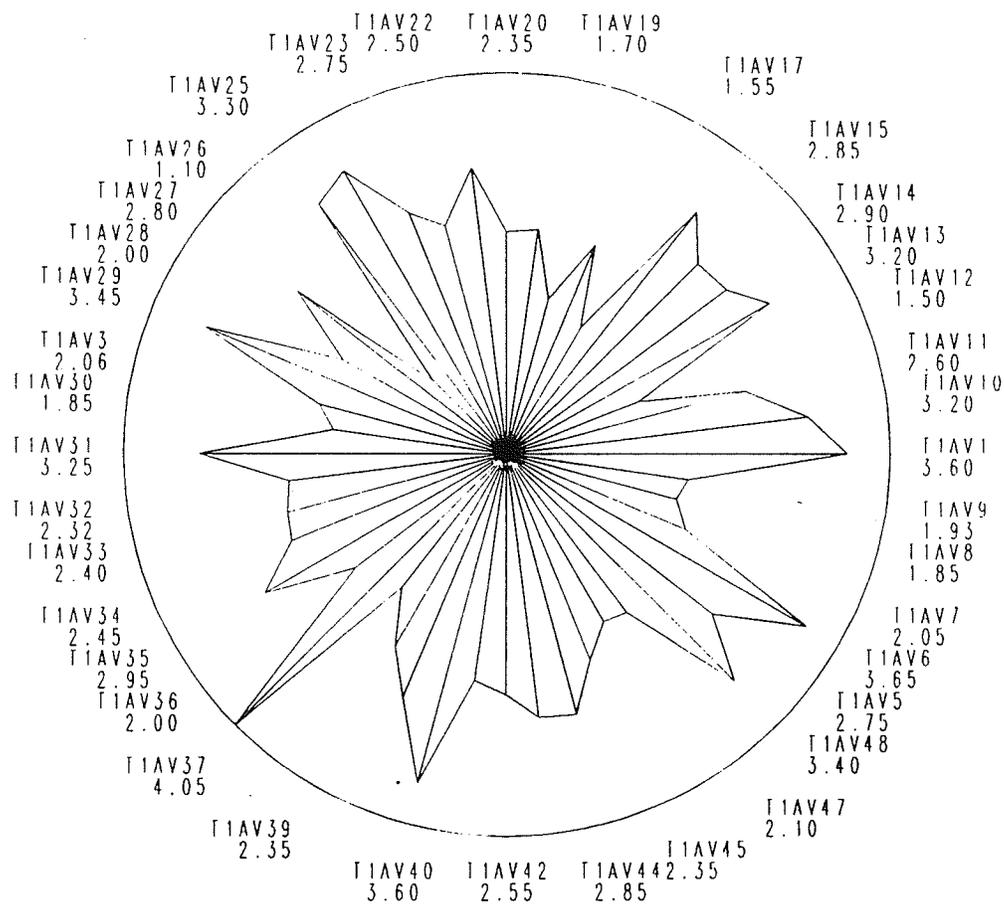


Figure 7. Star Plot - Concerns by Mean - Spouses -
(N=20) - Test 1

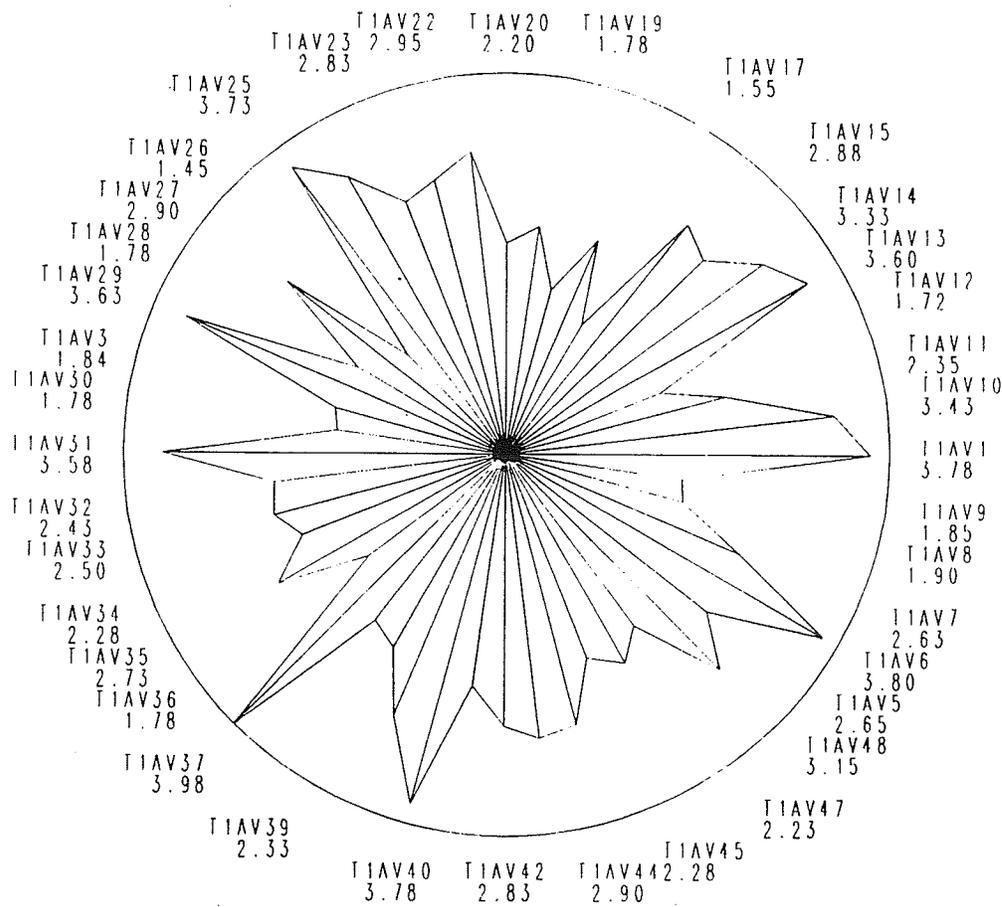
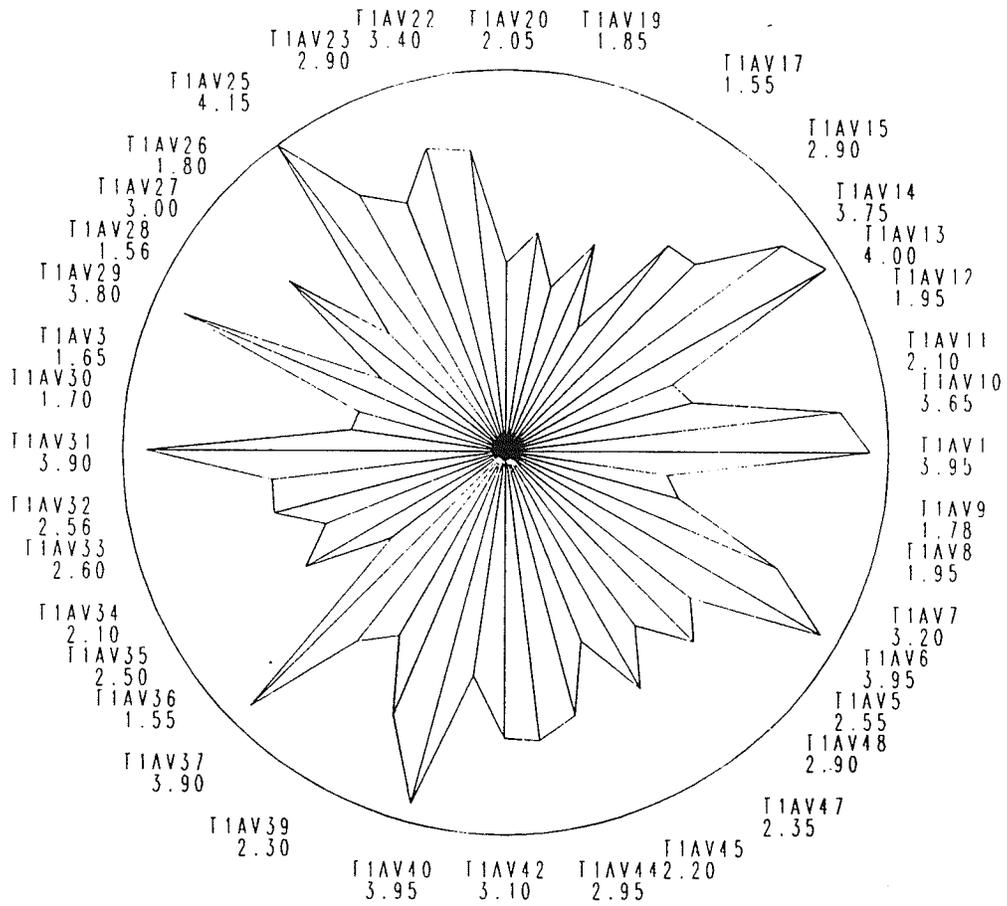


Figure 8. Star Plot - Concerns by Mean - Spouses - (N=20) - Test 2



No significant differences ($p < .05$) were detected between clients and spouses in terms of the ranking of their concerns during either test times 1 or 2.

Kendall's coefficient of concordance (W) results indicated significant agreement among all subgroups at the $p < .001$ level of significance (Table 4). The degree of concordance among respondents in each subgroup was low to moderate since the variance of the ranked sums ranged from thirteen to forty-three percent of the maximum possible ($p < .001$). Note that by its definition, W cannot be negative and its maximum value is one (Hayes, 1981).

Table 4. Kendall's Coefficients of Concordance (W) and Chi Square Values by Subgroup at time 1 and 2.

<u>SUBGROUP</u>	<u>Time 1</u>		<u>Time 2</u>	
	W	Chi Square	W	Chi Square
CURRENT CLIENT (N=11)	.13	65.78	.17	86.02
RECALL CLIENT (N=9)	.23	95.22	.24	121.44
CURRENT SPOUSE (N=11)	.36	182.16	.30	124.20
RECALL SPOUSE (N=9)	.29	120.06	.43	178.02

(all significant at $p < .001$)

Stability Over Time

All participants completed the test-retest procedure allowing an approximate 24 hour interval (N=40). Test-retest reliability using the Spearman's correlation coefficient was .73. This value, although slightly lower than the preset criterion of .80 for acceptability, demonstrates the scale was able to elicit similar responses to scale items at times 1 and 2. In view of this finding subsequent data analysis was based on the findings of test time 1.

Internal Consistency Reliability

The OC Scale achieved an internal consistency estimate as measured by Cronbach's standardized alpha coefficient of .92 at both initial and retest times. Although this estimate was well beyond the preset criterion of greater than .70 for an immature scale (Nunnally, 1978), the results must be considered in view of the small sample size and relatively large number of scale items. The internal consistency estimates using Cronbach's standardized alpha coefficient for the subgroups ranged from .82 to .95 and are shown in Table 5.

Table 5. Cronbach's Standardized Alpha Coefficients for OC Scale by Subgroup

<u>SUBGROUP</u>	<u>Time 1</u>	<u>Time 2</u>
CURRENT CLIENT (N=11)	.92	.90
RECALL CLIENT (N=9)	.90	.85
CURRENT SPOUSE (N=11)	.92	.95
RECALL SPOUSE (N=9)	.93	.82

The mean inter-item correlation for the total scale was .19 (s.d.=.23) at time 1. The range of inter-item correlations was from -.47 to .82. Twenty-one items (45 percent) achieved an inter-item correlation between .30 and .70. In four instances, the inter-item correlations suggested slight redundancy among items (i.e., items 8 and 11 (.79), items 19 and 43 (.77), items 25 and 29 (.78) and items 29 and 37 (.83). All subgroups were examined in terms of inter-item correlations as well, and are shown in Table 6.

Table 6. Mean Inter-Item Correlations by Subgroup

<u>SUBGROUP</u>	<u>\bar{X}</u>	<u>(s.d.)</u>
CURRENT CLIENT (N=11)	.22	(.40)
RECALL CLIENT (N=9)	.24	(.46)
CURRENT SPOUSE (N=11)	.20	(.39)
RECALL SPOUSE (N=9)	.07	(.47)

The item-total correlations were examined to assess for redundancy and items with low item-total correlations. Twenty-eight items (60 percent) achieved an item-total value between .40 and .75 suggesting that they contributed to measurement of the construct and most reliably represented the concerns of this particular sample. Six items (12 percent) appeared notably different (i.e., items 3, 5, 9, 28, 36 and 41). These items achieved item-total correlations between .03 and .18. It would be premature to suggest, however, that items be deleted from the scale prior to further testing with a larger, representative sample.

Internal Validity Estimates

Given the reasonable reliability results supporting the internal consistency and stability of the instrument over time, cluster analysis was used to identify possible subdimensions of the concerns scale. The analysis, illustrated in Table 7, reveals two main clusters. The first contains twenty-six of the items, and the second cluster yields the remaining twenty-two items.

The initial cluster of twenty-six items included concerns which refer to aspects of cancer, family, rehabilitation, body image and informational needs. Of particular interest is the fact that all four of the disease related items (i.e., those that refer to having cancer, needing further treatments, worrying one should have gone to the doctor earlier and

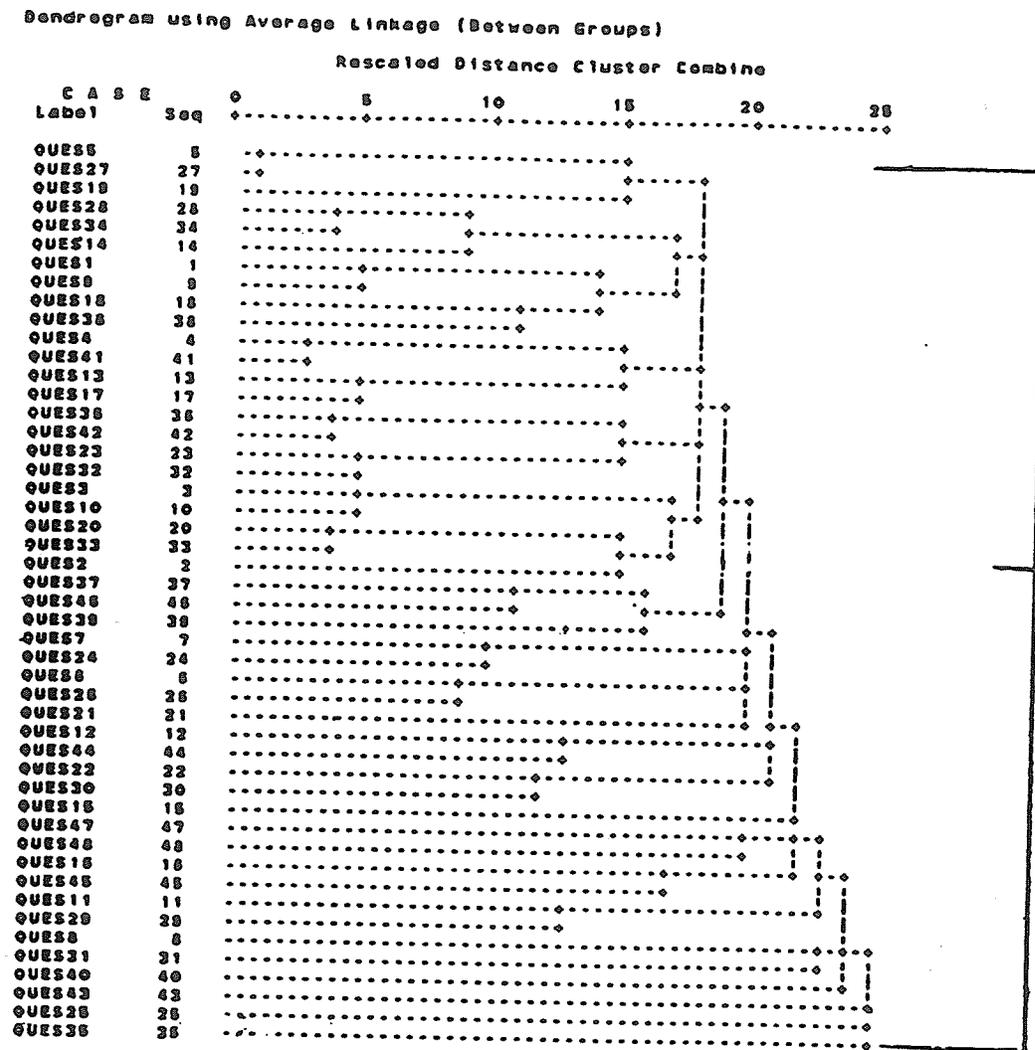
fearing death) are included within this cluster. These four items were consistently ranked by all subgroups as being of concern; the means ranged from $\bar{X}=3.7$ (1.6) to $\bar{X}=2.4$ (1.6). In fact, of the twenty-six items within this cluster, seventeen (60 percent) were ranked within the upper half of all concern items. All twenty-six items achieved item-total correlation values between .40 and .75 further suggesting they contributed to measurement of the construct. Items 35, 25 and 43 were the first three items to be separated from all other items. On further examination of the inter-item correlations it was revealed that these items correlated positively with all other items of the OC Scale (.01 - .73). Further, these items did not exhibit redundancy as evidenced by values yielded during the reliability analysis.

Further review of the concerns within this predominant cluster revealed common themes of personal threat, aloneness and uncertainty about self and one's future. A critical element in analyzing the content of the concerns that clustered together was the timing of data collection. Subjects were asked to identify the concerns they experienced within the first week of surgery. According to the conceptual framework that underpins this study, the immediate postoperative period often involves a response of shock and defensive retreat. Items related to feeling alone, having cancer, fearing the cancer may spread or fearing death all are characteristic of this phase of the experience. Referring

again to the work of Giacquinta (1977), five phases are encountered including impact, functional disruption, a search for meaning, informing others and engaging emotions. This continuum reflects the notion that in the immediate postoperative period an inward focus on oneself may need to be predominant before one is able to progress to aspects of concern involving contact with others or stoma management techniques. Therefore, this cluster was classified as "Internalization concerns related to the immediate postoperative period".

The second cluster of items included rehabilitative, postoperative, family and body image concerns. Many of the rehabilitative or adaptive items refer to the practical aspects of living with an ostomy. In particular, items 27, 34, 9, 41, 42, 32 and 33 are all items which pertain to practical aspects. Each of these items was ranked by the entire group as being of less concern; the means ranged from $\bar{X}=2.7$ (1.7) to $\bar{X}=1.8$ (1.3). Additionally, only item 42 from this group achieved an inter-item correlation between .30 and .70. Items 17 and 10 did not cluster meaningfully; one pertains to feeling embarrassed about the surgery and the other refers to not understanding medical terms. Item 17 ranked second lowest of all items in terms of concern ($\bar{X}=1.5$ (1.0)); item 10, however, ranked eleventh ($\bar{X}=3.2$ (1.7)).

Table 7. Cluster Analysis



Accordingly, concern about the latter concern, not understanding medical terms, seems more likely to be a priority issue earlier in the experience. Neither of these items achieved an inter-item correlation between .30 and .70. Item 19 is the sole item within this cluster that achieved an item-total correlation with the preset .40-.60 range of acceptibility. The remaining items in this cluster included concerns that refer to aspects of body image and resuming contact with family members; items that refer to subsequent aspects of the recovery phase. The conceptual framework includes an acknowledgement phase; a time when the client begins to accept the confrontation of reality. Following this stage is an adaptive phase in which the person moves on to a more realistic level of independence. This complete phase continues for up to twelve months following surgery. Thus it is believed that the second cluster may also be time-related in that the items of this grouping reflect the concerns of later phases of adjustment. The second cluster was therefore labelled, "Social re-entry concerns related to later phases of the postoperative period".

The cluster analysis therefore supports the results of the reliability estimates presented earlier suggesting two groups of items; those that may be more meaningful in testing the concerns during the immediate postoperative period and those concerns that may be more important during a social re-entry phase.

Summary

The results of the pilot testing procedures and subsequent testing of the OC Scale for reliability and validity were reported. The last chapter discusses the results in view of previous theoretical and empirical work with this population. Implications for nursing practise and future research are outlined.

CHAPTER V

DISCUSSION

Introduction

The purpose of the study was to assess the reliability and validity of an instrument, the OC Scale. This chapter discusses the results of the study and the value of completing this research in terms of the potential methodological, theoretical and clinical implications. Suggestions for further research and clinical practise are also presented.

Methodological Implications

The results of this study provide evidence for the internal consistency and stability of the scale over time. These results, however, must be viewed with caution because of the low sample size to scale item ratio. Additional testing with a larger sample is therefore required because all items require further analyses. Further, the nature of the study required the participation of couples. Consequently, the full sample could not be used for all analyses due to non-independence among observations. This is an additional consideration in determining future sample sizes. The limitation of memory for the subjects within the "recall"

subgroup is another consideration in terms of their ability to accurately recall the concerns they experienced as opposed to limiting the participants to a current group. Finally, empirical work to date has not specified criteria to determine "high" and "low" scores for the OC Scale. Further, the current investigation demonstrated homogeneity of the responses by subgroups in terms of concern rankings. It was therefore not possible to identify "high-risk" couples during this study. Subsequent testing is warranted to determine if the scale has this potential.

Gaps between nursing theory, research and practise are narrowed when the development of an instrument to measure clinical nursing phenomena in practise settings has qualitative beginnings and is tested with subsequent samples. Client assessments using reliable and valid measures are essential to nursing care.

Despite the above limitations it is important to note that the items of the OC Scale were developed and defined using a qualitative approach to guide the researcher in wording the scale items to retain the language and expression used by the target group. In this way, content validity of the scale items was built into the scale. As well, the scale items were further tested with a second sample to elicit meaningful priorities using a Q-sort methodology. Expert judgements were then obtained concerning the clarity, apparent

internal consistency and content validity using systematic pilot testing procedures (Imle & Atwood, 1988).

One aspect of the pilot testing procedures included the group's input into deciding the most meaningful response option descriptors. The outcome was to include adjectives that describe the frequency of concern. During subsequent testing a new alternative was suggested by one of the subjects. The suggestion was to maintain the descriptors of frequency (i.e., Never, Seldom, Occasionally, Frequently, Always), but eliminate the word "importance" and alter the scale's stem to read ... "Since my (spouses's) operation I am - _____ concerned about ...". This alternative warrants serious consideration during future testing efforts because it effectively places the adjectives describing frequency immediately prior to the term "concerned" within the stem. This option seems preferable and more specific to the intent of the scale.

In general, the tool proved easy to use and practical. Subjects had no difficulty marking their responses on the linear scale. Only two items yielded a response pattern of "not applicable" ("n/a") (i.e., one percent of all responses); those referring to concerns about resuming work and paying for medical supplies. This finding provides evidence for the appropriateness of OC Scale items. The fact that most of this client group are of retirement age and all are provided with their supplies on a no-direct charge basis explains the need

for the response of "n/a" for this sample. Future testing in alternate health care settings may result in different rankings of these concerns. An item judged to be a poor indicator was Item 26, ..."fear of transferring the cancer to others," because it was consistently ranked as the lowest priority concern and demonstrated zero variability.

A disadvantage of retaining all 48 items of the OC Scale is that a much larger sample size, and therefore more extensive time and costs are necessary, before confidence may be established for its use within a clinical arena. As well, the question of subject burden must be considered when a longer scale is used. Phase II demonstrated that each item was a priority concern for at least one subject, therefore a decision was made to retain all 48 items. However, Phase III results suggest that there may be groupings of items that represent subdimensions of concerns: internalization concerns related to the immediate postoperative period and social re-entry concerns related to later phases of the postoperative period. As well, some items appear to perform better than others, suggesting an abbreviated scale might be feasible. However, deletion of items would be premature based on this one sample. Therefore, it is necessary to use all scale items in additional testing before further refinements may be made.

The results of this initial testing indicate that subsequent testing efforts are worthy to pursue. Reliability estimates of the OC Scale are promising. The scale evidenced

a respectable test-retest reliability coefficient and estimates of internal consistency were well beyond the preset criterion for an immature scale. The outcomes of the current study contribute to empirical knowledge regarding initial instrument testing. To date, the Quality of Living Index (QLI) (Padilla & Grant, 1985) is the only instrument found in the literature that addresses the concerns of this target group. It has only been used with colostomy patients in the later stages of this experience. The OC Scale is intended for a wider range of surgical diversions and assesses concerns in the immediate postoperative period. Given the theoretical and empirical evidence suggesting that concerns may change over time, further validation of the OC Scale is warranted.

Theoretical Implications

The literature over the past four decades has consistently described a multitude of physical and psychological sequelae that must be considered in caring for these client couples. A crisis could be precipitated by either a diagnosis of cancer or the need for ostomy surgery. Cancer frequently connotes pain, disfigurement, debilitation and long term treatment. Ostomy surgery arouses fear, denial, grief, a sense of loss and the need to acquire technical skills. Lenneburg (1971) described the ostomate's needs as the 1) physical aspects (management, self care diet and skin care, 2) psychological aspects (emotional and social

adjustments), and 3) practical aspects (equipment and techniques). Hurny's (1985) subsequent work further supports these findings. The OC Scale encompasses a full range of concerns that pertain to these elements. The results demonstrated that the possible range of responses (48-240) was sufficiently large and sensitive enough to measure the actual range of concerns expressed (54-194).

Analysis of the data included the suggestion that the importance of various scale items may be time related; that concerns related to survival and uncertainty about oneself, for example, are likely to be experienced prior to concerns about stoma management techniques. As Imle & Atwood (1988, p.23) remind, the measures must be ... "sensitive to indices not only to the presence of the phenomenon but also to changes in its status".

Oberst and James (1985) reported similar findings based on their study involving 40 patients, newly diagnosed with bowel or genitourinary cancer and 40 respective spouses. One-half of the patients had a permanent ostomy as a result of the diagnosis. Content analysis of the interviews they conducted included the identification of major concerns. A process of impact and recovery that parallels the current findings was identified. The initial post-surgical concerns involved a process of internalization; existential concerns were also reflected. The authors reported that the majority of patients

and spouses still evidenced some degree of emotional distress at the time of discharge.

Similar to the findings of this study, the impact of the illness itself then became predominant; the primary concern voiced by both patients and spouses at the time of discharge and ten days after discharge was the "patient's health". Interestingly, by 30 days post-discharge the spouses' concerns shifted from the "patients' health" to "their own health".

Other findings, reported by Oberst & James (1985) corroborated the results of this study. Work and financial concerns were also infrequently reported; similarly, concerns about religion or religious beliefs were not identified by the participants. Concerns about family were an issue for 20 percent of the patients; concerns were more prevalent among the ostomy patients and reflected needs in terms of personal contact limitations imposed by the stoma. These concerns were more commonly expressed in the later stages of the adjustment period as were concerns about life-style disruption. During the first two months at home, the ostomy patients experimented with stoma management techniques. Uncertainty about being able to master the stoma continued to be reported during this time. Oberst & James (1985) observed that only one patient had persistent feelings of stigmatization and concern about how others would treat him if they knew about the surgery.

Of particular relevance to the findings from this study, is Oberst & James' (1985) comment regarding family members who

share the strain of the illness and face many of the same adaptive tasks as the client. They aptly point out that during a period of crisis the patient is in need of interaction and support from a person who is not in crisis; supportive care for both members of the couple is thus necessary. The degree of similarity between the findings of the two studies involving this population is confirming and indicates that subsequent research in this area is timely.

Clinical Implications

The future relevance of this research program for practise and further research is evident in a number of ways. First, the development and testing of a clinical assessment tool is a critical link in providing more appropriate and individualized care.

Previous studies have documented that couples face a wide array of fears and anxieties regarding role, body image and lifestyle changes (Craven & Sharp, 1972). The OC Scale may potentially assist in determining the priority concerns of couples in these situations. Use of this instrument could allow clients and spouses to participate more fully in their care.

Following testing to further establish the reliability and validity of the instrument, the tool may be used by nurses to elicit specific teaching directives and identify clients experiencing a high degree of concern. Identification of

priority concerns can direct care strategically. The benefits of such intervention have been documented. Watson (1983), for example, has demonstrated that postoperative, cancer patients with ostomies, who received counselling during the postoperative period, demonstrated significant positive alterations in self concept and esteem. In "high-risk" situations, use of the instrument may also lead to more appropriate referrals to consultants. The delineation of "high-risk" client couples is becoming more pressing from an administrative standpoint in terms of justifying costs of more expensive personnel. Ultimately, it may even be possible to use the instrument to document effectiveness of reducing concerns and therefore prompting adaptation following surgery. Valid and reliable quantitative means of acquiring this information to evaluate intervention is long overdue.

Both the results of this study and Phase II emphasize the priority concerns of subjects to be disease-related, rather than ostomy-related. This was also reported in the study by Dlin and Perlman (1969) who found that before surgery and in the early post surgical period, the primary concern of the patient is survival and success of the surgery. Oberst (1983), on the other hand, concluded that prior to discharge and for the first sixty days, ostomy patients focused almost exclusively on the stoma and its management. The psychological reaction to the cancer and the possible threat to life did not surface until approximately two months post

surgery. The spouses of these patients experienced even more distress and anxiety than the patients. The results of these studies further indicate the need to repeat the inquiry with a larger sample size and to note the priorities that are identified by either member of the couple during the experience.

Nursing practise must therefore continue to encourage expression of disease-related concerns and offer measures that foster hope (Freidenburgs et al, 1980; Giacquinta, 1977; Krumm, 1982; Sarles, 1980; Welch, 1981). Further research is needed to determine how priority concerns may change over time for either member of the couple. This information would allow the health care system to respond to concerns of these couples over time rather than assuming that all needs can be met in the immediate postoperative phase.

The results from Phases II and III yielded lower rankings of sexual concerns than might have been anticipated from the empirical and clinical literature on this topic. However, Padilla & Grant (1983) also found that for cancer patients the most frequently omitted response concerned sexual satisfaction.

Oberst & James (1985) reported that the ostomy patients and spouses in their study had problems that centered on sexual identity and sexual competence. However, they further speculated that..."given everything else that was going on in their lives, distress in this area was probably more prevalent

than either patients or spouses felt comfortable in reporting" (p.54). Given these inconsistent findings the following should be considered when conducting future research:

- 1) To what extent does the research method effect responses about items pertaining to sexual concerns? What form of data collection is most appropriate in eliciting these concerns? (e.g., interview, self report instruments, having couples participate together or individually)
- 2) To what extent does a social desirability effect influence low responses to this item?
- 3) How does the timing of data collection in terms of the adjustment period influence the identification of priority concerns?

More research must be pursued that addresses this particular area of concern, especially to guide interventions about the timing of these concerns within the overall experience.

Suggestions for Future Research

Phase III represents progress within a course of programmatic research. Suggestions are outlined for future methodological, theoretical and clinical research.

Methodological Research

1. Reliability estimates were problematic in the current study due to low subject to item ratio; future investigations must plan for a more representative sample size because all scale items are to be retained.
2. Further assessment of the OC Scale over time is required to enable factor analysis. This may determine the extent of subdimensions and support for their interdependence within the construct of ostomy concerns. Further testing may also contribute to a more complete interpretation in terms of the extent of clustering within the time frames suggested by the conceptual framework.
3. Other sampling issues that must be addressed in future include non-independence of the observations and the limitation of memory if a recall subgroup is to be used. The full potential sample could not be used in the analyses since the nature of the study involves comparisons among couples. The use of a recall subgroup was necessary in the current study due to time constraints, however it would be preferable in future to limit the sample to subjects currently undergoing the experience to most accurately reflect the realities at the time. A multi-site study may need to be planned to obtain a representative sample (e.g., 10 subjects per scale item, Kerlinger, 1986).
4. Consideration should also be given in future to the changes suggested for the response option descriptors. The use of

adjectives describing frequency placed immediately prior to the construct concern seems more appropriate in view of the scale's purpose. A pilot test to test the above suggestion would be useful.

5. As noted earlier, further study is required with consideration to method, social response effect and timing of data collection to monitor the frequency and occurrence of sexual concerns and to determine how best to measure these needs.

6. Comparisons could be completed regarding a nurse's assessment of "high-risk couples/individuals" versus self reported scores. Criterion validity may be assessed by this type of testing.

7. Concurrent validity may be assessed in future by means of conducting interviews in conjunction with the use of the OC Scale. Priority concerns identified by the OC Scale could be compared with those identified during qualitative interviews.

8. The effect of the patient/spouse completing the OC Scale together versus separately must be assessed because this data collection protocol may influence findings.

Theoretical Research

1. Once measurement issues are resolved, future research to explore how the construct of concern changes over time would be useful (e.g., same couple tested at 6 days, 6 weeks and 6 months post surgery).

2. Following further reliability and validity testing of the OC Scale, future research may include comparisons regarding priority concerns across geographic locations and various health care systems.
3. Research to further compare the extent of agreement between clients and spouses ostomy concerns.
4. To date, the OC Scale has been tested with patients and spouses. It is postulated that patients who do not have a spouse would also be able to respond to the OC Scale in a meaningful way. This theoretical stance requires testing.

Clinical Research

1. Future use of the scale may be helpful in documenting the effects of ET Nurse intervention in decreasing concerns.
2. Further understanding about how concerns may change within the immediate postoperative period for the same individual/spouse would be useful in adjusting care priorities.

Conclusions

The OC Scale was developed to quantitatively assess the concerns experienced by clients who have undergone ostomy surgery due to cancer and to compare the concerns experienced by spouses. The instrument is intended to

assist in care planning and ultimately to promote adaptive responses. The qualitatively generated items of the first two phases have provided a firm foundation for programmatic research. This third phase has contributed to the strategic testing and further scrutiny of the items. To further examine and refine the tool, additional studies in diverse settings are needed. Subsequent testing must be completed before the scale can be used with confidence in clinical practise.

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Appendix I - Summary of Crisis Theory*

- during his/her lifespan, an individual will encounter many situations that have the potential for upsetting his steady state

- such situations are known as hazardous events and are divided into two categories:

1) normative or developmental - incorporates Erikson's (1950) work regarding stages and developmental tasks; examples include birth, school entry and marriage

2) situational - accidental events; examples include loss or change in jobs, loss of significant other, illness

- these deviations in the steady state are thought to arise from the individual, the environment or both

Stage I

- for an event to have potential for crisis, the individual must perceive the change in his/her steady state to be a problem which results in heightened tension and evokes known problem-solving behaviours

- if these behaviours are adequate, no crisis develops and the individual returns to a state of equilibrium

Stage II

- if usual problem-solving behaviours are inadequate, he/she moves into a state of crisis

- the development of a crisis is dependent upon the individual's unique reaction to the event and not the event itself (or the perception of someone else)

- there is a further rise in tension, feelings of helplessness, ineffectuality, anxiety, fear and shame

- at this stage, the individual is amenable to intervention; in fact, may often solicit help from others

- Caplan (1964) stressed, that at this point, it is the quality of the intervention that determines a positive or negative outcome of the crisis, as compared to the nature of the hazard or the past experience of the individual

Appendix I - Summary of Crisis Theory (continued)

Stage III

- if resolution is successful, the individual learns new problem-solving behaviours and returns to a steady state that is at a higher level of functioning than that which he experienced before the crisis occurred
- it is the potential for growth that crisis theorists claim is one of the major factors that serve to distinguish crisis from stress; a second factor is that crisis is time limited
- there is general agreement that a state of crisis will most likely be resolved in one way or another within a six week period
- resolution may also result without a growth producing quality; this may be referred to as an unhealthy adjustment, lowering the level of an individual's functioning
- in extreme cases when no resolution can occur, tension mounts to a breaking point and major disorganization of the individual occurs

*Adapted from:

Parad and Caplan (1965), Infante (1982) and Murphy and Fawcett (1983)2

Appendix II - Summary of Crisis Theory Conceptual Framework

- includes aspects of crisis theory extended to the biophysical realm

- there are four concepts explicated in the framework:

- 1) Person - is described as an ..."integrated, biological, psychological, social and cultural being (who)...is viewed as an open system that can live in a state of dynamic equilibrium through constant adaptation to the environment" (Murphy and Fawcett, 1983, p.56).

- a person encounters developmental or situational hazards throughout life that have been further classified into the following seven major categories: loss of relationship; loss of mobility; loss of patency; loss of regulation; loss of protective mechanisms; loss of sensory-motor exchange; and loss of reproductive adequacy

- each person has evolving coping mechanisms that facilitate the ability to deal with hazardous events

- these ideas can be extended to the family and the community

- 2) Environment - is identified as everything outside the person inclusive of other people, organizations and physical objects

- the environment contains the necessary resources to augment the person's innate coping mechanisms; it also contains many hazardous events

- 3) Health - is viewed as a continuum from high-level wellness to illness (Dunn, 1982)

- a person may also be assessed when they are in a state of equilibrium (therefore application of the nursing process may commence prior to an actual crisis event)

- a person moves away from high-level wellness when their usual coping mechanisms are insufficient to overcome the threat

- precise placement on the continuum is based on the person's perception of the event, adequacy of coping mechanisms, available resources and the person's ability to use the resources

Appendix II - Summary of Crisis Theory Conceptual Framework
(continued)

- a state of illness does not constitute crisis; rather unsuccessful resolution constitutes a seriously ill state
- a person is more susceptible to intervention during a crisis period
- if intervention is effective, the crisis is resolved and high-level wellness is regained

4) Nursing - the primary goal of nursing is to foster high-level wellness:

Stage I - Pre-crisis - the goals are health promotion and disease prevention by enhancing equilibrium between the person and the environment

Stage II - Crisis - the goal is amelioration or cure by focusing on mobilization of internal and external resources

Stage III - Post-crisis - the goal is rehabilitation, maintenance and/or support by inclusion of measures to reverse or lessen effects of maladaptation

* Adapted from:

Murphy and Fawcett, 1983

* Framework developed by the Faculty of the University of Connecticut School of Nursing

Appendix III

DEFINITIONS

- Concern** - subject of importance in relation to ostomy surgery for cancer that causes the individual or spouse interest or anxiety
- Client** - an individual who has had ostomy surgery for cancer
- Spouse** - husband or wife of the client
- Ostomy Surgery** - surgically created opening on the abdomen for the elimination of body wastes

Appendix IV

Pilot Testing

Introduction to the Study

I am conducting a nursing research study titled "Development and Testing of the Ostomy Concern (OC) Scale" for my Master of Nursing thesis. The (OC) Scale is intended for use in future by patients to determine priority teaching needs. Your participation in the study would be helpful in making the questionnaire clear and relevant. I would like to know if you and your spouse would be willing to participate in the pilot test.

Participation would involve answering one verbal question and the completion of three written questionnaires about the OC Scale. The scale's items are concerns that have been reported during earlier study phases by either a patient who has had ostomy surgery for cancer or his/her spouse. You would also be asked to list any other concerns not identified in the questionnaire. Your spouse would be asked to answer the question and to complete the same questionnaires separately to provide an opportunity to each identify individual concerns. It is expected to take about one hour to complete all aspects of the pilot test.

Your participation is voluntary and will in no way interfere with the care you (your spouse) receive(s). You may withdraw from the study at any time by simply telling the investigator you choose to do so. Your refusal to participate will in no way affect you (your spouse's) treatment. The information obtained from you (your spouse) will be strictly confidential because your name will not be associated with the information you provide. Any information provided during the study will be for the sole purpose of testing the OC scale and the results of the study will be presented in a manner that no one individual response could be identified.

Do you have any questions about the study or about your participation in the study? If you are interested in participating in the study and meet the selection criteria, please remain following this meeting.

Principal Investigator:

Thesis Chairperson:

Appendix V

Pilot Testing Disclaimer

Development and Testing of the Ostomy Concern Scale

A nursing research study titled "Development and Testing of the Ostomy Concern (OC) Scale" is being conducted by an enterostomal nurse, _____, for her Master of Nursing thesis. The OC Scale is intended for use in future by patients and spouses to determine priority teaching needs.

Participation in pilot testing will involve answering one verbal question and the completion of three written questionnaires about the OC Scale. Each item of the OC Scale is a concern that has been reported during earlier study phases by either a patient who has had ostomy surgery or his/her spouse. By participating in the rating procedures you will be giving your consent to participate in the study. It is expected to take approximately one hour to complete all aspects of the pilot test. The only known risks are the time required to complete the questionnaires and the possibility of feeling discomfort about sharing details with the investigator about the concerns you may have experienced.

Your spouse will be asked to separately complete the same questionnaires on an individual basis and to answer the one verbal question. Your participation is voluntary and you may withdraw from the study at any time by simply telling the investigator. Your refusal to participate will in no way affect your (your spouse's) care or treatment. The information will be strictly confidential because no identification will be associated with the information you provide. Any information provided during the study will be for the sole purpose of testing the OC Scale. The results of the study will be presented in a manner that no one individual response could be identified.

Principal Investigator:

Thesis Chairperson:

Appendix VI

Response Option Descriptors

"In your opinion, in order to answer the questions about the concerns on this scale, should the response choices be worded according to the amount or degree of concern? To help me decide this please indicate which of the following choices you think would be the best descriptors:

1) describing the degree of the concern, e.g.,

Very Unimportant	Unimportant	Important	Fairly Important	Very Important
1	2	3	4	5

OR 2) describing the frequency of the concern, or how often the concern might be experienced? e.g.,

Never Important	Seldom Important	Occassionally Important	Frequently Important	Always Important
1	2	3	4	5"

OR 3) is there an alternate way of responding to these questions that might be more meaningful to you?"

Appendix VIII

CLARITY

Instructions:

This questionnaire is based on concerns reported by clients and their spouses regarding ostomy surgery for cancer. You are being asked to rate the overall questionnaire on its clarity since you are familiar with this content.

- (a) Read each concern on the **scale** as you answer the question on the **response sheet**. Beside each item number on the **response sheet** circle **C** (clear) or **U** (unclear) to indicate whether the item is clear to you.
- (b) Write any comments in the space provided below each response.
- (c) After you finish you may discuss your comments individually with the researcher.

Thank you for your assistance.

LIST OF ITEMS
CLARITY

RESPONSE SHEET:

Since my operation, I am concerned about...

1. wanting to be involved in the learning about the stoma.	C	U
--	---	---

Comments _____

2. touching the stoma.	C	U
------------------------	---	---

Comments _____

3. needing more information.	C	U
------------------------------	---	---

Comments _____

Appendix IX

APPARENT INTERNAL CONSISTENCY

Instructions:

In this section, you are being asked to look at the items of the scale and decide if you think they seem to belong together. You will be given several sets to rate, but only one list at a time.

With each list of scale items is a response sheet with questions on it for your answers about the set of items. Read the entire set of items on the list first. After you finish reading the entire set of items, answer question (A) at the top of the response sheet. Then answer question (B) for each item in the set. Answer by circling the response you choose under question (B). Add any comments you want to explain your answers.

Thank you for your assistance.

LIST OF ITEMS

Since my operation, I am concerned about...

1. touching the stoma
2. looking at the stoma for the first time.
3. the stoma appearance

RESPONSE SHEET:CONSISTENCY

A. Do these items generally belong together?

Y N

B. Does each item belong in the set?

	Circle one	Comments
1.	Y N	_____
2.	Y N	_____
3.	Y N	_____

Appendix X

CONTENT VALIDITY

Instructions:

In this section, you are asked to look at the items of the scale and tell if they seem to measure various aspects of adaptation to having an ostomy following surgery due to cancer.

You will be given a list of items. Attached to the list is a response sheet with a label and definition. Four questions will be asked about each item. The four questions are:

- (a) In **general**, does the label and definition fit the whole set of items?
- (b) Does each item belong to the label and definition?

Please answer **Y** (Yes) or **N** (No) next to each item number on the **response sheet**.

- (c) Save this question until you finish (A) and (B). Is each item unique (ie. not repetitious)? Answer **Y** (Yes) or **N** (No) next to each item number on the **response sheet**.
- (d) Are there concerns left off the list you think should be there?

e.g.

LIST OF ITEMS

Since my operation, I am concerned about...

1. touching the stoma
2. looking at the stoma the first time
3. the stoma appearance

Appendix X (Continued)

e.g. RESPONSE SHEET: CONTENT VALIDITY

Label: Ostomy Concern Scale

Definition: Instrument intended to measure the degree of concern experienced by persons who have required ostomy surgery due to cancer and the concerns experienced by their spouses.

- a) In general, does the label and definition fit the whole set of items? Answer once for entire set by circling Y for Yes or N for No.

Y

N

- b) Does each item fit the label and definition?

Circle one

Comments

1. Y N

2. Y N

3. Y N

- c) Is the item unique (not repetitious) ?

Circle one

Comments

1. Y N

2. Y N

3. Y N

- d) Is there anything left off the list that you think should be there?

THANK YOU FOR YOUR PARTICIPATION

Appendix XI

Request for Access to an Institution

School of Nursing
University of Manitoba
Winnipeg, Manitoba

Dear _____ :

I have developed a research study entitled "Development and Testing of the Ostomy Concern (OC) Scale" as the project for my Masters of Nursing thesis. The OC Scale is intended for use in future by patients and spouses to determine priority teaching needs. The testing phase is the third phase of the investigation based on the qualitatively generated items of the first two phases, the results of which have already been forwarded to you. The first two phases were conducted as an Enterostomal Nurse with the Manitoba Ostomate Program. The purpose of this letter is to request access to hospitalized patients to gather data for the third phase of this investigation. The focus of the current study is to assess the instrument for internal consistency and stability of the instrument over time.

The enterostomal nurse responsible for care within your facility, _____ R.N., has agreed to identify potential subjects for this study based on the following selection criteria: 1) postoperative ostomy patient or spouse (surgery completed at least one week prior), 2) surgery required due to a diagnosis of cancer known to each member of the couple, 3) able to read and understand English, and 4) geographically accessible for contact. The enterostomal nurse would give potential subjects a copy of the study introduction that I have prepared (see attached). I will then contact those couples who report to the enterostomal nurse that their names may be referred to me to determine if they are interested in participating in the study. Participation in the this study would involve ostomy patients and their spouses each completing one instrument, the 48-item Likert-type format OC Scale. The instrument would be completed again by each participant approximatey 24 hours later for comparative purposes. The scale is to be completed by each member of the couple separately to provide the opportunity to each identify individual concerns. The investigator may administer the scale in the home of the spouse if preferred by the latter. It is expected to take approximately 30 minutes to complete the scale each time.

Participation in the study is voluntary and subjects may withdraw from the study at any time by simply telling the investigator. Refusal to participate will in no way

Appendix XI (continued)

affect the care received. Information yielded by the study will be associated with the identification of the subjects by numerical code only. Any information provided during the study will be for the sole purpose of testing the OC Scale. Study results will be presented in a manner that no one individual response would be identified.

This study has been submitted for approval by the Ethics Review Committee, School of Nursing, University of Manitoba and is under the direction of my advisor _____, University of Manitoba, School of Nursing. I look forward to hearing from you in this regard.

Yours sincerely,

Appendix XII

Subsequent Testing - Introduction to the Study

Dear patient and spouse:

My name is _____. I am an enterostomal nurse who is conducting a nursing research study titled "Development and Testing of the Ostomy Concern (OC) Scale" which is being conducted for my Master of Nursing thesis. The (OC) Scale is intended for use in future by patients to determine priority teaching needs. Your participation in the study would be helpful in testing its relevance. I would like to know if you and your spouse would be willing to have your names given to me as individuals who might be interested in participating in the study.

Participation would involve completing a questionnaire, the Ostomy Concern Scale. The items of the OC Scale are concerns that have been reported during earlier study phases by either a patient who has had ostomy surgery for cancer or his/her spouse. You would be asked to indicate on a scale how much of a concern that particular item is to you at the present time. You would also be asked to list any other concerns not identified in the questionnaire. To see if your concerns change over time, you would be asked to complete the same questionnaire approximately 24 hours later. Your spouse would be asked to complete the same questionnaire separately to provide an opportunity to each identify individual concerns. It is expected to take about 30 minutes to complete each of the questionnaires.

Your participation is voluntary and will in no way interfere with the care you (your spouse) receive(s). You may withdraw from the study at any time by simply telling the investigator you choose to do so. Your refusal to participate will in no way affect you (your spouse's) treatment. The information obtained from you (your spouse) will be strictly confidential because your name will not be associated with the information you provide. Any information provided during the study will be for the sole purpose of testing the OC scale and the results of the study will be presented in a manner that no one individual response could be identified.

If you are interested in participating in the study please let your E.T. know that it is acceptable to you to have your names provided to me. I can then contact you while in hospital to review the purpose of the study and to answer any questions you may have about the study or your participation.

Principal Investigator:

Thesis Chairperson:

Appendix XIII

Subsequent Testing Disclaimer

Development and Testing of the Ostomy Concern Scale

A nursing research study titled "Development and Testing of the Ostomy Concern (OC) Scale" is being conducted by an enterostomal nurse, _____, for her Master of Nursing thesis. The OC Scale is intended for use in future by patients and spouses to determine priority teaching needs.

Participation in the study will involve completing a questionnaire, the Ostomy Concern Scale. Each item of the OC Scale is a concern that has been reported during earlier study phases by either a patient who has had ostomy surgery or his/her spouse. By indicating on a scale how much of a concern a particular item is to you at the present time and to list any concerns not identified on the questionnaire based on your experience, you are giving consent to participate in the study. You will be asked to complete the same questionnaire approximately 24 hours later. It is expected to take approximately 30 minutes to complete each of the scales. The only known risks are the time required to complete the questionnaires and the possibility of feeling discomfort about sharing details about the concerns you may be experiencing at the present time.

Your spouse will be asked to separately complete the same questionnaires on an individual basis. Your participation is voluntary and you may withdraw from the study at any time by simply telling the investigator. Your refusal to participate will in no way affect your (your spouse's) care or treatment. The information will be strictly confidential because no identification will be associated with the information you provide. Any information provided during the study will be for the sole purpose of testing the OC Scale. The results of the study will be presented in a manner that no one individual response could be identified.

Principal Investigator:

Thesis Chairperson:

Appendix XIV

OSTOMY CONCERN (OC) SCALE

This instrument was developed to assist in identifying specific areas of concern so that your nurse may assist in meeting your learning needs. The 48 concerns that are listed have been reported by patients and spouses who have had ostomy surgery due to cancer. Please read each concern and circle the number which best describes how important the concern is for you at the present time. Please note that some items have been especially worded for spouses.

e.g. odor 1 2 3 4 5
 never seldom sometimes frequently always
 important important important important important

If you feel that you are seldom concerned about odor, you would circle the number 2; or, if you are frequently concerned about odor you would circle the number 4.

If a concern is not applicable to you please write in "n/a" beside the numbers.

NEVER IMPORTANT	SELDOM IMPORTANT	SOMETIMES IMPORTANT	FREQUENTLY IMPORTANT	ALWAYS IMPORTANT
--------------------	---------------------	------------------------	-------------------------	---------------------

1	2	3	4	5
---	---	---	---	---

Since my (spouse's) operation, I am concerned about...

- | | | | | | |
|---|---|---|---|---|---|
| 1. being involved in learning about the stoma | 1 | 2 | 3 | 4 | 5 |
| 2. touching the stoma | 1 | 2 | 3 | 4 | 5 |
| 3. being able to resume sex | 1 | 2 | 3 | 4 | 5 |
| 4. emptying and cleaning the pouch | 1 | 2 | 3 | 4 | 5 |
| 5. suffering by our family because of me
(my spouse) | 1 | 2 | 3 | 4 | 5 |
| 6. needing more information | 1 | 2 | 3 | 4 | 5 |
| 7. looking at the stoma for the first time | 1 | 2 | 3 | 4 | 5 |
| 8. feeling alone | 1 | 2 | 3 | 4 | 5 |
| 9. worrying about my (spouse's) return to work | 1 | 2 | 3 | 4 | 5 |

NEVER IMPORTANT	SELDOM IMPORTANT	SOMETIMES IMPORTANT	FREQUENTLY IMPORTANT	ALWAYS IMPORTANT
1	2	3	4	5
Since my (spouse's) operation, I am concerned about...				
10. not understanding medical terms			1	2 3 4 5
11. (my spouse) having to wear a pouch that's noticeable			1	2 3 4 5
12. changes in my (spouse's) wardrobe			1	2 3 4 5
13. knowing how to offer encouragement			1	2 3 4 5
14. dealing with (my spouse's) pain			1	2 3 4 5
15. wondering how it will affect my (spouse's) usual activities, e.g. sports, hobbies			1	2 3 4 5
16. wondering if I've been told the truth			1	2 3 4 5
17. feeling embarrassed about the surgery			1	2 3 4 5
18. (my spouse) trying to sleep while wearing a pouch			1	2 3 4 5
19. wondering how family members will accept it			1	2 3 4 5
20. deciding who to tell			1	2 3 4 5
21. believing the pouch will stick without leaking			1	2 3 4 5
22. fearing (my spouse's) death			1	2 3 4 5
23. (my spouse) not feeling well enough to bother with the ostomy care			1	2 3 4 5
24. having odor apparent			1	2 3 4 5
25. fearing the cancer may spread			1	2 3 4 5
26. fearing I (my spouse) will transfer the cancer to others			1	2 3 4 5
27. (my spouse) being able to have a bath or shower			1	2 3 4 5
28. wondering if the pouch will interfere while having sex			1	2 3 4 5
29. (my spouse) having cancer			1	2 3 4 5

NEVER IMPORTANT	SELDOM IMPORTANT	SOMETIMES IMPORTANT	FREQUENTLY IMPORTANT	ALWAYS IMPORTANT	
1	2	3	4	5	
Since my (spouse's) operation, I am concerned about...					
30. changing the appearance of my (spouse's) body	1	2	3	4	5
31. learning how to care for the stoma	1	2	3	4	5
32. having a tube in my (spouse's) nose	1	2	3	4	5
33. having to take extra supplies when going out	1	2	3	4	5
34. (my spouse) passing gas	1	2	3	4	5
35. looking after myself (my spouse) in other peoples' homes	1	2	3	4	5
36. keeping the surgery a secret	1	2	3	4	5
37. (my spouse) needing to have further treatments	1	2	3	4	5
38. wondering about the stoma appearance	1	2	3	4	5
39. accepting that it is a permanent change	1	2	3	4	5
40. knowing about the sanitary aspects	1	2	3	4	5
41. paying for the medical supplies	1	2	3	4	5
42. having to change the pouch for the first time	1	2	3	4	5
43. worrying about my spouse's reaction to the surgery	1	2	3	4	5
44. wondering what I (my spouse) can eat	1	2	3	4	5
45. (my spouse) not feeling like a whole person	1	2	3	4	5
46. worrying I (my spouse) should have gone to the doctor earlier	1	2	3	4	5
47. knowing when and how to tell family members	1	2	3	4	5
48. wondering how I will cope in the days to come	1	2	3	4	5

Do you have any other concerns not listed above? If so please write them here:

THANK YOU FOR YOUR PARTICIPATION

Appendix XV
Demographic Sheet

DEVELOPMENT AND TESTING OF THE OSTOMY CONCERN SCALE

I.D. # _____

1. Knowledge of diagnosis _____

2. Ostomy Surgery: type _____

date ____/____/____

postop day _____

A. Patient

: age _____

: gender _____

: location code _____

B. Spouse : age _____

: gender _____

: location code _____