Social adjustment of persons with ileostomies or colostomies.

Janet Miller. Towell
University of Windsor
NOTICE

The quality of this microfiche is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us a poor photocopy.

Previously copyrighted materials (journal articles, published tests, etc.) are not filmed.

Reproduction in full or in part of this film is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30. Please read the authorization forms which accompany this thesis.

THIS DISSERTATION HAS BEEN MICROFILMED EXACTLY AS RECEIVED

AVIS

La qualité de cette microfiche dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de mauvaise qualité.

Les documents qui font déjà l'objet d'un droit d'auteur (articles de revue, examens publiés, etc.) ne sont pas microfilmés.

La reproduction, même partielle, de ce microfilm est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30. Veuillez prendre connaissance des formules d'autorisation qui accompagnent cette thèse.

LA THÈSE A ÉTÉ MICROFILMÉE TELLE QUE NOUS L'AVONS RÉCU
SOCIAL ADJUSTMENT OF PERSONS WITH
ILEOSTOMIES OR COLOSTOMIES

by

Janet Miller Towell

A Thesis
submitted to the Faculty of Graduate Studies
through the School of Social Work
in Partial Fulfillment
of the requirements for the Degree
of Master of Social Work at
The University of Windsor

Windsor, Ontario
1981
RESEARCH COMMITTEE

Professor Patricia Taylor, Chairperson

Dr. James Clarke, Member

Dr. Akira Kabasigawa, Member
ABSTRACT

This study was classified as a quantitative-descriptive type and had the following purposes: (1) To describe the characteristics and level of social adjustment of persons with stomas, (2) To identify relationships between levels of social adjustment and several independent variables, and (3) To consider the implications for social work counselling with the ostomy patient and his family.

The review of literature was presented on four primary life aspects of persons with ostomies: (1) Psychological adjustment to ostomy surgery, (2) Aspects in regard to the family of the person with an ostomy, (3) Sexual adjustment after ostomy surgery, and (4) Employment following ostomy surgery. This review was intended to serve as a basis for the development of the research methodology.

The research sample consisted of seventy males and females, over the age of seventeen, who had a permanent colostomy or ileostomy. Subjects were drawn by accidental sampling procedures, from the Hamilton and District branch of the United Ostomy Association. The Social Adjustment Scale-Self Report (SAS-SR) was incorporated into the questionnaire, and was the instrument of measure of levels of social adjustment. The usable return rate of the questionnaires was 51%.

Sub groups from within the sample were formed in
order to identify relationships between levels of social adjustment and the independent variables, age, gender and type of stoma. An existing community sample was designated to represent the norm, for purposes of comparison of life area role functioning and social adjustment of the 'normal' population, with the life area role functioning and social adjustment of persons with ileostomies and colostomies.

The following conclusions were drawn in this study:

(1) The modal subject of the sample group was retired, married, Protestant and of a middle class socioeconomic level.

(2) Marital status was not adversely affected by ostomy surgery.

(3) Males are at risk of sexual dysfunction following ostomy surgery, and that dysfunction is likely to involve erectile inability.

(4) Persons with an ostomy are likely to perceive their body in negative terms.

(5) The majority of persons with ostomies are likely to have received counselling in relation to their surgery, and that counselling is usually provided by a member of the U.O.A. or an enterostomal therapist. Few ostomy patients are counselled before surgery.

(6) Persons with ileostomies tend to demonstrate impaired social functioning in family and marital roles.

(7) Persons with colostomies tend to achieve high
levels of social-leisure role functioning, and overall social adjustment.

The following recommendations were made:

(1) A further study should be carried out, using larger and matched sample sizes, to examine the influence of relative youth and type of stoma on social adjustment of persons with an ostomy.

(2) The Hamilton Ostomy Association should examine its policies and activities, to determine if and why relatively young, non Protestants of lower socioeconomic levels are under represented in the association.

(3) Persons with ostomies should be referred to the Social Work Department of the hospital, before surgery if possible, and after surgery otherwise.
This research study is dedicated with love and affection, to my mother, Mrs. Pearl Miller, who funded the study, and to my children, Bonita, Robert and Gregory, who cheerfully endured the sacrifices required by their mother—the student, throughout this study, and for the last five years.
ACKNOWLEDGEMENTS

The researcher wishes to express her thanks to the members of the Research Committee: Professor Patricia Taylor and Doctor James Clarke of the School of Social Work, and to Doctor Akira Kobasigawa of the Department of Psychology.

A special thank you to a dedicated teacher, Professor Forrest Hansen, Co-ordinator of Research of the School of Social Work.

A very special thank you to A. Claude Campbell, President of the Hamilton and District Ostomy Association, for his approval of this research project and for his kind assistance.

Deepest gratitude is extended to the members of the Hamilton and District Ostomy Association for their time and trust in completing the questionnaires. Humble apologies and a warm thank you to the members, especially the children, whose responses could not be included in this study.

Sincere gratitude to Detroit Memorial Hospital, Detroit, Michigan, for their generosity in assuming the cost of several computer searches, and to Theresa Ocholik, Librarian at D.M.H., for her diligent assistance in the search for literature.
Thank you too, to Dr. Myrna Weissman, Yale University Medical School, for permission to use the SAS-SR-test.

Warm appreciation is expressed to Neil Harrington, B.C.S., and Robert Dunham, B. Comm., B.C.S., for their valuable assistance with the computer program and analysis. A sincere thank you to Karen Walp, for a prompt and well-typed manuscript.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>INTRODUCTION</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Identification of the Problem</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Statistics</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Etiology and Physiology of Ostomy Surgery</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Social Functioning and Social Adjustment</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Summary</td>
<td>12</td>
</tr>
<tr>
<td>II</td>
<td>REVIEW OF THE LITERATURE</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Literature Search</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Psychological Adjustment</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>The Family With An Ostomy</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Sexuality After Ostomy Surgery</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>Work Adjustment After Ostomy Surgery</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td>Summary</td>
<td>36</td>
</tr>
<tr>
<td>III</td>
<td>METHODOLOGY</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Purpose of the Study</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Classification of Study</td>
<td>39</td>
</tr>
<tr>
<td></td>
<td>Population</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td>Type of Sample</td>
<td>43</td>
</tr>
<tr>
<td></td>
<td>Location of Study: Hamilton, Ontario</td>
<td>44</td>
</tr>
<tr>
<td></td>
<td>Hamilton Ostomy Sample</td>
<td>46</td>
</tr>
<tr>
<td></td>
<td>Return Rate of Questionnaire</td>
<td>47</td>
</tr>
<tr>
<td></td>
<td>Comparative Sample</td>
<td>48</td>
</tr>
</tbody>
</table>

ABSTRACT ........................................................................ v

ACKNOWLEDGEMENTS .................................................. ix

LIST OF TABLES ......................................................... xiv

Chapter

I

INTRODUCTION ......................................................... 1

Identification of the Problem ...................................... 1

Statistics .................................................................. 3

Etiology and Physiology of Ostomy Surgery .................. 6

Social Functioning and Social Adjustment .................... 9

Summary .................................................................. 12

II

REVIEW OF THE LITERATURE ...................................... 13

Literature Search .................................................. 13

Psychological Adjustment ....................................... 15

The Family With An Ostomy ..................................... 21

Sexuality After Ostomy Surgery ............................... 25

Work Adjustment After Ostomy Surgery ...................... 32

Summary .................................................................. 36

III

METHODOLOGY ......................................................... 38

Purpose of the Study .............................................. 38

Classification of Study .......................................... 39

Population .......................................................... 41

Type of Sample .................................................... 43

Location of Study: Hamilton, Ontario ....................... 44

Hamilton Ostomy Sample ........................................ 46

Return Rate of Questionnaire .................................. 47

Comparative Sample ............................................... 48
DATA COLLECTION METHOD ........................................ 49
DATA COLLECTION INSTRUMENT .................................. 51
THE SOCIAL ADJUSTMENT SCALE:
SELF REPORT (SAS-SR) ............................................ 52
LIMITATION OF THE SAS-SR ..................................... 53
VALIDITY AND RELIABILITY OF THE SAS-SR .................... 54
LIMITATIONS OF THIS STUDY .................................... 54
DATA ANALYSIS ..................................................... 55
OPERATIONAL DEFINITIONS ....................................... 57
SUMMARY ........................................................... 61

IV
ANALYSIS OF DESCRIPTIVE DATA ................................. 62
Age of Subjects .................................................... 62
Sex of Subjects .................................................... 63
Marital Status ...................................................... 64
Change of Marital Status ........................................ 64
Type of Ostomy ..................................................... 65
Diagnosis That Lead To Ostomy
Surgery ............................................................. 65
Period of Time Passed Since Original
Stoma Surgery ..................................................... 66
State of Health as Stated by
Subject ............................................................. 68
Country of Birth .................................................... 68
Religion ............................................................. 69
Level of Education ............................................... 69
Present Employment Status ...................................... 69
Income ............................................................. 70
Sexual Problems ................................................. 72
Body Image ......................................................... 74
Counselling ........................................................ 79
Status of Counsellors ............................................. 84
Time Period of Counselling ..................................... 85
Topics Discussed During Counselling ......................... 87

V
ANALYSIS OF QUANTITATIVE DATA .............................. 97
Scoring of the SAS-SR Test ...................................... 98
Analysis of Computer Generated T-Test ....................... 99
Males Versus Females With Ostomies ......................... 100
Persons With Colostomies Versus
Persons With Ileostomies .......... 106
Implications of Age on Role
Functioning and Overall Social
Adjustment .......................... 108
Young Adults With Ostomies Versus
Middle Aged Adults With
Ostomies ............................ 109
Young Adults With Ostomies Versus
Retired Adults With Ostomies .... 114
Middle Aged Persons With Ostomies
Versus Retired Persons With
Ostomies ............................ 116
Persons With Ileostomies and
Persons With Colostomies Versus
A Comparative Group .............. 117
Summary ............................. 127

VI SUMMARY, CONCLUSIONS AND RECOMMENDATIONS .... 132
# LIST OF TABLES

<table>
<thead>
<tr>
<th>TABLE</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Age of Subjects</td>
</tr>
<tr>
<td>2</td>
<td>Change of Marital Status</td>
</tr>
<tr>
<td>3</td>
<td>Diagnosis That Led To Ostomy Surgery</td>
</tr>
<tr>
<td>4</td>
<td>Period of Time Passed Since Original Stoma Was Formed</td>
</tr>
<tr>
<td>5</td>
<td>State of Health as Stated by Subject</td>
</tr>
<tr>
<td>6</td>
<td>Country of Birth</td>
</tr>
<tr>
<td>7</td>
<td>Level of Education of Subjects</td>
</tr>
<tr>
<td>8</td>
<td>Present Employment Status</td>
</tr>
<tr>
<td>9</td>
<td>Income</td>
</tr>
<tr>
<td>10</td>
<td>Problems Experienced During Intercourse During the Two Week Period Prior to Answering Questionnaire</td>
</tr>
<tr>
<td>11</td>
<td>Body Image: Description of Stoma</td>
</tr>
<tr>
<td>12</td>
<td>Body Image: Feelings That Describe Subject's Body Since Having Ostomy Surgery</td>
</tr>
<tr>
<td>13</td>
<td>Status of Those Who Counselling Subjects</td>
</tr>
<tr>
<td>14</td>
<td>Time Period of Counselling</td>
</tr>
<tr>
<td>15</td>
<td>Topics of Possible Discussion During Counselling</td>
</tr>
</tbody>
</table>
16 Social Adjustment Role Means and
   Overall Adjustment .................. 101
17 Work Role Mean Scores ............... 104
18 Primary Work Role Areas ............. 106
19 Age By Group .......................... 109
20 A Comparison of the Mean Averages
   Scored by Persons With Colostomies
   and Ileostomies, with the Mean Average
   Scores Achieved by a Community Sample ... 122
21 Characteristics of the Sample ........ 133

Note: Tables 16, 17 and 20 are comprehensive reports
of inferential tests, and are, therefore, especially pertinent to this study.
CHAPTER I
INTRODUCTION

Identification of the Problem

The purpose of this study is to describe the characteristics and social adjustment of a group of individuals who have been subjected to a surgical procedure that has altered the natural process of elimination. These persons are called ostomates. All persons who have experienced surgical removal of limbs, breasts and other exterior body parts, suffer a blow to their self image and lifestyle (Lane, 1975-76, p. 192). However, ostomy surgery represents a particularly traumatic insult to the patient, because it involves surgical excision of a body part, alteration of the exterior of the body, and alteration of a body process as well. Specifically the ostomy patient has undergone removal of some part of the intestines, possible excision of the rectum, possible closure of the anus, and they are now forced to pass body waste through a hole that has been created in their abdominal wall (Druss, 1969, p. 53; Burnham, 1977, p. 673).

The tremendous psychological overtones generated by this surgery can be understood in terms of the North American emphasis on beauty and youth. Having been
socialized to believe that he must present himself attractively groomed and perfumed, the ostomy patient must now acknowledge existence of an "anus" on the exterior wall of his abdomen. In addition the process of elimination is affected and the ostomy patient must become more actively involved in the passing of intestinal waste from the body.

This may involve manually flushing out the stoma with a water solution, or it may involve applying a bag over the "hole" to collect faeces. As a child, attention is concentrated on elimination of body wastes, and the child learns that he will be loved and praised if he controls his bowel movements, and punished and rejected if he does not (Dlin, 1973, p. 117). He integrates these values into his personal habits and self image and grows beyond this stage of anal concentration.

However ostomy surgery thrusts the patients back to the concentration on elimination that they knew as a child. Consequently ostomy patients may feel ashamed and unclean, or they may experience embarrassment over spillage, odor or the passing of flatus. They may worry whether or not they are still attractive to the opposite sex, or if they will be rejected by their family or friends.

\[\text{Note: The writer will use the word "he" to refer to both sexes, whenever possible throughout the text for, (1) clarity of word flow and (2) to protect the anonymity of the subjects.}\]
To the adult incontinence is intolerable and implies a return to infancy and helplessness, with concomitant loss of self esteem (McCawley et al, 1975, p. 151).

Dlin tells us that the decision to create a stoma is a "procedure of last resort - to save a life" (Dlin, 1973, p. 114). Unfortunately this life saving procedure may result in a variety of life problems for the person with an ostomy and for his family. Marital tension, unhappiness and marriage breakdown have been attributed to the presence of the stoma (Burnham et al, 1977, p. 673). The person with an ostomy, and his family are likely to have problems that require professional help and these problems may be psychological, sexual or physical (Fussell, 1976, p. 655). Hence the stoma may inadvertently create an obstacle that interferes with one's role performance, and, therefore with one's social adjustment.

Statistics

If we assume the likelihood that persons with ostomies are experiencing psychosocial problems as a result of their surgery, we are lead to consider the magnitude of their problems. When a number of individuals experience a common problem it ceases to be an individual matter and becomes a social concern. In order to assess whether or not the ostomy population is large enough to
consider their needs and problems as a social issue, we must first examine its numbers and problems.

According to Statistics Canada 101 ileostomies per 100,000 population, and 2,379 colostomies per 100,000 population were performed in 1976 in Canada (Statistics Canada, 1980, p. 90). If we consider the Canadian population of 22,992,604, we can estimate that one in every 900 Canadians underwent ileostomy surgery and one in every forty-two Canadians underwent colostomy surgery in 1976 (Walters, 1980). However, in considering these statistics, we must acknowledge several factors:

(1) The number of ostomies performed does not denote the number of individuals who have become ostomates, because ostomy surgery is often performed on the same patient more than one time (Lenneberg and Weiner, 1973, p. 14).

(2) These statistics do not differentiate between those individuals having a temporary ostomy and those who have become permanent ostomates.

(3) Statistics Canada advises that a further 160 per 100,000 persons underwent enterostomy surgery (Statistics, Canada; 1980, p. 20). This category includes various types of ostomies (i.e. ureterostomies) as well as ileostomies and colostomies (Dr. Lorne Thorner, personal communication).
Consequently, the ileostomy-colostomy statistics become inaccurate.

The Detroit Free Press stated that there is a likelihood that one in every 150-200 persons are ostomates (Pilate, November 8, 1979, pp. 1D, 5D). Considering the Canadian statistics referred to on the previous page, this estimate seems reasonable and likely. The Detroit Free Press stated, in the same issue that there are 1.5 million ostomates in the United States. An United Ostomy Association publication estimates that 50,000 new stomas are added to the ostomy population of the United States annually (Lenneberg and Weiner, 1973, p. 6). In a journal published by the United Ostomy Association, Dr. Marvin Schuster states that there are one million ostomates in the United States and Canada (Schuster, 1977, p. 25).

The disparity between the estimates of the Detroit Free Press and Schuster is not unreasonable in view of the millions of persons in the United States and Canada. As indicated earlier statistics regarding ostomies are in terms of the frequency of the surgical procedure itself. Statistics of the total number of persons with permanent ostomies are not determined in either country. Consequently in order to generate a total ostomy population, we will consider the estimate of one in 150-200 members of the general population, and the given Canadian population.
Extrapolating in this manner we can deduce that 100,000 Canadians may have permanent ostomies. If approximately 100,000 Canadians have common psychosocial problems as a result of ostomy surgery, the weight of their numbers is sufficient to consider their problems an important and current social issue.

**Etiology and Physiology of Ostomy Surgery**

This research study concerns itself with the psychosocial aspects of persons with an ostomy. However an empathic understanding of these persons requires some comprehension of the etiology and physiology of ostomy surgery. For this reason these aspects are briefly discussed at this point in the presentation of the study.

In addition, a number of medical terms are inherent in the study of any surgical process. Therefore a defined list of the medical terminology appearing in this study has been included in Chapter III, Methodology, for the convenience of the reader.

There are approximately twenty diagnoses that lead to the formation of a stoma, including congenital malformation, disease and trauma (Lenneberg and Weiner, 1973, p. 6).

Four out of five ileostomies are done for inflammatory bowel disease, including ulcerative colitis and Crohn's disease (Gambrell, 1973, p. 3).
Most ileostomies are performed on younger persons of dating and reproducing ages (Gambrell, 1973, p. 3). Most colostomies are caused by cancer of the colon or rectum, and by inflammation and obstruction and they are most often performed on the over-forty age group (Gambrell, 1973, p. 3-4).

In simple terms an ostomate is an individual who has undergone surgery of the digestive tract. This surgery has resulted in internal organ changes and the formation of an artificial opening in the abdominal wall, and it is through this opening that the individual must now defecate.

There are two more common types of stomas, the ileostomy and the colostomy (Lanneberg and Weiner, 1973, p. 4). The basic difference between the two, is that the ileostomy is made of the small intestine and the colostomy is made of the large intestine. An ileostomy is formed by bringing an end of the small intestine through the abdominal wall to serve as an opening for discharge of intestinal contents (Druss et al, 1968, p. 53). A colostomy is similarly formed with a section of the large intestine, the colon (Druss et al, 1968, p. 53). Both types of stomas are on the exterior wall of the abdomen and are observable to the eye.
An ostomy may be temporary, in which case it will eventually be closed surgically and normal elimination patterns will be resumed (Lenneberg and Weiner, 1973, p. 4). Just this May, 1981 Pope John Paul experienced a temporary colostomy to facilitate physical recovery from gunshot wounds suffered at the hands of an assassin. This study however concerns itself with ostomies of a permanent nature, where the end section of the colon or rectum requires permanent rest or removal, (Lenneberg and Weiner, 1973, p. 4). The anus itself may or may not be permanently closed surgically (Gambrell, Reprint).

The stoma, being made of the intestine, does not have a sphincter muscle with which to control the process of elimination, as does the anus. Further the location of the stoma, on the abdomen, does not lend itself to the use of regular toileting facilities. For these reasons fecal matter is usually collected in a bag called an appliance, that is placed over the stoma, and which may be secured to the outer abdomen with an adhesive.

In the case of an ileostomy, the discharged contents of the intestine are not formed and cannot be regulated; therefore an appliance must be worn at all times (Druss et al, 1968, p. 53). In the case of a colostomy, depending on which section of the large intestine is used, the contents are more formed and elimination may be more controllable; hence a light covering
may provide adequate protection from embarrassing accidents (Gambrell, Reprint). This difference can be understood if we consider that the small intestine absorbs food value, and waste and water is then passed into the large intestine, where most of the water is absorbed, leaving a formed mass to be disposed of through elimination.

Social Functioning and Social Adjustment

Whether the individual is young or not so young, has an ileostomy or a colostomy, his lifestyle will undergo change. Whether the ostomy patient is confronted with changes of a major or of a profound nature, he will experience a period of disequilibrium. He will be required to adjust to the effects of the surgery. The level of adjustment and state of functioning of persons with ostomies are a major focus of this study. For this reason social adjustment and social functioning will be briefly discussed here.

Social adjustment, broadly defined, is the interplay between the individual and the social environment (Weissman, 1975, p. 357).

As part of our socialization, we are assigned life roles, and we are expected to fulfill these roles with specific behaviours and attitudes in terms of the norms of our own referent group. Weissman states that "social
adjustment is not a unitary or a global concept. The concept includes functioning in different roles" (Weissman, 1975, p. 357). Therefore social functioning is a component of social adjustment. It "includes the activities that are essential to satisfying relationships in the variety of social experiences of daily living" (Skidmore and Thackeray, 1976, p. 19). Consequently, an individual may be perceived as being socially well adjusted and yet he may be experiencing considerable maladjustment in a specific life role area, e.g. work or marriage. According to Gurland et al, social maladjustment (1) refers to "ineffective performance in the roles and tasks for which an individual has been socialized", (2) it includes "failure to achieve satisfaction from performance in these activities", and (3) it refers to "observable behaviours and subjective reactions in a given social context" (Gurland et al, 1972, p. 259).

The Social Adjustment Scale--Self Report, (SAS-SR) test used in this study examines social adjustment as an entity unto itself (see Appendix B, Section II of questionnaire). It further measures social functioning in the following life role areas: (1) work, (2) social-leisure, (3) extended family, (4) marital role, (5) parental role, and (6) the nuclear family unit. As a consequence of the broad scope of this scale, persons with ostomies will be examined on a number of variables in a single test. In addition, in that each role area, and overall social
adjustment are scored individually, it becomes possible to make intrasample comparisons as well. Therefore this study will involve:

(1) A description of members of the Hamilton and District Ostomy Association, who have permanent colostomies and ileostomies and who are over the age of seventeen.

(2) A measurement of their social functioning and social adjustment,

(3) Comparisons of the level of social functioning and social adjustment of the following subgroups:
   (i) males versus females,
   (ii) persons with ileostomies versus persons with colostomies,
   (iii) young adults versus middle-aged and retired adults, and middle-aged adults versus retired adults.

(4) A comparison of the ostomy sample of this study to a community sample of a previous study. In this way the writer hopes to:
   a) describe the characteristics of persons with an ostomy.
   b) locate specific areas of impairment, and
   c) identify persons with ostomies, who are predisposed to social maladjustment.
Summary

In this chapter, the writer has introduced the reader to the person with an ostomy, and to the purpose of the study. In addition an overview of the psychological aspects of this surgery has been presented, and the etiology and physiology of ostomy surgery was discussed. Further to this, the impact of psychological and physiological factors on the ostomy patient, in terms of social adjustment was briefly considered. Social adjustment, social functioning and social maladjustment were defined. In addition, the Social Adjustment Scale-Self Report version that was used in this study to measure the levels of Social Functioning and Social Adjustment, was described. The relationship of this study to the literature will be discussed in the next chapter.
CHAPTER II

REVIEW OF THE LITERATURE

Literature Search

A search of the literature on persons with ostomies, revealed that this subject has received little attention to date. Many existing studies proved to be as much as two decades old. Much of the information on the subject of ostomies is published by The United Ostomy Association, Inc., of Los Angeles, California, which is a self help group largely composed of Canadian and American persons with ostomies. The writer found only one article written from a social work perspective. This article considered the social and personal life changes experienced by individuals after ostomy surgery (Lane, 1975-6, p. 191-98).

In order to underscore the limited attention that the person with an ostomy has received, the writer will describe the broad scope of the computer searches used to seek out literature pertinent to this research project.

The computer searches utilized five data bases:

1. Medline: which scans 3000 publications in the United States and seventy other countries, plus selected monographs from the present back to 1968.
2. Psychological Abstracts: which scans 1500 world monographs, and 900 on-line journals back to 1967.


4. CODOC: (Canadian and Other Government Documents on-line).

5. SISTI: (Canadian Institute for Scientific and Technical information).

The search from the first three data bases, looked for information on (a) The Family and the Ostomy Patient, (b) Ostomies and Psychological Adaptation, (C) Ostomies and Therapy, (d) Ostomies and Family, and Ostomies and Psychological or Sexual Adjustment. This search located seventeen articles in medical, nursing and psychology journals of six countries, the United States, Canada, Germany, Great Britain, Norway and the Union of the Soviet Socialist Republic. The last two data bases, both Canadian, located one monograph, a book on nursing care of the ostomate.

While the writer acknowledges that studies from European countries may not be specific to a Canadian population, there are obvious physiological, anatomical and psychological commonalities. Consequently in this
study the phenomenon of ostomies will be identified and examined from a social work perspective, employing information gleaned from the field of medicine and the social sciences.

It has been established that literature regarding ostomies is limited. In addition in many cases journal articles address a confusing array of topics. This problem relates to the reality that no one area in an individual's life is separate unto itself. Impaired psychological adjustment threatens one's role as a sexual partner, an employee, and so forth. Impaired work functioning effects one's role as a sexual partner, an employer and so forth. Indeed combinations of life areas effect other combinations of life areas. However, while acknowledging this interaction, the writer will present the review of the literature in specific topic areas to promote clarity. These areas are as follows:

1. Psychological adjustment after ostomy surgery,
2. The family with an ostomy,
3. Sexuality after ostomy surgery, and

**Psychological Adjustment**

The psychological trauma of ostomy surgery involves a number of components. As was mentioned in Chapter I, the ostomy patient makes a reluctant return
to the childhood emphasis on elimination. In addition the patient's negative feelings toward the sight of the stoma are amplified by society's adoration of the young and the perfect. As a result of these factors the patient suffers a blow to his self image. Further, the natural response of the patient is to mourn the loss of a body part, the loss of a body function and the loss of a familiar self (McCawley et al, 1975, p. 151).

The emotional reaction of the patient is influenced by a number of factors, including the personality of the patient, previous psychiatric problems and the diagnosis that necessitated the surgery (McCawley, et al, 1975, p. 151).

McCawley et al illustrate their opinion by comparing the response of some cancer patients with the response of ulcerative colitis patients in the following manner: The cancer patient has had only a brief period of illness before surgery, and has had little time to become emotionally prepared for the surgery. As a consequence of little or no suffering in combination with little or no emotional preparation, the cancer patient tends to perceive the benefits of surgery in a theoretical manner, and his response to surgery is dramatic. Ulcerative colitis patients, on the other hand, have had years of suffering before their surgery, and the relief from this
suffering compensates for the formation of the stoma. For this reason ulcerative colitis patients react more favourably to ostomy surgery.

This illustration merits comment for, as in the case of most general statements, while the content may be accurate it is unlikely to be complete. Could it be possible that the cancer patient is reacting to the diagnosis that lead to the ostomy surgery? Perhaps the stoma represents a threat of death to the cancer patient. In addition, perhaps the less overt response of the ileostomy patient is an unhealthy response. He may feel obligated to suppress existing negative feelings to the health care team that provided him with this life-saving surgery. Even if his initial reaction to ostomy surgery is genuine relief, he may demonstrate negative psychological reactions once he becomes habituated to an improved state of health. Jackson states, "...at the time of discharge crisis resolution, if begun at all, has not been completed (Jackson, 1976, p. 424). In relation to the patient and tasks he must master post-surgically, Jackson asks, "Is it fair to conclude that because they do their care independently, they have adapted and need no further help during hospitalization and after discharge?" (Jackson, 1976) p. 423).

Lane believes that a patient who has lost a body part reacts intensely to the loss, whether or not
the patient's reaction is overt (Lane, 1975-76, p. 192). Accepting Lane's viewpoint as logical, emotional reactions to ostomy surgery, that have been addressed in the literature will be discussed at this time.

Studies have shown that depression is a common reaction to ostomy surgery and this depression can be severe enough to elicit thoughts of suicide (Druss et al, 1969, p. 425). Morrow explains that depression among ostomy patients is due to feelings of inadequacy, rigidity and helplessness (Morrow, 1976, p. 370). In regards to severity of depression, younger people tend to experience the deepest depression (Druss et al, 1969, p. 425). Perhaps the young are particularly vulnerable to the social stigma of an ostomy.

Wirsching et al compared 214 persons who had a colostomy as a result of rectal cancer, with 110 rectal cancer patients who had undergone colonic resection but had no colostomy (Wirsching et al, 1975, p. 246). They noted the following reactions to ostomy surgery:

(1) Suicidal thoughts among ten per cent of the colostomy patients.
(2) Significant rates of depression among males with colostomies.
(3) High levels of loneliness among twenty-seven percent of the colostomy patients.
(4) Significant rates of fear of death.
(5) A tendency to withdraw socially among the colostomy patients, for fear of loss of sphincter control.

Rush states:

Perhaps the biggest problem people must face when having ostomy surgery is a change in their own body image (Rush, 1976, p. 11).

Studies indicate that the development of a negative self image is a common response among ostomy patients. In one study of 48 post-operative colostomy patients, the patients saw themselves as dirty, diseased and contaminated (Orbach, 1974, p. 271). Women in particular became preoccupied with cleansing their bodies and bathrooms with strong disinfectants.

In a further study Meyers et al looked at eleven ileo-colitis patients (non-ostomates) and fourteen ileostomists following surgery (Meyers et al, 1980, pp. 1-6). They noted a less favourable outcome for the ileostomists in five psychosocial areas, as well as for physical symptoms and overall satisfaction. Of particular note was a significantly more negative self-image among the ileostomists.

Druss states that the ostomy patient feels mutilated, and perceives the body as being weaker, more fragile and unattractive (Druss et al, 1969, p. 425).
Women tend to feel violated and eviscerated, while men may view their surgery as castration due to the initial bleeding of the stoma, which they perceive as menstruation (Druss et al, 1969, p. 425); Morrow, 1976, p. 370).

Lane concurs with the belief that the ostomy patient invariably experiences an altered self image (Lane, 1975-76, pp. 191-98). She warns that the patient must be able to integrate this changed self-image during the recovery process or he will perceive himself as mutilated and be prevented from achieving a psychological sense of "wholeness".

After patients have undergone ostomy surgery they develop anxieties in relation to a number of concerns: They worry about the possibility of spillage and odor, and they worry that the appliance may become exposed and cause them embarrassment (McCawley, 1975, p. 151). They fear social rejection and are concerned about their attractiveness and their sexual adequacy (Dyk and Sutherland, 1956, p. 138). Orbach noted that in the case of persons who irrigitated their colostomy, the time away from home and the distance travelled was determined by the schedule for irrigation (Orbach and Tallent, 1965, p. 126-33). Evidently their concern in regard to elimination is so intense as to let their stoma control a major part of their life.
Other studies indicate that ostomy patients tend to withdraw from social participation and emotional relationships (Morrow, 1976, p. 370). Druss noted that 72% of the patients in his study showed a deterioration in their social life (Druss et al., 1969, p. 425). Dyke and Sutherland agree and state: "A colostomy has profound consequences on social participation in the community" (Dyk and Sutherland, 1956, p. 123). Persons with ostomies may limit their social participation and emotional relationships for a variety of reasons, (i.e.) fear of rejection or embarrassment, depression or low self esteem. Whatever their reasons, the result seems to be that people who would profit from additional social and emotional support and interactions are experiencing less and as a consequence their emotional health may be further jeopardized.

The Family With An Ostomy

According to the Family Systems Theory, if one family member changes, all the members of the family are required to make compensatory changes (Carter et al., 1976, p. 193). Ostomy surgery produces a myriad of changes in the patient's life, such as anatomical and physiological changes, and possible changes in self image, employment, sexual activity and so forth. These changes represent an arduous task toward social adjustment for the patient and for his family.
The family may have to cope with the fear they have for the patient, and for themselves. The patient may worry whether or not he will be able to fulfill his role as a family member, and the family members will experience a similar anxiety. A male ostomy patient may worry whether he is still sexually potent, and whether his wife will reject his sexual overtures, and his wife may share this worry, and feel anxious regarding her own response as well. Family members must cope with the sense of powerlessness they feel regarding their inability to change the situation, or eliminate the anguish of the patient. The family and the ostomy patient will have to work through their fears, and the feelings of guilt, shame or anger they may have toward the patient and his illness.

It can be said that when a person experiences ostomy surgery, his family will share the pain. Yet in spite of the obvious stress that ostomy surgery inflicts on the family of the patient, few studies consider the needs of the family. Indeed little has been written in regards to the family in relation to the needs of the patient.

Dyk and Sutherland state that the spouse is of primary importance to the colostomy patient's ability to adapt to the effects of that surgery (Dyk and Sutherland, 1956, p. 138). They also stress the importance of the family in this regard.
Since the family is the institution in which primary social interaction takes place, the kind of emotional response the individual experiences within his family after he has suffered an injury becomes an important factor in his efforts to restore social function and self esteem (Dyk and Sutherland, 1956, p. 138).

Druus et al, also recognizes the importance of the family, and the spouse in particular, to the post surgical concept of the patient. They state that the spouse of the ostomy patient is often "the key to (the) patients eventual success or failure in adapting to his disability" (Druus et al, 1968, p. 54).

McCrae states, "A warm, interested, loving partner has been identified as the best adaptive assistance any disabled person can have". While this is no doubt true, it is difficult for the partner to be warm, loving and interested if he has not been able to work through his own feelings of guilt, anger or fear.

Where family relations are based on mutual affection, they provide important emotional support for resolving depression and restoring function. Where relationships in the family are characterized by hostility and tension, the colostomy accentuates these problems. The family, in this instance is a deterrent to the recovery (Sutherland et al, 1952, p. 868).

Dyk and Sutherland say that the medical profession assumes that the family will provide the emotional support the patient needs upon returning home (Dyk and Sutherland, 1956, p. 135). In a study they noted that this is not
always the case, but that while the husband of a woman with a stoma is relatively accepting of her stoma, the wife of an ostomy patient frequently disparages and humiliates him.

In a further study, Dlin et al noted, "again and again in the individual responses that when understanding and support in the home were positive they became a major factor in a favourable recovery" (Dlin et al, 1969, p. 377).

Lenneberg and Weiner recognize the importance of the family to the rehabilitation of the ostomy patient, and they further acknowledge the existence of fears and doubts that the family members experience. They recommend counselling for the patient and the family, and stress the importance of early family contact.

Druss suggests early involvement of the family when he says, "It might be useful if key family members were included in the plans for the patient's recovery before he returns home" (Druss et al, 1969, p. 426). In fact, it is probably essential that all family members be included in the plans for the patient's recovery before he has surgery and before he returns home.
Sexuality After Ostomy Surgery

In Victorian times sexuality was not a topic for polite discussion, and males and females were given to interact socially "as though neither possessed any sexual organs" (May, 1970, p. 273). Women were expected to submit to their husband, and the only socially acceptable purpose of sexual intercourse was that of procreation.

May states that, "In an amazingly short period following World War I, we shifted from acting as though sex did not exist at all to being obsessed with it" (May, 1970, p. 273).

Dlin tells us, "the single most important problem in the mind of the ostomate after the 'live or die' struggle is that of sexual function". (Dlin, 1973, p. 128). The most obvious source of information regarding sexual potency is the surgeon and it is to him the ostomy patient is most likely to turn for reassurance in this matter. (Sutherland et al, 1952, p. 87).

According to Belliveau and Richter:

Patients who come to the average doctor with a sex problem have little chance of being treated successfully. Many physicians and others who offer counsel are very poorly prepared to give advice about sexual matters. (Belliveau and Richter, 1970, pp. 223-24).
Dr. William Masters of Masters and Johnson is quoted as saying:

"There are very few physicians practicing medicine today who have ever had a moment's training in human sexual response while they were in medical school. Most of them were out of medical school when this was beginning to be taught in the mid 1960's" (Belliveau and Richter, 1970, p. 219).

While this situation has been altered somewhat by the passing of time, it stands that there are few experts to whom the ostomy patient may appeal for assistance regarding sexuality. Dlin states:

Sexual adjustment after this surgery, a matter of prime concern to the patient, is rarely discussed openly. The average patient remains uninformed, fearful and the victim of various myths, such as the loss of potency in the male (Dlin, 1973, p. 128).

This comment indicates that remnants of Victorian sexual attitudes still exist. It is underscored by the fact that there are few studies available regarding female sexuality after ostomy surgery.

In regard to the question of sexual functioning following ostomy surgery, various authors acknowledge the possibility of anatomical injury during surgery. Norris and Gambrell assert that the anatomical location of the prostate glands and the nerve system that controls sexual functioning, predisposes the male to inadvertent damage
during ostomy surgery (Norris and Gambrell, 1972, p. 5).

Druss explains:

"Erection results from stimuli travelling along parasym pathetic pathways originating the the sacral spinal cord". If these nerve fibres are damaged during surgery the male will lose the ability to achieve penile erection. He adds, ejaculation is "dependent on the integrity of sympathetic supply to the internal genitalia". Should these sympathetic nerve endings be damaged during surgery the male will suffer impaired ejaculatory ability (Druss et al, 1968, p. 57).

Burnham et al looked at 303 married ileostomists, some of whom had experienced rectal excision and some who had not (Burnham et al, 1977, p. 673). (During ostomy surgery the rectum may be partially or totally removed or left intact.) They reported that nearly 1/3 of the males who had experienced rectal excision suffered some degree of sexual dysfunctioning, but there was no indication of sexual dysfunction among those who were left with the rectum intact. Burnham et al stress the need for improved surgical techniques which will decrease anatomical trauma. An additional consideration might be whether the ileostomists with rectal excision may have suffered a double blow to their self image by the formation of the stoma and by the removal of the rectum as well.

Gruner et al did a follow up study of 178 patients who had been operated on for ulcerative colitis (Gruner et al
1977, p. 193-97). Of these individuals 134 had ileostomies and 44 had undergone ileorectal anastomosis, a technique where a section of the intestine is removed and the ends are reattached. Impaired erectile and ejaculatory functioning was reported by 15 of the 52 male ileostomists in the sample. Dyspareunia (painful intercourse) was reported by five of 50 female ileostomists and loss of libido by another two women. Coital frequency did not differ from that of the general population. Premarital intercourse among male and female ileostomists was lower than that of the general population and was ascribed to psychological effects of the stoma and appliance.

Dlin et al did a survey study of 500 members of ostomy groups from 23 American states and five Canadian provinces, with the purpose of examining the psychosexual response of the persons with ileostomies and colostomies to their surgery (Dlin et al, 1969, pp. 374-81). They reported that 75% of the males had no ejaculatory or erectile dysfunction and 87% of the females were able to achieve orgasm. Pre-surgical patterns of masturbation, petting or pre-marital sex were unaffected by the ostomy surgery, but a significant decline in extramarital sex was noted. Dlin et al state that "slashing of the pelvic nerve is not sufficient to alter the capacity for normal sexual response in either sex" (Dlin et al, 1969, p. 375).
Wirsching et al looked at psychosocial aspects of 214 patients who had permanent colostomies as a result of cancer of the rectum (Wirsching et al, 1975, pp. 245-56). As a control group they used 110 patients who had undergone colonic resection for cancer of the rectum but had not required a colostomy. Seventy-five percent of the male colostomy group reported decreased sexual activity following the surgery. No significant decrease was noted among the women in the colostomy group. They conclude:

...the fact that the male group predominantly shows sexual disturbances (is that it) cannot be due to organic damage, but (it) is an expression of loss of self esteem and feelings of castration..... (Wirsching et al, 1975, p. 375).

Fussell, a surgeon at Royal Albert Edward Infirmary, England, acknowledges the possibility of impotence and dyspareunia following excision of the rectum, but asserts that normal intercourse and reproduction are quite possible (Fussell, 1976, p. 660). She states that psychological factors are extremely important with regard to sexuality of the person with an ileostomy or colostomy.

In a study of 41 ileostomists, Druss et al concluded that the spouse is an important factor in sexual adjustment after surgery (Druss et al, 1968, p. 57). They emphasized the importance of a feeling of "bodily worth and integrity that the person retains after surgery and the actual and imagined response of the sexual partner" (Druss et al, 1968, p. 58).
Dlin et al believe that every individual who undergoes ostomy surgery experiences a change in his self-image, and the capacity to reestablish a suitable self-image is "intimately related to his capacity to respond sexually" (Dlin et al, 1969, p. 380).

Frager et al state:

The psychological impact of ostomy surgery is generally greater than the physical impact. Depression following major surgery, interruption in normal routines and interactions, excessive medication, and alteration in body-image and self concept may result in sexual difficulty. Although the first three usually improve after the immediate postoperative period, altered body image and self-concept may continue to cause problems (Frager et al, Unpublished paper).

Self image (including body image) and sexuality are interactional. If an individual is able to function sexually his self image is increased. Conversely, an individual must have a positive self image to function sexually.

Lenneberg and Weiner recognize surgical damage as a contributing factor to sexual dysfunction, but assert that attitudes toward sexuality and toward the stoma are considered major determinants toward satisfactory sexual relationships (Lenneberg and Weiner, 1973, p. 11). They state that sexual impotency is often only delayed and the delay can be extended by fear that the condition is permanent.

Lane explains that the patient may have such strong fears of sexual impotency that he may convey the
message to his wife that he no longer finds her sexually attractive (Lane, 1975-76, p. 196). She, in turn, responds by assuming emotional distance, thereby affirming his fears, which are then driven deeper.

Norris and Gambrell make three important statements in regard to sexual functioning (Norris and Gambrell, 1972, p. 5) They state:

(1) "It is estimated that about 10-20 percent of male ileostomists suffer impairment of sexual function and potency, but fortunately in many cases only temporarily".

(2) "Male colostomates vary anywhere from full potency (can have erection and orgasm) to complete impotency."

(3) "Temporary sexual dysfunction can linger as long as two years in all types of ostomies."

Perhaps if the ostomy patient can be assured that time and statistics are in his favor he will feel under less pressure to perform sexually. As a consequence he will be more inclined to postpone sexual attempts until he has had time to adapt physically and emotionally. Premature attempts at intercourse are likely to result in failure, and can frequently establish destructive expectations of failure in future efforts. In addition he will be able to assure his wife of his likely return to potency. Perhaps the married couple could be encouraged to use this interim
period to strengthen their bonds of love and affection. Their efforts in this regard would promote eventual restoration of sexual functioning.

Work Adjustment After Ostomy Surgery

Our society has two values, in relation to employment, that are pertinent to the person who has undergone ostomy surgery. Firstly, a person's worth is evaluated according to his work status, (i.e. When two men meet for the first time, the questions 'What do you do?' and 'Is the pay good?' are certain to be asked within a short period of time. Secondly, work roles are fairly specific in relation to gender. In spite of women's liberation efforts, the man of the family is expected to be the provider, and if the wife also works, her income is considered secondary. If the wife has to begin paid employment to maintain the family because her husband has had surgery, a role reversal takes place within the home. This is in opposition to the values stated above; therefore it can result in anger on the part of the wife, and diminished self esteem on the part of the husband (Dyk and Sutherland, 1956, p. 133).

When a person has undergone ostomy surgery, how does this effect his return to work? Although reference to employment after ostomy surgery is almost nonexistent, several articles made some reference to this concern.
According to Gambrell, an ostomy is not an illness but a cure or a remedy for an illness (Gambrell, Reprint). If the patient is able to regain his health through ostomy surgery, there is no reason why he cannot return to his work. The only exceptions to this are if his occupation involves heavy lifting, or contact sports, such as hockey or football. In these instances the ostomy patient will be required to retrain for another type of work.

Lenneberg and Weiner state that many colostomy patients may choose to retire after this surgery (Lenneberg and Weiner, 1973, p. 9). They assert that this is understandable as most colostomy patients are of older years.

In a study, Druss et al noted this tendency in a sample of colostomy patients with a mean average age of 56 years (Druss et al, 1969, p. 426). They conclude:

For them the trauma of a colectomy was similar to forced superannuation and taken as evidence that productive and useful life had ended (Druss et al, 1969, p. 426).

In a further study of ileostomists, whose stoma was required by ulcerative colitis, Druss et al noted a fear of poor job performance and stoma injury among the males (Druss et al, 1969, pp. 53-59). The mean average age of this group was 28 years.

Dyk and Sutherland interviewed 57 persons with colostomies of both sexes (Dyk and Sutherland, 1956, pp. 123-38). The median age of subjects was 50, and all the subjects were in good health at the time of the
interview. They noted that 44% of the males were working reduced hours or at a lower status of work than they had before surgery. They state that, with this reduced productivity, "family attitudes, however positive, could not compensate for the individual's feeling of lack of value and worth" (Dyk and Sutherland, 1956, p. 123).

With regards to when the ostomy patient should return to work, Dlin advises that this decision depends on the length of time that is necessary for regained physical and emotional health (Dlin, 1973, p. 127). However, he warns that a prolonged delay in returning to work can lead to emotional disorders such as depression or phobias.

According to Lane:

If the work setting for the patient has been the source of meaningful, need-meeting social interaction, its loss can carry crucial consequences, undermining self-esteem, self worth, and the patient's attitude about his future (Lane, 1975-76, p. 195).

Gambrell states that the ostomate who does not return to his former place of employment will find it difficult to gain work with the larger companies (Gambrell, 1971, Reprint). He attributes this, in part, to the fact that a person with an ostomy is considered ineligible for insurance. This writer contacted two insurance companies in this regard. Mr. Bert Hoogendam, Manager-Owner of an independent company, Bert Hoogendam Insurance, Sarnia, states that, "insurance coverage has become more lenient in the past five years. If a person with an ostomy has
regained an acceptable stage of recovery, he can purchase life insurance now*. He admits, however, that the purchaser may be surcharged. Dr. R.D. Atkinson, Senior Medical Director of Mutual Life Assurance Company of Canada, Waterloo, responded to this enquiry with this prepared statement:

The existence of an ostomy does not bring an automatic declination or rating. During the first two post operative years excess deaths will occur due to complications, usually small bowel obstruction or perforation, and an extra premium will be charged. Once an ostomy has become established and the patient has been restored to full health, as an ulcerative colitis, only a small rating would be assessed. In many cases acceptance would be at standard rates.

In assessing the risk for life insurance of a colostomy or ileostomy, the underwriter must first establish the underlying disease process which resulted in the ostomy — for example, carcinoma of bowel, or regional enteritis (Crohn's disease), or some other condition. This will determine whether or not the risk is acceptable and, if so, at what extra mortality assessment.

The history of cancer does not always result in declination for insurance, as today it is possible to provide coverage for many of these individuals. Many factors, such as type, site, treatment, and spread, must be taken into consideration.

Gambrell maintains that, "Employees have been released, placed on early retirement or placed in inferior jobs because of ostomy surgery" (Gambrell, 1971, Reprint).

There was only one reference to this type of work discrimination in the literature. This involved an incident wherein an employee, who worked for a catering service,
was threatened with dismissal because his employer regarded him as 'dirty' (Fussell, 1976, 657). It is apparent that additional studies are needed (1) to establish whether or not an employment problem exists and if so, (2) to determine the nature of the problem.

Summary

In this chapter a review of the literature was presented on four primary life aspects of the person with an ostomy: (1) Psychological adjustment, (2) The family of a person with an ostomy (3) Sexual functioning and (4) employment. The literature revealed that ostomy surgery makes a definite psychological impact on the patient. Negative body image and depression are noted to be common responses to the surgery. In addition, the patient fears death, spillage, odor and social rejection. The family of the patient, and the spouse in particular are seen as key factors toward rehabilitation of the ostomy patient. Presurgical marital relationships tend to determine whether the family will provide the emotional support the patient needs to adjust. If the family responds to the patient with positive affection his rehabilitation is facilitated, and if the family responds negatively the rehabilitation process is threatened. Counselling is recommended for the patient and the family.
According to the literature, ostomy surgery can result in impotence and dyspareunia. However, previous studies indicate that sexual problems are more likely to be a result of psychological factors.

There are few studies on employment after ostomy surgery, and those studies postulate that (1) the colostomy patient is likely to retire after colostomy surgery. (2) Persons with stomas often work less hours, or at lower status employment than they did before surgery, (3) No or lesser employment adversely affects the ostomy patient's self esteem, and (4) Persons with ostomies, who have regained their health, are as employable as persons without ostomies.

A discussion of the review of the literature, was intended to serve as a base for the methodology of this study, which is described in the next chapter.
CHAPTER III
METHODOLOGY

Purpose of the Study

The purpose of this research study focuses on the post convalescent social adjustment of persons with ileostomies and colostomies. The social adjustment of these persons was assessed by the standardized Social Adjustment Scale-Self Report Version to determine whether or not impaired adjustment existed. A number of variables, such as age, sex, type of stoma and so forth, were considered in an effort to determine factors associated with social dysfunction. It was hoped that by establishing a relationship between these factors and social adjustment, it would also become possible to:

(1) Identify characteristics of populations likely to be in need of intervention, and
(2) Determine what life areas were involved in social adjustment or social maladjustment.

In addition, at the request of A. Claude Campbell, President of the Hamilton branch of the United Ostomy Association, the questionnaire used in this study was
utilized to collect data regarding the cost of appliances, stoma care products, hospitalization and medical coverage of persons in the sample group. These data was given to Mr. Campbell for possible use in his efforts to have hospital insurance coverage extended to include payment of special products required by persons with ostomies, and will not be included in this study.

Classification of Study

A research study is classified by the research design and by the purpose of the study itself. Research is classified as one of the following types: experimental, quantitative-descriptive and exploratory (Tripodi et al., 1969, p. 38).

The category of quantitative-descriptive studies includes research investigations having various purposes with respect to the seeking of knowledge. These purposes fall into two general classes: (1) the testing of hypotheses, and (2) the description of quantitative relations among specified variables (Tripodi et al., 1969, p. 34).

A main purpose of this study is the assessment of the social adjustment of persons with ostomies. This purpose concurs with the second purpose of quantitative-descriptive studies as described above.

Beyond the purpose of the research, the quantitative-descriptive study must meet several requisites:
1. The study must not be classifiable as an experimental study,
2. It must include variables that are measurable and,
3. It must provide for systematic data collection in a manner that permits accurate description of the relationship between the variables.

In order to be classifiable as an experimental study (1) an hypothesis must be implicit or explicit, (2) the independent variable must be manipulated by the experimenter, and (3) subjects must be assigned according to randomization procedures (Tripodi, 1969, p. 29). This study does not have a hypothesis and the independent variables are not manipulated by the writer. Furthermore the sample used in this study is accidental and not randomly drawn; consequently this study does not meet the criteria required to be classifiable as an experimental study. It does include measurable variables, and data has been collected in a systematic manner so that relationships between the variables can be accurately described. Therefore, this study is classifiable as quantitative-descriptive research.

Within this category of quantitative-descriptive research are four sub-types: (1) hypothesis testing studies, (2) program evaluation, (3) population description studies and (4) studies that search for relationships between variables (Tripodi, 1969, p. 38).
Studies search for variable relationships are those quantitative-descriptive studies which are concerned with the finding of variables pertinent to an issue or situation and/or the finding of the relevant relations among variables. Usually neither a priori hypotheses nor specific questions are formulated to the research. Survey procedures may be used, and a large number of potentially relevant variables are included in such studies. Often there is an interest in seeking variables with predictive value (Tripodi, 1969, p. 44).

This study looks for a relationship between the level of social adjustment and specific variables, and falls within sub-types (3) and (4) of Tripodi's typology. It further attempts to identify those variables that are predictive of low levels of social adjustment. The data for this study was collected by the use of a survey-type questionnaire. For the reasons this study can be subtyped a variable relationship study. The study is thus classifiable in the following manner; Major type: Quantitative-descriptive, subtype: Variable relationship study.

Population

In regard to determining the population for this study the writer considered the "representativeness" of persons with ostomies from the Canadian city, Hamilton, to a Canada-United States population.

The writer concluded that Canadian and American people are likely to have relatively common political, religious, social and philosophical views for the following reasons:
(1) Canadians, especially those near the Canada—United States border, have access to American television and radio programs and films.

(2) Canadians have ample access to American published material. In particular, the majority of educative literature on ostomies is published by the United Ostomy Association, Incorporated, which has its base in Los Angeles, California.

(3) Both the United States and Canada are populated for the most part by persons who have immigrated from, or are descendants of immigrants of like countries. In fact, many Canadians have American family members.

(4) Canadians and Americans share a high standard of living and enjoy the same or similar products and opportunities.

(5) Both Canadian and American people are highly mobile and travel and associate freely with one another.

For these reasons it was determined that a Canadian population is representative of fellow Canadians as well as our American neighbours.

The next consideration was whether members of the United Ostomy Association could be considered "representative" of persons with ostomies who were not members. It was determined that membership in the United Ostomy Association
may alter the perception of its members in regard to their ostomy status. If so, non members may be functioning at a different level of adjustment in relation to their acceptance of their ostomy status.

For the reasons just discussed, it was determined that data gained from Canadians who have ostomies, and are members of the United Ostomy Association, may be generalized to Americans who have ostomies, and who are also members of the United Ostomy Association. The population of this study, therefore, may be all Canadian and American persons with permanent ostomies, over the age of seventeen, who are among the 37,000 Canadian-American members of the United Ostomy Association.

Type of Sample

There are two major types of samples, probability and nonprobability, and the basic characteristic of probability sampling is that every element within the population has an equal opportunity to be included in the study (Selltiz et al, 1976, p. 516). The primary advantages of nonprobability sampling are economy and convenience (Selltiz et al, 1976, p. 516). To select two
hundred members from the approximately 34,000 of the United Ostomy Association would be expensive, time-consuming and perhaps impossible. For these reasons the sample for this study was selected by nonprobability procedures.

There are three major types of nonprobability samples: accidental, quota and purpose (Selltiz et al., 1976, p. 517).

In accidental sample, one simply reaches out and takes the cases that are at hand, continuing the process until the sample reached a designated size (Selltiz, 1976, p. 517).

In view of the fact that the elements involved in this study "just happened" to be members of a group, this sample will be considered a nonprobability sample of the accidental type.

The sample group for this study was drawn from the Hamilton and District Ostomy Association of Hamilton, Ontario, which is one of 527 chapters of the United Ostomy Association (Wray, 1979, p. 11). It is a self supported group whose purpose is to provide emotional support and education to persons with ostomies and their families, and to promote public understanding of persons with ostomies.

Location of Study: Hamilton, Ontario

The city of Hamilton, one of Canada's largest cities, is located near the western end of Lake Ontario.
The population of 529,371 includes the metropolitan area and the City of Burlington (Statistics Canada, 1978). Hamilton is 42 miles southeast of Toronto, and 50 miles northeast of Niagara Falls, New York. Both these cities are easily accessible via the Queen Elizabeth Way expressway. Hamilton is an industrial city that accounts for more than 52% of Canada's total steel production (Hamilton Chamber of Commerce, 1979, p. 54). It is the site of McMaster University and the McMaster University Medical Center. Hamilton has a theatre-auditorium, an art gallery, and the Hamilton Philharmonic and McMaster University orchestras.

More than 425,000 persons of the population of the city speak English as their first language, but Italian, French, and Ukrainian peoples are heavily represented, as are other ethnic communities (Statistics Canada, 1978). Hamilton has six medical hospitals, two of which have enterologist therapists on staff. Burlington has one hospital and one enterologist therapist on staff. Of interest to this study is the historical fact that Hamilton was settled by United Empire Loyalists who fled from United States after the American War of Independence.

The catchment area for the Hamilton and District Ostomy Association extends from Oakville to a westerly midpoint between Oakville and Guelph, and from Oakville in the north to Dunville in the south.
Hamilton Ostomy Sample

A list of all members of the Hamilton and District Ostomy Association, as of December, 1980, was obtained from the president of that association. There were 204 persons listed as members. Eighteen members were disqualified from participation in the study for the following reasons:

(1) Thirteen members were identified as persons who did not have ostomies by the president of the association.

(2) Four members had moved a considerable distance from the Hamilton area.

(3) The president of the association had participated in the pre-testing of the data collection instrument, and acted as unofficial advisor in several instances.

While the study was designed to consider all members having permanent ileostomies and colostomies, who were over the age of 17, there was no way of differentiating persons who did not meet these specifications from the total group. Consequently questionnaires were mailed to 186 members.
Return Rate of Questionnaire

Of the 186 questionnaires mailed, 13 were returned not filled out for a variety of reasons:

(1) One was marked, "address unknown".
(2) One was refused.
(3) One was returned blank with no explanation.
(4) Six were returned by persons who stated they did not have an ostomy.
(5) Four were returned, presumably by family members, because the members had died.
(6) One member telephoned to say the questionnaire was too long and he would not be returning it.

A return of 97 completed questionnaires represented 52% of the total number mailed. Of this number, 18 were not included in the study for the following reasons:

(1) Five arrived too late to be included.
(2) Two were from children.
(3) It appeared that two were from persons with temporary ostomies.
(4) One person had been hospitalized for several months; thus a measurement of social adjustment was not appropriate (Paykel et al, 1978, p. 127).
(5) One was from a blind person who had an ostomy;
consequently any impairment noted could have been due to a double stress.

(6) Two persons answered for their spouse, but did not indicate whether or not the answers had been dictated by their spouse.

(7) Three questionnaires were improperly filled out.

(8) Nine were filled out by persons whose ostomy was neither a colostomy nor an ileostomy.

(9) Two were filled out by the spouses of members who were deceased.

As a result of these exclusions, seventy respondents made up the study. Of these persons, 40 had colostomies and 30 had ileostomies. All were over the age of seventeen years.

Comparative Sample

The Social Adjustment Scale, Self Report Version, was utilized within the questionnaire, to test the level of social functioning of persons with ileostomies or colostomies within the sample. It was felt that a criteria, by which the level of functioning of the ostomy group could be compared, would be advantageous. A community group as selected and tested in a former study was utilized. This group has been described by Weissman et al. (1978,
p. 318), and her description is partially presented below.

Weissman's community sample was drawn from a longitudinal study of New Haven, Connecticut in 1967.

A systematic sample of 1095 households was selected and one adult (18 years of age or over) was chosen at random from each for inclusion in the sample (Weissman et al, 1978, p. 318).

This sample includes all ethnic, racial and socio-economic groups. Of the group interviewed in 1967, 77% were reinterviewed again in 1969, and 72% of those interviewed a second time were interviewed a third time in 1975-76.

No significant differences in social adjustment were noted in the initial and follow up interviews. Thus this group was considered a stable criterion by which the social functioning of the subjects of this study was examined.

Data Collection Method

A questionnaire was used to gather the data for this study for the following reasons:

(1) This was an efficient and economical method,
(2) The use of a questionnaire would eliminate interviewer bias,
(3) Identical wording and ordering of questions ensured a consistent data-seeking pattern.
(4) This method avoided face-to-face contact, thus giving the subject (a) a sense of anonymity and thus an opportunity to express his views without fear of confrontation or embarrassment, and (b) more time to comprehend the questions and determine an accurate answer.

During an interview with the president of the sample group, this writer was given the most recent list of the names and addresses of the members. He was assured that this information would be strictly confidential, and used only to mail out the questionnaire and a subsequent letter.

The risk of utilizing a questionnaire is that the return rate may be low. In order to compensate for this possibility:

(1) A letter containing an explanation and a pledge of subject-anonymity, and a stamped, self-addressed envelope was included with each questionnaire.

(2) A mailbox was arranged at the University of Windsor School of Social Work to increase the credibility of the study.

(3) The president of the Hamilton and District Ostomy Association submitted two articles in the association's February and April bulletin, explaining
the study and urging his fellow members to take part in the study. (see Appendix)

(4) The president of the association explained the study and urged his fellow members to participate, during a January meeting.

Data Collection Instrument

The instrument used to gather data for this study was a questionnaire that was divided in three sections. Section one consisted of closed-ended questions that would elicit qualitative information. Section two was made up of the Social Adjustment Scale--Self Report Version (Weissman et al, 1976, p. 1113-1115). Section three consisted of closed and open-ended questions that sought information regarding the cost of stoma maintenance equipment and medical coverage. (This information was not used in this study, but was given to C. Campbell, President of the Hamilton and District Ostomy Association for his own use.)

The two sections pertaining to the study were highly structured with fixed, alternative answers. This type of questionnaire is quickly completed and analyzed (Selltiz et al, 1976, p. 312). In addition this allowed the writer to precode the answers for quick and accurate analysis.
A disadvantage of fixed alternative answers to questions is that they may not offer the answer favoured by the subject. To overcome this a category "Other", was provided for some of the questions in Section I. Also, the writer pretested the questionnaire during interviews with ten persons with ostomies who were not included in the study.

The Social Adjustment Scale: Self Report (SAS-SR)

The SAS-SR instrument was included as a subsection of the questionnaire used in this study. The SAS-SR was derived from the Social Adjustment Scale (SAS), (Weissman, 1976, pp. 1111-15) which in turn was derived from the Scaled Interview to Assess Maladjustment (SSIAM) (Gurland et al, 1972, pp. 259-264).

This instrument recognizes that Social Functioning involves functioning in a variety of roles, (i.e. with family, at work, socially and so on), and that dysfunction in one role does not necessarily indicate total overall dysfunction (Gurland et al, 1972, pp. 259-64). Consequently the questionnaire is designed to measure functioning within six specific roles (i.e. Work, Social and Leisure, Extended Family, Marital, Parental and as a member of the Family Unit). The SAS-SR contains forty-two questions that measure both instrumental and expressive role performance in the six roles just delineated. These questions consider:

1. How the subject is performing the expected tasks of each role area,
(2) The amount of friction in each role area.
(3) Interpersonal relations, and

In addition it measures overall social functioning, which is the sum total of the above role measures (Weissman, 1976, p. 1112).

Limitations of the SAS-SR

Subjects who do not have all the roles contained within the SAS-SR test, are not rated in missing roles. As a consequence the aggregate scores only include persons who do have these roles, and therefore may not be reflective of the total sample.

In addition, if a person has moved from a level of impairment wherein, for example, he has not been able to work, to employment at the time of testing, even though he was functioning poorly in that role, he would have shown improvement. The SAS-SR would not indicate that improvement.

In addition, if a person was working at a level beneath his training and potential, he could rate his job performance highly, and thus the impairment that lead to his employment in a lesser field, would not be noted.
Validity and Reliability of the SAS-SR

The stability of results of a measuring instrument is determined on the basis of the consistency of measures on repeated applications (Selltix et al., 1976, p. 183).

Data collected with SAS-SR was compared with data gathered with the interview version of the test, the Social Adjustment Scale (SAS), on seventy-six depressed patients. It was statistically determined, using a Pearson R correlation and a comparison of means, that the self report version is comparable to the interview version for assessing role areas and overall adjustments (Weissman, 1976, pp. 1113-5).

Limitations of This Study

With regard to the reliability of the writer-designed section of the questionnaire, repeated measurements were not possible due to a short term deadline for completion of this study. Consequently the reliability of this section is not assured. Further the Accidental Sample was drawn using nonprobability techniques; therefore members of the total population did not have an opportunity to be included in the study. This study utilizes a small sample group, which represents less than .05 percent of the total population; therefore
external validity of the study is weakened. A further limitation of the study is the lack of a control group.

While the questionnaire designed by the researcher was pretested by ten persons with ostomies outside the sample of this study, the questionnaire contained a notable flaw. This flaw surfaced in the question regarding what topic's had been discussed during counselling. (See Appendix B, question 21). The answers 'yes' and 'no' had been considered sufficient to cover all possible answers. However, the subjects tended to check the yes answer and leave the no answer blank. As unmarked answers were not acceptable for this study, this segment of the study was marred. Consideration was thus given to the affirmative answers only.

An additional limitation of this study was the small number of young persons who were included in the sample. Lastly, this issue merits a study of more intensive research than the researcher had time to carry out.

Data Analysis

Part of the questionnaire was precoded for efficient and accurate analysis (i.e. Section I of the questionnaire and questions 71, 73, and 83 of Section II). Data from these areas were transferred onto IBM coding
sheets. The SAS-SR tests were scored manually and the scores were then transferred onto the coding sheets. All calculations and coding were double checked for accuracy by the writer and by one of two persons with undergraduate degrees in Psychology, Commerce and Computer Science. The Statistical Analysis Systems package was used to carry out a computer analysis of the data.
Operational Definitions

Appliance: The bag or pouch that is secured over the stoma, for the purpose of collecting faeces.


Colitis: Inflammation of the colon (part of the large intestine) Taber, 1970, C-67).

Colon: The large intestine from the end of the ileum (a section of the small intestine) to the anus (Taber, 1970, p. C-69).

Colonic resection: Surgical removal of part of the colon (Taber, 1970, R-19).

Colostomate: A person who has had colostomy surgery.

Colostomy: "Incision of the colon for the purpose of making a more or less permanent fistula between the bowel and the abdominal wall" (Taber, 1970, p. C-70).

Crohn's Disease: Inflammation of the intestines, usually of the small intestine (Taber, 1970, E-32).

Enterostomal Therapist: A person trained and certified in the complete health care of the ostomate (Hamilton and District Ostomy Association November, 1980, p. 2).
Ileo-colitis: Inflammation of the ileum (part of the small intestine).

Ileo-rectal anastomosis: A surgical procedure wherein the ileum (lower part of the small intestine) is joined end-to-end with the rectum (lower part of the large intestine). It involves surgical excision of part of the intestine.

Ileostomist: (also ileostomee) A person who has had an ileostomy.

Ileostomy: "Creation of a surgical passage through the abdominal wall into the ileum" (Taber, 1970, p. I-4).


Impotence: The inability to achieve or maintain an erection (Hyde, 1979, p. 532).

Irrigation Apparatus: The tubing, pitchers and assorted equipment used to put water or a water solution into the intestine through the stoma, with the purpose of "flushing out" faeces.

Married: Living with a person of the opposite sex in a permanent relationship.
Ostomates: Persons having had a "Surgically-formed fistula connecting the bowel or intestine to the outside, usually through the abdominal wall" (Thomas, 1977, p. 0-36). Thus an artificial anus exists at the site of the stoma.

Ostomy: "The surgically formed artificial opening which serves as the exit site for connections which the surgeon has made from the bowel or intestine to the outside" (Thomas, 1977, 0-36). Includes both colostomies and ileostomies, as well as other types that are not included in this study. It also refers to the surgical process itself.

Parasympathetic Nervous System: A division of the Autonomic Nervous System. The parasympathetic nerves dilate the blood vessels, slow the heart rate and are essential to the achievement of penile erection (Thompson and Murphy, 1966, p. 148) (Druss et al, 1968, p. 57).

Persons-at-risk: Individuals who are predisposed to social dysfunction as a result of ostomy surgery.

Post-convalescent: Beyond the first ten weeks after surgery.

Sacral Spinal Cord: The portion of the Spinal cord located in the lower back.
Social Functioning: "Includes the activities that are essential to satisfying relationships in the variety of social experiences of daily living" (Skidmore and Thackeray, 1976, p. 19).

Stoma: (pl. stomata) "An artificially created opening between a cavity or passage and the body's surface" (Thomas, 1977, p. S-104).

Sympathetic Nervous System: A division of the Autonomic Nervous System. The sympathetic nerves speed up the heart rate, constrict blood vessels and are essential to the ability to ejaculate (Thompson and Murphy, 1966, p. 148) (Druss et al, 1968, p. 57).

Ulcerative Colitis: Inflammation of the colon with ulceration of the lining of the colon (Taber, 1970, C-67).
Summary

In this chapter methods that were used in the process of implementing this study are presented in the following order. The purpose of this study, which is to examine and describe the characteristics and social adjustment of persons who have experienced ostomy surgery, was stated. The study was classified as a Quantitative-Descriptive Study of the Variable Relationship type. A population to which results of the study may be generalized was suggested, and the sample used in the study was classified. An overview of the city of Hamilton, the city from which the data was drawn was then presented, and the method used to develop the sample group of this study was outlined. At this point an existing sample from New Haven, Connecticut was described. The method by which data was collected was outlined, and the data collection instrument was described, as was the SAS-SR test of Social Adjustment. Validity and reliability of the SAS-SR test were considered. Finally, the limitations of the study were discussed, and the method used for data analysis was presented. Analysis of the data will be presented in the next two chapters. Chapter IV will deal with analysis of descriptive data.
CHAPTER IV

ANALYSIS OF DESCRIPTIVE DATA

The data collected for this study were of two types, descriptive and qualitative. For this reason both descriptive and inferential statistics were used in the analysis of the data. Descriptive data serves to summarize qualities of the subjects being studied. Analysis of descriptive data presents a picture of the sample group in terms of percentages and averages. Quantitative data reduces information to numerical form so that it can be measured. In this case a measurement was sought of the level of Social Adjustment of persons with ostomies. With this measurement statistical tests and comparisons could be made. In view of the differing natures of the data collected for this study, and the differing purposes of each type of data, the analysis of the data will be presented in separate chapters. This chapter will concern descriptive data, and information will be presented in the form of tables and an explanation of those tables.

Age of Subjects

The age of the subjects ranged from 20 years to 89 years. One subject declined to give her age. Four (5.79%) of the subjects were in their 20's and six (8.69%) individuals were in their 30's. Five (7.24%) of the subjects were in their 40's, and 12 (17.39%) were in their
TABLE 1 - Age of Subjects

<table>
<thead>
<tr>
<th>Age</th>
<th>Number of Subjects</th>
<th>Percentage of Subjects</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 - 29</td>
<td>4</td>
<td>5.79%</td>
</tr>
<tr>
<td>30 - 39</td>
<td>6</td>
<td>8.69%</td>
</tr>
<tr>
<td>40 - 49</td>
<td>5</td>
<td>7.24%</td>
</tr>
<tr>
<td>50 - 59</td>
<td>12</td>
<td>17.39%</td>
</tr>
<tr>
<td>60 - 69</td>
<td>21</td>
<td>30.43%</td>
</tr>
<tr>
<td>70 - 79</td>
<td>15</td>
<td>21.73%</td>
</tr>
<tr>
<td>80 - 89</td>
<td>6</td>
<td>8.69%</td>
</tr>
<tr>
<td>TOTALS</td>
<td>69</td>
<td>99.96%</td>
</tr>
</tbody>
</table>

Note: The age of one subject was not given.

50's. Twenty-one (30.43%) of the subjects were in their sixth decade of life. This group constituted the modal class average of the ages of individuals included in this research study. A further 15 (21.73%) were in their 70's, and six (8.69%) were in their 80's. Table 1 illustrates the distribution of age.

Sex of Subjects

Thirty-one (44.28%) of the subjects were female, and 39 (55.71%) of the subjects were male.
Marital Status

Eight (11.4%) of the subjects were unmarried, and four (7.1%) were widowed or widowers. Fifty-seven (81.4%) of the subjects were married, representing a great majority of the sample. None of the subjects were separated, divorced or lived within a common-law relationship.

TABLE 2 - Change of Marital Status After Ostomy Surgery

<table>
<thead>
<tr>
<th>Change of Marital Status</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change</td>
<td>4</td>
<td>5.71%</td>
</tr>
<tr>
<td>No Change</td>
<td>63</td>
<td>90.0</td>
</tr>
<tr>
<td>No Answer</td>
<td>3</td>
<td>4.28</td>
</tr>
<tr>
<td>TOTALS</td>
<td>70</td>
<td>99.99</td>
</tr>
</tbody>
</table>

Change of Marital Status

When questioned in regard to whether or not their marital status had changed after ostomy surgery, three individuals (4.2%) chose not to answer.

A further four subjects (5.7%) stated that their marital status changed in the following manner:

Two persons with ileostomies, of both sexes, and in their thirties, reported having gotten married after their surgery. A third person with an ileostomy stated that he would be getting married soon. A fourth person, also with an ileostomy, and in his thirties, stated that he had become divorced and had remarried after surgery.
Sixty-three individuals (90.0%) stated that their marital status had not changed following ostomy surgery. This frequency distribution is illustrated in Table 2.

**Type of Ostomy**

Forty (57.14%) subjects were permanent colostomates, and 30 (42.85%) subjects were permanent ileostomists.

**TABLE 3 - Diagnosis that Lead to Ostomy Surgery**

<table>
<thead>
<tr>
<th>Type of Illness</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ulcerative Colitis</td>
<td>25</td>
<td>35.71%</td>
</tr>
<tr>
<td>Crohn's Disease</td>
<td>2</td>
<td>2.85%</td>
</tr>
<tr>
<td>Congenital Birth Defect</td>
<td>1</td>
<td>1.42%</td>
</tr>
<tr>
<td>Cancer</td>
<td>37</td>
<td>52.85%</td>
</tr>
<tr>
<td>Trauma due to Accident or Combat</td>
<td>0</td>
<td>0.00%</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>4.28%</td>
</tr>
<tr>
<td>Don't Know</td>
<td>2</td>
<td>2.85%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td>70</td>
<td><strong>99.96%</strong></td>
</tr>
</tbody>
</table>

**Diagnosis that Lead to Ostomy Surgery**

Twenty-five (35.7%) of the subjects had required ostomy surgery due to ulcerative colitis, while two persons (2.8%) had Crohn's Disease. One subject had undergone
surgery at the age of one year (1.4%) due to a congenital birth defect. Cancer represented the modal average with 37 subjects (52.8%) having undergone ostomy surgery as a result of the disorder.

Two subjects attributed their need for ostomy surgery to radiation burns: one of these individuals stated that a further "cause" was diverticulosis.

One subject stated that formation of the stoma was required as a result of a non-malignant sigmoid tumor.

Two subjects (2.8%) did not know the diagnosis that necessitated ostomy surgery.

**Period of Time Passed Since Original Stoma Surgery**

In terms of the length of time that subject's had been ostomates, the range was from less than a year to 30 years. Four subjects (5.7%) had undergone surgery one year ago or less. Eighteen persons (25.7%) had been ostomates for a period of 2 - 2 1/2 years. A further 13 (18.5%) individuals had undergone surgery three to five years ago. Eighteen persons (25.7%) representing the modal average, had been ostomates for 6 - 10 years. Eleven persons (15.7%) had been ostomates for 11 - 15 years. A further six subjects (8.5%) had undergone stoma formation more than 15 years ago.
### TABLE 4 - Period of Time Passed Since Original Stoma was Formed

<table>
<thead>
<tr>
<th>Time Passed</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 year or less</td>
<td>4</td>
<td>5.71%</td>
</tr>
<tr>
<td>2 - 2 1/2 years</td>
<td>18</td>
<td>25.71%</td>
</tr>
<tr>
<td>3 - 5 years</td>
<td>13</td>
<td>18.57%</td>
</tr>
<tr>
<td>6 - 10 years</td>
<td>18</td>
<td>25.71%</td>
</tr>
<tr>
<td>11 - 15 years</td>
<td>11</td>
<td>15.71%</td>
</tr>
<tr>
<td>15 years or more</td>
<td>6</td>
<td>8.57%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>70</strong></td>
<td><strong>99.98%</strong></td>
</tr>
</tbody>
</table>

### TABLE 5 - State of Health as Stated by Subject

<table>
<thead>
<tr>
<th>Description of Health</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor</td>
<td>1</td>
<td>1.42%</td>
</tr>
<tr>
<td>Fair</td>
<td>15</td>
<td>21.42%</td>
</tr>
<tr>
<td>Good</td>
<td>35</td>
<td>50.00%</td>
</tr>
<tr>
<td>Excellent</td>
<td>19</td>
<td>27.14%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>70</strong></td>
<td><strong>99.98%</strong></td>
</tr>
</tbody>
</table>
State of Health as Stated by Subject

The majority of persons, 35 (50.0%) of the subjects perceived their health to be good, and a further 19 (27.1%) stated their health was excellent. Fifteen persons (21.4%) described their health as fair, and one subject (1.4%) described his health as poor.

TABLE 6 - Country of Birth

<table>
<thead>
<tr>
<th>Place of Birth</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td>55</td>
<td>78.57%</td>
</tr>
<tr>
<td>Britain</td>
<td>7</td>
<td>10.00%</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>2</td>
<td>2.85%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>8.57%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td>70</td>
<td><strong>99.99%</strong></td>
</tr>
</tbody>
</table>

Country of Birth

Fifty-five subjects (78.57%) were born in Canada; thereby making Canada the modal class average place of birth. A further seven subjects (10%) had been born in Britain, and two subjects (2.8%) had been born in The Netherlands. The six remaining subjects (8.5%) had been born in Bulgaria, Czechoslovakia, Germany, The United States, The Ukraine and Japan.
Religion

Fifty-five of the total number of 70 subjects were Protestant (78.5%), and 13 subjects (18.5%) were Catholic. The remaining two subjects (2.85%) were Buddhist and Greek Orthodox.

Level of Education

The education of the subjects as illustrated in Table 7. Eight subjects (11.4%) had received only an elementary school education, while 25 (35.71%) had attended high school from one to four years, thus representing the modal class. Five (7.1%) had graduated from grade 13. Seventeen (24.2%) subjects had a post secondary non-university education. With regard to university education, nine subjects (12.8%) had attended university but had not achieved a degree, and a further five (7.1%) had earned a postgraduate degree. Therefore a total of 15 persons (21%) had experienced some form of university education. While grades 9-12 represented the modal class, it is notable that 37 (52%) subjects had attained a level of education at or beyond grade 13.

Present Employment Status

Twenty-six persons (37%) of the sample group stated that they had retired from gainful employment. This group represented the modal class average. Sixteen persons (22%)
TABLE 7 - Level of Education of Subjects

<table>
<thead>
<tr>
<th>Level of Education</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elementary School: Grade 8 or less</td>
<td>8</td>
<td>11.4%</td>
</tr>
<tr>
<td>Secondary School: Grade 9-12 (incl.)</td>
<td>25</td>
<td>35.71%</td>
</tr>
<tr>
<td>Grade 13</td>
<td>5</td>
<td>7.14%</td>
</tr>
<tr>
<td>Post-Secondary Non-University</td>
<td>17</td>
<td>24.28%</td>
</tr>
<tr>
<td>University: Some University</td>
<td>9</td>
<td>12.85%</td>
</tr>
<tr>
<td>University Degree</td>
<td>1</td>
<td>1.42%</td>
</tr>
<tr>
<td>Post Graduate Degree</td>
<td>5</td>
<td>7.14%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>70</strong></td>
<td><strong>99.96%</strong></td>
</tr>
</tbody>
</table>

chose not to answer this question. A further 15 persons (21%) were employed on a full-time basis, while eight persons (11%) worked only part-time. Four persons reported that they were presently unemployed, and one person (1.4%) stated that he was on sick leave. Of those persons who were retired, 31 (88%) stated that they had not retired as a result of ostomy surgery.

**Income**

Eight persons (11.4%) declined to report their income. A further nine persons (12.8%) stated that their annual income was less than $5,000. Twelve persons (17.1%)
### TABLE 8 - Present Employment Status

<table>
<thead>
<tr>
<th>Type of Status</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Answer</td>
<td>16</td>
<td>22.85%</td>
</tr>
<tr>
<td>Retired</td>
<td>26</td>
<td>37.14%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4</td>
<td>5.71%</td>
</tr>
<tr>
<td>On Sick Leave</td>
<td>1</td>
<td>1.42%</td>
</tr>
<tr>
<td>Part Time</td>
<td>8</td>
<td>11.42%</td>
</tr>
<tr>
<td>Full Time</td>
<td>15</td>
<td>21.42%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>70</strong></td>
<td><strong>99.96%</strong></td>
</tr>
</tbody>
</table>

### TABLE 9 - Income

<table>
<thead>
<tr>
<th>Income</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Answer</td>
<td>8</td>
<td>11.4%</td>
</tr>
<tr>
<td>Under $5,000</td>
<td>9</td>
<td>12.8%</td>
</tr>
<tr>
<td>$5,000 - $9,999</td>
<td>12</td>
<td>17.1%</td>
</tr>
<tr>
<td>$10,000 - $14,999</td>
<td>11</td>
<td>15.7%</td>
</tr>
<tr>
<td>$15,000 - $19,999</td>
<td>8</td>
<td>11.4%</td>
</tr>
<tr>
<td>$20,000 and up</td>
<td>22</td>
<td>31.4%</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td><strong>70</strong></td>
<td><strong>99.8%</strong></td>
</tr>
</tbody>
</table>
reported an annual income of $5,000 to $9,999 inclusively. A further 11 persons (15.7%) reported a yearly income of $10,000 to $14,999 inclusively. Eight persons stated that their annual income was from $15,000 to $19,999 annually. Twenty-two persons (31%) represented the modal class average, with an annual income of $20,000 or more.

**Sexual Problems**

Of the 38 persons who answered this question, 19 (50%) reported having no sexual problems, and 19 (50%) reported sexual problems. Of the 19 persons who did not experience sexual problems, 13 were female and six were male. Of the 13 females who did not experience sexual problems, six had a mean average age of 65 and their stoma was a colostomy. The other seven females had a mean average age of 43 years and their stoma was an ileostomy. Of the six males who reported having no sexual difficulties, four had a mean average age of 43 and their stoma was an ileostomy. The other two males had a mean average age of 50 and their stomas were colostomies.

Of the 19 persons who reported sexual problems, 15 were male and four were female. Three of the females were ileostomists who reported pain during intercourse. The fourth female had a colostomy and reported having no interest in sexual activity. Of the 15 males who reported sexual problems, 11 could not achieve an erection, one complained
of premature ejaculation, one could not achieve ejaculation, one experienced fear of pain or physical damage during intercourse, and one complained of loss of libido. Of the 11 males who could not achieve an erection, five were ileostomists with a mean average age of 67, and six had a mean average age of 64, and their stoma was a colostomy. The four males who reported sexual problems other than erectile impairment had colostomies, and their mean average age was 70 years.

The mean average age of the females who reported having no sexual difficulties was 53 years, and the mean average age of males not having sexual problems was 50 years. The mean average age of males experiencing sexual problems was 67 years. The mean average age of the females who reported sexual problems could not be calculated as one woman declined to give her age; however the other three women were 39, 58 and 65 years of age.

It can be seen that the males of the sample of this study tended to experience considerably more sexual impairment than the females, and that impairment was likely to involve erectile dysfunction. Further, male sexual dysfunction appears to be associated with age, rather than type of stoma.
TABLE 10 - Problems Experienced During Intercourse During the Two Week Period Prior to Answering Questionnaire

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>3</td>
<td>7.89%</td>
</tr>
<tr>
<td>Fear of Embarrassment</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Fear of Pain or Physical Damage</td>
<td>1</td>
<td>2.63</td>
</tr>
<tr>
<td>No Interest</td>
<td>2</td>
<td>5.27</td>
</tr>
<tr>
<td>Premature Ejaculation</td>
<td>1</td>
<td>2.63</td>
</tr>
<tr>
<td>Inability to Ejaculate</td>
<td>1</td>
<td>2.63</td>
</tr>
<tr>
<td>Inability to Achieve Erection</td>
<td>11</td>
<td>28.95</td>
</tr>
<tr>
<td>No Problems</td>
<td>19</td>
<td>50.00</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td>38</td>
<td><strong>100.00%</strong></td>
</tr>
</tbody>
</table>

Body Image

As reported in the review of literature chapter, ostomy surgery represents a blow to self-image, and self-image is an important consideration of healthy adjustment. Meyers et al noted a tendency toward negative self-image among persons with ileostomies (Meyers et al, 1980, p. 3). Two questions in regard to body image were included in the questionnaire, one question dealt with the stoma, and the other with the body. It was felt that similar answers in each case, would indicate an inclusion of the stoma into
### TABLE 11 - Body Image: Description of Stoma

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Embarrassing</td>
<td>7</td>
<td>10.0%</td>
</tr>
<tr>
<td>Easily Hurt or Damaged</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Inconvenient</td>
<td>15</td>
<td>21.4%</td>
</tr>
<tr>
<td>Nuisance</td>
<td>12</td>
<td>17.1%</td>
</tr>
<tr>
<td>Acceptable</td>
<td>21</td>
<td>30.0%</td>
</tr>
<tr>
<td>Tolerable</td>
<td>8</td>
<td>11.4%</td>
</tr>
<tr>
<td>Life Saving</td>
<td>47</td>
<td>67.1%</td>
</tr>
<tr>
<td>Serves its Purpose</td>
<td>15</td>
<td>21.4%</td>
</tr>
<tr>
<td>Destroys Femininity/</td>
<td>4</td>
<td>5.7%</td>
</tr>
<tr>
<td>Masculinity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>8.5%</td>
</tr>
</tbody>
</table>

The subject's self-image. In addition, the answers would determine whether or not a negative self-image had been established. For these reasons Tables 11 and 12 will be discussed together under the heading of Body Image.

In regards to how the subjects perceived their stoma, 47 persons (67%), a large majority, viewed it as life saving. While the stoma was described as a nuisance by 12 persons, and as inconvenient by 15 persons, it was also considered to serve its purpose by 15 persons, acceptable by 21 persons (30%), and tolerable by eight
persons. The stoma was described as embarrassing seven
times, and considered destructive of the subject's
sexuality by four persons. Six subjects chose to de-
scribe their stoma in their own words. In each case their
descriptions indicated a positive attitude toward the
stoma. One person stated that the stoma gave him, "Freedom
from bathrooms and from being housebound". Another person
said, "Gives me a chance to be free of disease". The
subjects, thus, overwhelming perceive their stoma posi-
tively.

In this section of the subject of Body Image,
feelings in relation to the body itself are discussed
(see Table 12). The list of possible bad feelings toward
the body was drawn from an article that reported on a
psychosocial study of persons with Chrohn's disease
(Meyers et al, 1980, p. 6).

Twenty-six persons (44%) chose to describe their
feelings toward their body in their own words. Only two
of these persons felt negative in regard to their body,
(i.e. These persons comment, "Inconvenience or embarrassing
when passing gas" and "Embarrassed and non-confident sex-
wise". The remainder of these persons expressed happiness
and gratitude; however several persons reported feeling
"different". One person asked, "Why all the bad feelings?
Where are the good ones". Another person commented,
TABLE 12 - Body Image: Feelings That Describe Subject's Body Since Having Ostomy Surgery

<table>
<thead>
<tr>
<th>Feelings</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weak</td>
<td>3</td>
<td>5.08%</td>
</tr>
<tr>
<td>Ashamed</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Freak</td>
<td>1</td>
<td>1.69</td>
</tr>
<tr>
<td>Dirty</td>
<td>3</td>
<td>5.08</td>
</tr>
<tr>
<td>Guilty</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Unattractive</td>
<td>14</td>
<td>23.72</td>
</tr>
<tr>
<td>Angry,</td>
<td>4</td>
<td>6.77</td>
</tr>
<tr>
<td>Sad</td>
<td>4</td>
<td>6.77</td>
</tr>
<tr>
<td>Not a Full Man</td>
<td>4</td>
<td>6.77</td>
</tr>
<tr>
<td>or Woman</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>26</td>
<td>44.06</td>
</tr>
<tr>
<td><strong>TOTALS</strong></td>
<td>59</td>
<td>99.94%</td>
</tr>
</tbody>
</table>

Note: Some subjects chose not to answer this question, while others selected more than one answer.

"Never did have a good figure--so what the heck? But they say I have a kind face".

In relation to those who chose to check a provided adjective, 14 persons (23%) felt unattractive. Four persons felt their sexuality had been damaged. (Possibly these were the same persons who indicated a like feeling in regard to the stoma.) No one felt ashamed or guilty, one person felt
like a freak, and three persons felt dirty. Four persons expressed sadness, four persons reported feeling angry, and three persons described themselves as weak.

On the overall, 35 persons described negative feelings in relation to their body, while 24 persons reported neutral or positive feelings. In considering the words chosen to describe the stoma, and the adjectives chosen to describe their feelings about their body, there appears to be a considerable degree of incongruity. Perhaps this is the failure to achieve a psychological sense of wholeness described by Lane referred to earlier in the study (Lane 1975-76, pp. 191-98).
Counselling

During the review of literature regarding persons with ostomies, the writer noted a general agreement that these persons were in need of help. However, there appeared to be a lack of consensus as to which profession should attend to this matter. Dyk and Sutherland state that the medical profession assumes that the family of the patient will provide the needed emotional support. (Dyk and Sutherland, 1956, pp. 123-38). Dlin et al state that psychiatric help is not necessary, and adequate emotional support can be provided by the physician (Dlin et al, 1969, pp. 374-81). According to Morrow, "Especially immediately after surgery the surgeon is the most important person in the patient's life" (Morrow, 1976, p. 369). She adds, "The patient is afraid of antagonizing the person he needs most. As a result the patient may be afraid of discussing certain of his feelings or problems with the surgeon" (Morrow, 1976, p. 369). Perhaps this is an indication that counselling by a professional outside the field of medicine would benefit the patient. Lane believes that the social worker is best prepared to counsel the patient. (Lane, 1975-76, pp. 191-98).

In the last decade a new specialist, the enterostomal therapist has emerged as an expert in patient care of persons with ostomies. Self help groups (i.e. The United Ostomy
Association) have formed to attend to the needs of the ostomy patient.

The evident lack of agreement in this issue, lead to the following questions:

(1) Do persons with ostomies and their families want help?

(2) Are persons with ostomies receiving counselling?

(3) If so, what professions are involved in this counselling?

(4) When are persons with ostomies being counselled, before surgery, post-operatively or post-convalescence?

(5) What concerns are being discussed during counselling?

A series of questions were included in the research instrument, in an attempt to find answers to these questions. It is not the intent of the writer to "put down" those individuals who are giving assistance to the persons with an ostomy. Rather the purpose was to develop an overview of the existing situation. Observations will be presented in tabular form, and a short interpretative commentary is included. Relevant comments made by the subjects of this study are also included.

In order to answer the question, "Do persons with ostomies and their families want help?, it is appropriate to make use of comments and letters that were returned with
the questionnaire, as well as to look at the return rate of the questionnaire itself.

The questionnaire was excessively long, (12 pages, 87 questions). The questions were often personal and sought out information regarding age, sexual activity, interpersonal relationships and income, et cetera. In spite of these barriers, 95 (51%) of the questionnaires were returned completed, and the persons who completed them were from the very young (9 years) to the very old (89 years), from persons enjoying good health to a lady dying of terminal cancer.

One lady filled out the questionnaire for her ostomy husband who had passed away. (This data was excluded from the study). In addition she included an eight page handwritten letter. Following are excerpts from that letter:

In regards to first becoming informed that her husband had cancer, she states, "The Specialist told my husband he had cancer... 'You have the worst kind... Absolutely no sex. Any questions?' Later when he (her husband) would run into an old friend... 'How are you, you're looking good', my husband would reply, 'Oh I've got cancer... the worst kind'. It would just tear me apart," she added.

In relation to concerns that she and her husband may have wished to be counselled on, this lady states, "We were just dumb! Couldn't think of any questions and had my husband dead and buried in two weeks".
In relation to swelling of her husband's testicles, she says that the specialist told them this was due to the operation and "It's just something you have to live with". She adds, "That made me mad!"

In relation to her first sight of the stoma she says, "I just about reeled over when I first saw it".

In relation to her reason for writing the letter, she states, "If it helps only one person or changes one doctors attitude I will be most grateful".

Another spouse of a recently deceased person with an ostomy, returned the questionnaire with the comment, "If I could be of any help in this form or part of it, I would be very pleased to oblige. Thank you".

The widow, of a recently deceased person with an ostomy, included the following comment in a letter, "I have answered the general questions on your questionnaire and would be happy to answer any others that you may have".

A gentleman with an ostomy included the following comment in a letter in which he describes a pleasant life, "I appreciate the efforts on behalf of the ostomates".

One elderly gentleman did not fill in the questionnaire but wrote pages of comments on the back of the sheets of paper. He states that "doctors won't tell you anything that you want to know" and "if they did they would probably
scare you to death". He then filled two pages with alternative sources of information, which he states are "not on the street corner, Dance Hall Tavern or any other haunts of sin, filth and degradation". He states that in regards to the questions on family relationships, and social-leisure, "I am quite beyond such things, of such a petty and trivial nature". He further writes, "I have often had the words fired at me, of course by ignorant people, "Why Don't you Grow Up?, and in a great many cases there is a lot of truth in it". This man is communicating fear, anger and a sense of isolation, and his rather disjointed comments can be considered a plea for help. He includes his name and address.

The return rate, the letters and comments indicate that the person with an ostomy does want help.

When the subjects were queried as to whether they had received any counselling in relation to their stoma, 51 (72.85%) stated that they had, and 18 (25.71%) stated that they had not. One subject did not answer the question.

One subject who stated that he had not received any counselling, chose to explain that he had received a "few friendly visits from ........." which he described as "more social than professional but welcome".

Six subjects who had answered positively qualified their answer with comments. One subject stated "not much", another commented "very little", a third added "some", and
a fourth subject stated "just in caring for it" (the stoma). A fifth subject stated that he had "received limited counselling during hospital stay following surgery--mainly concerning the care of stoma". This subject also described his counselling as a "superficial discussion".

The sixth subject stated that his counselling consisted of "just a small description by surgeon". This subject further stated that (1) "there is much more knowledge now" than there had been at the time of his surgery (16 years ago), (2) "there was no close Association at the time of his surgery" (referring to the United Ostomy Association) and "Enterostomal therapists are very good".

From the above information, it appears that persons with ostomies are receiving counselling. There is some question, however, as to whether or not the counselling is usually sufficient and appropriate. In regards to which professions are involved in counselling persons with ostomies, see Table 13.

Status of Counsellors:

The enterologist therapist represents the modal class counsellor, as 38 subjects (54%) of those who answered this question reported having been counselled by this professional. Twenty-nine persons (41%) reported that they had received counselling from a member of the United Ostomy Association. A further 17 persons (24%) stated that their
TABLE 13 - Status of Those Who Counselling Subjects

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clergy</td>
<td>1</td>
<td>1.4%</td>
</tr>
<tr>
<td>Surgeon</td>
<td>17</td>
<td>24.2</td>
</tr>
<tr>
<td>Physician</td>
<td>10</td>
<td>14.2</td>
</tr>
<tr>
<td>Social Worker</td>
<td>2</td>
<td>2.8</td>
</tr>
<tr>
<td>Enteroologist Therapist</td>
<td>38</td>
<td>54.2</td>
</tr>
<tr>
<td>Nurse</td>
<td>11</td>
<td>15.7</td>
</tr>
<tr>
<td>Member of U.O.A.</td>
<td>29</td>
<td>41.42</td>
</tr>
</tbody>
</table>

surgeon had provided this service. Ten (14%) and 11 (15%) persons stated that they had received counselling from their physician and from a nurse, respectively. Only one person (1.4%) reported their clergyman as a counsellor, and only two persons (2.8%) stated they had received counselling from a social worker.

**Time Period of Counselling**

The majority of subjects (26%) reported that they had received counselling after the surgery had been performed, and during postconvalescence (10 or more weeks after surgery). A further 13 (25%) had received counselling after surgery only. Nine persons (17%) had been counselled
TABLE 14 - Time Period of Counselling

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before Ostomy Surgery</td>
<td>5</td>
</tr>
<tr>
<td>After Ostomy Surgery</td>
<td>13</td>
</tr>
<tr>
<td>Post Convalescence (10 or more weeks after surgery)</td>
<td>2</td>
</tr>
<tr>
<td>Before and After</td>
<td>7</td>
</tr>
<tr>
<td>Before and Post-convalescence</td>
<td>2</td>
</tr>
<tr>
<td>After Ostomy Surgery and Postconvalescence</td>
<td>14</td>
</tr>
<tr>
<td>Before, After and Post-convalescence</td>
<td>9</td>
</tr>
<tr>
<td>TOTALS</td>
<td>52</td>
</tr>
</tbody>
</table>

Note: Eighteen persons did not receive any counselling and therefore did not answer this question.

before, and after surgery as well as in the postconvalescent period as well. Five persons (9.6%) reported receiving counselling before the surgery, and a further two persons (3.8%) stated they had received counselling at least 10 weeks after surgery only. Seven persons (13%) stated they had received counselling before and after surgery, but not beyond that time period. Two persons (3.8%) stated that they had received counselling before ostomy surgery and at least 10 weeks after surgery. Eighteen persons, 25% of the ostomy sample, had never received any counselling.
Topics Discussed During Counselling

With regard to the question of concerns discussed during counselling, a flaw in wording on the questionnaire has impaired the data. (See page 2, question 21 of questionnaire in appendix). The provided answers (yes and no) were considered sufficient to cover all possible choices. However a large number of persons indicated only the affirmative answer, and left the negative answer blank. It appears that the answer, no, was to be assumed; however only a definite answer was acceptable for this study. Consequently large numbers of "No answers" distort the results of this question. Subjects were instructed to answer this question only if they had received counselling. As stated earlier in the paper study, 51 (72.8%) of the sample group indicated that they had received counselling. Comments about Table 15, will be restricted to affirmative answers only. (See page 88.)

According to the "yes" answers, it appears that:

1) Only 26 of the 70 subjects (37%) were given the opportunity to discuss their concerns in relation to possible rejection by their friends.

2) Only 16 (22%) persons stated they had a chance to discuss whether or not they should tell their friends and employer about their stoma.
TABLE 15 - Topics of Possible Discussion During Counselling

<table>
<thead>
<tr>
<th>Topic</th>
<th>Yes Frequency</th>
<th>No Frequency</th>
<th>No Answer Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance of you as an ostomate by friends</td>
<td>26 (37.1%)</td>
<td>15 (21.4%)</td>
<td>29 (41.4%)</td>
</tr>
<tr>
<td>Return to previous athletic activities</td>
<td>30 (42.8%)</td>
<td>11 (15.7%)</td>
<td>29 (41.4%)</td>
</tr>
<tr>
<td>Feelings whether or not to reveal ostomy status to friends, employer</td>
<td>16 (22.85%)</td>
<td>25 (35.7%)</td>
<td>29 (41.4%)</td>
</tr>
<tr>
<td>Feelings whether or not to let your spouse, children and other family members see your stoma</td>
<td>15 (21.4%)</td>
<td>26 (37.1%)</td>
<td>29 (41.4%)</td>
</tr>
<tr>
<td>Future surgery</td>
<td>23 (32.8%)</td>
<td>20 (28.5%)</td>
<td>27 (38.5%)</td>
</tr>
<tr>
<td>Irrigation</td>
<td>15 (21.4%)</td>
<td>19 (27.1%)</td>
<td>36 (51.4%)</td>
</tr>
<tr>
<td>Appliances</td>
<td>43 (61.4%)</td>
<td>5 (7.14%)</td>
<td>22 (31.4%)</td>
</tr>
<tr>
<td>Future Pregnancy</td>
<td>4 (5.7%)</td>
<td>14 (20.0%)</td>
<td>52 (74.2%)</td>
</tr>
<tr>
<td>Attractiveness to opposite sex</td>
<td>11 (15.7%)</td>
<td>19 (27.1%)</td>
<td>40 (57.1%)</td>
</tr>
<tr>
<td>Sexual problems</td>
<td>21 (30.0%)</td>
<td>18 (25.7%)</td>
<td>31 (44.2%)</td>
</tr>
<tr>
<td>Employment</td>
<td>17 (24.2%)</td>
<td>15 (21.4%)</td>
<td>38 (54.2%)</td>
</tr>
<tr>
<td>Intestinal noises, gas or odor</td>
<td>34 (48.5%)</td>
<td>13 (18.5%)</td>
<td>23 (32.8%)</td>
</tr>
<tr>
<td>Fears of dependency</td>
<td>15 (21.4%)</td>
<td>26 (37.1%)</td>
<td>29 (41.4%)</td>
</tr>
<tr>
<td>Fears of dying</td>
<td>4 (5.7%)</td>
<td>31 (44.2%)</td>
<td>35 (50.0%)</td>
</tr>
</tbody>
</table>
(3) Only 11 (15%) persons had the opportunity to verbalize their concerns in regard to their attractiveness as an ostomate to members of the opposite sex.

The above three topics may be of real concern to the person with an ostomy. The stoma patient tends to isolate himself from a social environment because he fears being a nuisance because of lost sphincter control, (Wirsching et al, 1975, p. 250). Morrow states that the new ostomy patient, "experiences profound feelings of horror, shame, degradation, and fear of rejection by others (Morrow, 1976, p. 369). She further reports, "a tendency toward withdrawal and seclusion perhaps in an attempt to avoid social rejection" (Morrow 1976, p. 360). Often the ileostomy patient must adjust to his new status during the years of dating, courtship, marriage, childbirth and career choice (Druss et al, 1969, p. 425). Dyk and Sutherland report that all the subjects in their study demonstrated fear of social rejection and anxiety in areas of social relationships (Dyk and Sutherland, 1956, p. 123). Counselling on issues of social relationships appears to be an important issue, that may be overlooked by professionals that provide counselling to the ostomy patient.

(4) Fifteen (21%) of the subjects stated that they had had the opportunity for counselling in regard
to feelings about whether or not they should let their spouse and other family members see their stoma. Whether or not this is an issue of importance to a person with an ostomy remains unanswered. However in a previous study it was noted that:

.....the patient's attitude toward having the colostomy seen and the family's response to seeing the colostomy were important determinants of the quality and extent of care given from upon discharge from the hospital and return home (Dyk and Sutherland, 1956, p.125).

Dyke and Sutherland further report that the person with a colostomy preferred to receive help with stoma care from their spouse, even though they feared that their spouse would be repulsed by the stoma and the care of it. Children tended to experience strong conflict regarding stoma sight and care, and became, (1) overly protective, (2) openly rejective, and (3) often developed fears of having rectal cancer (Dyk and Sutherland, 1956, pp. 128-29).

Twenty-three persons (32%) stated they had been able to discuss concerns they had in relation to future surgery. This is a valid issue in the ostomy surgery is often performed on the same patient more than one time (Lenneberg and Weiner, 1973, p. 14). In addition, fear of surgery may
be so intense that the preostomy patient may delay surgery or seek other kinds of treatment (Dyk and Sutherland, 1956, p. 124). Of the 38 patients in the Dyk and Sutherland study it is reported that:

Anxiety and fear of injury, in some cases mounting to confusion, panic or despair, were reported by all as reactions to impending surgery (Dyk and Sutherland, 1956, p. 124).

(6) Forty-three persons (61%) reported having the opportunity to discuss the use of appliances. A further 15 persons (21%) stated that they had received counselling in relation to irrigation. Both these issues would not be of concern to the ostomy patient, as they constitute an either/or situation. The patient who irrigates his ostomy does not use appliances and the patient who makes use of an appliance does not irrigate the ostomy. It has been estimated that only 50% of persons with ostomies utilize irrigation as a form of control of elimination. (Personal communication with Yvonne Forler, Reg. N., E.T., Henderson General Hospital, Hamilton, Ontario).

(7) Four persons reported having discussed future pregnancy during counselling. This small number of persons is consistent with the ages of the
subjects of this study i.e. Sixty persons (85%) were over 40 years of age; therefore this topic would be of little personal importance to the majority of persons in the sample.

Twenty-one persons (30%) stated that they had had an opportunity for counselling in regard to sexual problems. Types of sexual problems were dealt with a specific question (See Table 10). This question was incorporated into marital role functioning; therefore persons without a spouse did not have the opportunity to comment on possible sexual difficulties. In addition persons over 80 years appeared reluctant to answer questions regarding sexual activity, and the writer chose not to insist that they do so. As can be seen in Table 10, 38 persons answered question 73, which dealt with sexual problems. Nineteen (50%) of these persons reported sexual difficulties. Obviously sexuality is an issue of real concern to the person with an ostomy. However, whether those persons reporting sexual problems were the same persons who reported receiving sexual counselling remains unknown.

Seventeen persons (24%) stated that they had received counselling in relation to employment.
In view of the large number of retired persons in this sample, it appears that most persons who would benefit from counselling in this regard had occasion to receive this counselling, \(n=26; 37\%\) see Table 8).

(10) In regard to counselling about intestinal noises, gas or odor, 34 persons (48\%) reported having received counselling on this topic. In a previous study 72\% of the patients questioned, reported that they had decreased their social relationships, and fear of odor or spillage was most often given as the reason (Morrow, 1976, p. 370). This fear of spillage and odor are of real concern to the person with an ostomy (Druss et al, 1968, pp. 53-9).

(11) Fifteen persons (21\%) reported having received counselling in relation to their fears of dependency. According to a previous study, both sexes consistently expressed concern lest they become dependent on their children for physical care or financial assistance (Dyk and Sutherland, 1956, p. 130).

(12) In regard to the fear of dying, only four persons (5.7\%) reported having received counselling on this subject. This appears rather ironic in view of the fact that 30 persons (42\%) reported
having received counselling in regard to athletic activities, a valid but lesser important issue. In addition, this writer was provided with a current list of members of the Hamilton Ostomy Association in mid-December of 1980. When the questionnaires were returned in May, 1981 six members had died. In a previous study 21% of 214 colostomy patients, expressed a fear of dying (Wirsching et al, 1975, p. 248). McCawley et al state:

Whatever the pattern of response (to the ostomy) patients need to express their feelings of grief and anger and their fears including the fear of death (McCawley et al, 1975, p. 152).

It appears that most ostomy patients are not given this opportunity to discuss their fears of death during counselling.

Summary

This chapter has included demographic and other descriptive characteristics of the research sample of this study. In addition, a brief description of counselling received by the subjects in relation to their surgery has been presented, so that implications for social work involvement with persons with ostomies might be more accurately considered.

In terms of the data, the average member is of the research sample can be described in this manner:
The typical subject is male and in his sixth decade of life. He is married and the marriage has remained intact despite the formation of a stoma. The subject was born in Canada and is Protestant. The stoma is a colostomy, necessitated by a diagnosis of cancer, and created from 6 - 10 years ago. The subject is likely to have attained a post high school level of education, and his income is upwards of $20,000 annually. He is retired from gainful employment, and enjoys good health. He may experience erectile dysfunction. The subject perceives his stoma as life-saving and acceptable, but describes his body as unattractive since the surgery.

The subject received counselling in relation to ostomy surgery, from an enterostomal therapist after the surgery and after he left hospital. While it cannot be specifically stated, there are indications that he may have received counselling in the following matters:

1. Whether or not his friends would accept him with a stoma.
2. Whether or not he would be able to return to presurgical athletic activities.
3. Future surgery.
5. Sexual functioning.
6. Noise, gas, and odor from the stoma.

In addition there are indications that he was
not counselled in the following issues:

(1) Whether or not he should conceal his ostomy status from his friends and employer,

(2) Whether or not he should conceal the stoma itself from his wife, children and other family members,

(3) His feelings of attractiveness to the opposite sex,

(4) His fears of dying and dependency,

(5) Irrigation,

The next chapter will present an analysis of the level of social adjustment of the sample subject, on an overall basis, and in relation to family, work and social-leisure role areas.
CHAPTER V

ANALYSIS OF QUANTITATIVE DATA

In Chapter IV an analysis of descriptive data provided the reader with a profile of the subjects of this study. This chapter will present the analysis of quantitative data that was gathered in order to examine the social adjustment of those subjects. As the data was being coded a number of possible tendencies lead to several questions:

(1) Do males tend to adapt to formation of a stoma more successfully than females?

(2) Does age have any bearing on the level of social adjustment of a person with an ostomy?

(3) Is there a significant difference between the social adjustment of a person with an ileostomy and a person with a colostomy?

(4) How does the level of social adjustment of a person with ileostomies and colostomies compare to the level achieved in a random community sample?

A number of statistical tests were utilized in order to seek out answers for these questions.

The components of this chapter are presented in the following sequence:
(1) In that the data was collected according to a standardized test of social adjustment, comments are made in relation to the scoring methods used for that instrument of measure.

(2) Then an explanation of the method used to analyze computer generated t-tests is given.

(3) An analysis and interpretation of various intra-sample tests are presented in the following order:
   (i) Males versus Females with ostomies,
   (ii) Age related tests,
   (iii) Persons with ileostomies and colostomies versus a comparative group,

Scoring of the SAS-SR Test

The SAS-SR test is composed of 54 questions with five graduated possible responses that are answered by circling the most appropriate response. Seven role areas are calculated by summing the items circled in each role area and dividing the sum by the number of questions answered in that role area. The Overall Social adjustment score is the sum of all items divided by the number of items scored. Subjects score only those roles that are appropriate to their own life situation. The writer took the liberty of making two special concessions regarding age of subject and questions concerning sexual intercourse and dating.
(1) Persons over 65 years of age and not living in a marital arrangement were not scored on questions that concerned dating i.e. (54(28) and 55(29)).

(2) Persons' 80 and over and living in a marital arrangement, were not scored on questions regarding sexual intercourse i.e. ((70)44; (71); (72)45; and (73)).

Analysis of Computer Generated T-Tests

Comments regarding interpretation of computer generated t-tests are appropriate at this point. The SAS Institute Statistical Analysis System was used to test the means of various groups. This procedure provides a t-value to test the hypothesis that there is no difference between the means of the two groups (a non-directional t-test) (SAS User's Guide, 1979, p. 425). This study concerned itself with the one tail (directional) t-test. Consequently the two-tail probability provided by the computer was divided by two to arrive at a probability value with which to reject or accept a directional hypothesis.

A second characteristic of the SAS t-test procedure is that it is "valid only for variables that are normally and independently distributed within each group". (SAS User's Guide, 1979, p. 425). The computer generates a t-value, the degrees of freedom and the probability level
on an equal variance. In the case of unequal variance, the t-statistics are calculated according to Satterthwaite's approximation. An F value is also generated so the interpretation of the t-test can be made according to the appropriate type of variance.

Interpretation of the t-tests, therefore consisted of a series of steps.

(1) The first step was to examine the probability of F, to determine whether variance was equal or not.

(2) If the F probability was less than .05 percent, the t-related values for an unequal variance were used. If it was greater than .05 percent the t-related values for an equal variance were used.

(3) Then the probability of t was divided in half to test a directional hypothesis.

(4) If the reduced probability of t was less than .05, the confidence level, the null hypothesis was rejected and the stated hypothesis was accepted. A key table of the results of the t-tests can be seen on page 101 for a comprehensive comparison.

Males Versus Females with Ostomies

There was no significant difference at an alpha level of .05, between the mean averages scored by the
<table>
<thead>
<tr>
<th>Populations</th>
<th>Social Adjustment Role Means</th>
<th>Overall Adjustment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Work</td>
<td>Social-Leisure</td>
</tr>
<tr>
<td>Hamilton Sample</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>29</td>
<td>1.39</td>
</tr>
<tr>
<td>Male</td>
<td>21</td>
<td>1.21</td>
</tr>
<tr>
<td>p-value</td>
<td>.04</td>
<td>N.S.</td>
</tr>
<tr>
<td>ileostomy</td>
<td>26</td>
<td>1.37</td>
</tr>
<tr>
<td>p-value</td>
<td>N.S.</td>
<td>.03</td>
</tr>
<tr>
<td>Young Adult</td>
<td>11</td>
<td>1.31</td>
</tr>
<tr>
<td>Middle-Age</td>
<td>23</td>
<td>1.30</td>
</tr>
<tr>
<td>p-value</td>
<td>N.S.</td>
<td>.03</td>
</tr>
<tr>
<td>Young Adult</td>
<td>11</td>
<td>1.31</td>
</tr>
<tr>
<td>Retired</td>
<td>16</td>
<td>1.33</td>
</tr>
<tr>
<td>p-value</td>
<td>N.S.</td>
<td>.005</td>
</tr>
<tr>
<td>Middle-Age</td>
<td>23</td>
<td>1.30</td>
</tr>
<tr>
<td>Retired</td>
<td>16</td>
<td>1.33</td>
</tr>
<tr>
<td>p-value</td>
<td>N.S.</td>
<td>N.S.</td>
</tr>
</tbody>
</table>

Note: Numbers vary because not all subjects had all six roles.
N.S. Not significant
females and males in Overall Social Adjustment and in five of the six roles tested. The Work Role functioning test did result in a significant difference.

The scores of the five roles and those of Overall Social Adjustment were normally distributed. However there was some difference between the mean average of the scores of the males and females in Family Unit functioning (i.e. females scored 0.23 higher than males in this role). Weissman et al reported similar results:

Of considerable interest is the absence of substantial sex differences in role performance in all populations with the exception of family unit role depressives (females more impaired); work and family unit for the community sample (females more impaired) (Weissman et al, 1978, p. 321).

No significance in the Family Unit Role in this study may be due to the difference in sample size this life role area (i.e. While 57 observations were tested in this case, the Weissman Family Unit test includes 464 observations).

Of further interest is the similarity of the mean average scores of the males and females of the Weissman community sample in the Extended Family and Marital Roles (i.e. The difference was only 0.01 and 0.05 respectively). While the differences between the mean average scores of the females and males of this study in the Extended Family and Marital roles is not significant, they are greater than
the differences in Weissman's community sample. (Males with ostomies scored 0.12 higher than females with ostomies scored only 0.14 higher than males with ostomies in Extended Family Role Functioning). Perhaps this slight difference is an indication that males and females may function differently than each other in these role areas, after ostomy surgery. Further studies with increased sample sizes may magnify this difference. Noted previously, it is concluded that females with ostomies achieve significantly higher scores than males with ostomies, on a test of work role functioning, thus demonstrating a more impaired level of adjustment in this life role area. This conclusion raises two questions:

(1) Why are the females with ostomies exhibiting more dysfunction than males with ostomies, in the work role area?

(2) Did the males and females with ostomies, in this study, score higher than the males and the females in Weissman's community sample, in a test of work role functioning?

Upon comparing the standard deviations and the mean averages of the ostomy group, with the data from Weissman's community sample, it was found that there were no significant differences between, (1) the scores of the females of the two groups and (2) the scores of the males of the two groups at an alpha-level of .05. (see Table 17)
### TABLE 17 - Work Role Mean Scores

<table>
<thead>
<tr>
<th>Sample Groups</th>
<th>N</th>
<th>X</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hamilton Ostomy Group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>29</td>
<td>1.39</td>
<td>.45</td>
</tr>
<tr>
<td>Male</td>
<td>21</td>
<td>1.21</td>
<td>.29</td>
</tr>
<tr>
<td>p-value</td>
<td></td>
<td>.04</td>
<td></td>
</tr>
<tr>
<td>Hamilton Ostomy Group Females</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Sample (Weissman's) Females</td>
<td>272</td>
<td>1.46</td>
<td>.50</td>
</tr>
<tr>
<td>p-value</td>
<td></td>
<td>N.S.</td>
<td></td>
</tr>
<tr>
<td>Hamilton Ostomy Group Males</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Sample Males</td>
<td>127</td>
<td>1.26</td>
<td>.31</td>
</tr>
<tr>
<td>p-value</td>
<td></td>
<td>N.S.</td>
<td></td>
</tr>
</tbody>
</table>

Thus we conclude:

1. Males with ostomies demonstrate a level of work functioning that is similar to the level achieved by males who do not have ostomies.
2. Females with ostomies and females who do not have ostomies function similarly in a work role area.
3. Both females with ostomies and females not having
ostomies exhibit more impairment than males with ostomies and males not having ostomies, in tests of work role functioning. Consequently we conclude that while females with ostomies tend to function less effectively than males with ostomies, the impairment is more likely to be due to sexual status than due to formation of a stoma.

Our original question then becomes, why do females exhibit more dysfunction than males in a test of work role functioning? Perhaps the significant difference between the scores of the males and females is due to the type of work they consider to be their primary role. The SAS-SR assesses the work role in three areas, housework, school and employment outside the home. Each subject is directed to answer only those questions that pertain to his primary work role area. Table 18 describes the frequency distribution of the subject-selected work role areas.

Fourteen percent of the males and 72% of the females perceived their primary work to be housework. Eighty-five percent of the males and 24% of the females denoted their primary work role as employment outside of the home. Hence the majority of the males were employed outside the home and the majority of the females worked as homemakers. Perhaps gainful employment increases one's sense of self-worth, or perhaps employment outside the
TABLE 18 - Primary Work Role Areas

<table>
<thead>
<tr>
<th>Work Role Area</th>
<th>Males</th>
<th></th>
<th>Females</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percentage</td>
<td>Frequency</td>
<td>Percentage</td>
</tr>
<tr>
<td>Housework</td>
<td>3</td>
<td>14.2</td>
<td>21</td>
<td>72.4</td>
</tr>
<tr>
<td>Student</td>
<td>0</td>
<td>0.0</td>
<td>1</td>
<td>3.4</td>
</tr>
<tr>
<td>Employed Outside of Home</td>
<td>18</td>
<td>.85.7</td>
<td>7</td>
<td>24.1</td>
</tr>
<tr>
<td>TOTALS</td>
<td>21</td>
<td>100%</td>
<td>29</td>
<td>100%</td>
</tr>
</tbody>
</table>

home enforces social interaction that in turn enhances the work role. Weissman et al reported that in their community sample, work adjustment is better for males than females, and better for employed women than for housewives (Weissman et al, 1980, p. 323). This study concurs with that opinion. In a study which compares the work role scores of housewives with those of working wives, it was noted that housewives demonstrated significantly more impairment than wives who were gainfully employed outside the home (Newberry et al, 1979, p. 282).

Persons with Colostomies Versus Persons with Ileostomies

As can be seen in the second row of Table 16, there were no significant differences at an alpha level of .05, between the mean average scores of the ileostomies group and the mean average scores of the group with
colostomies, in the life role areas of work, marriage and parent. Thus we can conclude that the group with ileostomies are functioning at a level that is similar to the group with colostomies, in these life role areas.

With regard to the area of parental role however, the difference between the standard deviation of 0.57 of the ileostomist group and the standard deviation of 0.77 of the colostomy group merits comments. Upon examining the scores of the two groups, it was noted that four of the six persons with colostomies achieved a score of 1.00. This score was lower than any attained by persons in the ileostomist group. This score was attained by colostomates who were 68, 78, 80 and 89 years of age; therefore it is unlikely that the children living in the subject's home, for the two week period preceding the test, were natural offspring. The other two subjects in the colostomy group were aged 44 and 56, and achieved a score of 2.50. This score was higher than 12 of the 13 ileostomists tested in this role. The mean average age of the ileostomists tested in the parental role was 48.8. Although these facts do not make a significant comment, they describe the difference between the standard deviations of the two groups, and they suggest that the parenting role may be perceived differently by the parents and grandparents.

In the following three role areas, social-leisure, extended family and family unit, the ileostomist group
demonstrated significantly higher levels of impairment than the group with colostomies. This significance is at alpha levels of 0.003, 0.01 and 0.008 respectively. (see Table 16) In addition, persons with ileostomies achieved higher scores than the persons with colostomies, in a test of Overall Social Adjustment, thereby demonstrating a higher overall level of maladjustment. (see Table 16)

Implications of Age on Role Functioning and Overall Social Adjustment

Differences in the scores achieved by the younger and older persons was apparent as early as the coding stage of this study. In addition, tests of inference of those with colostomies and those with ileostomies pointed out that persons with ileostomies demonstrated significantly more impairment. According to the literature persons with ileostomies are usually of dating and reproducing age, while persons with colostomies are usually over forty (Gambrell, 1973, p. 3). An important consideration surfaced: "Are persons with ileostomies functioning at a more impaired level as a result of that type of ostomy, or because they are younger? In order to develop a clearer understanding of the ileostomist, the writer prepared an "if statement" to direct the computer to divide the data into three specific age groups. As the age of the subjects extended over a range of 69 years, the groups were formed in the following manner: Persons
between the ages of 18 and 40, inclusively were considered to be Young Adults; (Group 1) persons between the ages of 41 and 65 inclusively were considered to be Middle aged adults; (Group 2) and those age 66 and above were considered Retired adults; (Group 3). (see Table 19)

Repeated t-tests were then carried out on each possible combination (i.e. 1 vs. 2, 1 vs. 3, and 2 vs. 3). The results of those tests are reported at this time.

TABLE 19 - Age by Group

<table>
<thead>
<tr>
<th>Age</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young Adults (18-40 incl.)</td>
<td>11</td>
<td>15.71%</td>
</tr>
<tr>
<td>Middle Aged (41-65 incl.)</td>
<td>27</td>
<td>38.57%</td>
</tr>
<tr>
<td>Retired (65 and up)</td>
<td>32</td>
<td>45.71%</td>
</tr>
<tr>
<td>TOTALS</td>
<td>70</td>
<td>99.99%</td>
</tr>
</tbody>
</table>

Young Adults with Ostomies Versus Middle Aged Adults with Ostomies

There was no significant difference between the mean average scores of young adults (under 41) and middle-aged adults (younger than 66 and older than 40), at an alpha level of 0.05 in five of the six roles, and
in Overall Social Functioning. (see row three of Table 16.)

There was a significant difference between the two age
groups in the Social-Leisure role.

Interest is the difference in the mean average
scores achieved by the middle-aged group in the role of
Marital Functioning, as a spouse. The mean average score
of the Young Adult group was 1.71 and the mean average
score of the Middle Aged Group was 2.00. Consequently some
idiosyncracy of marital functioning was indicated. The
scores of the Middle-Aged Group ranged from 1.33 to 3.13,
and the scores of the Young Adult group ranged from 1.44
to 2.20. Closer examination of the answers provided the
following information.

In the Young Adult Group:

1. All six persons (100%) had sexual intercourse at
   least twice a week, although two females stated
   they had pain during intercourse.

2. All six persons (100%) had ileostomies.

3. Two women (33%) had gotten married after
   ostomy surgery.

4. One man had gotten divorced and remarried
   after ostomy surgery.

5. All six persons were between 35 and 40 years
   of age.
In the Middle Aged Group:

(1) Eight persons (33%) did not engage in sexual intercourse. Of these persons six had colostomies and two had ileostomies, and seven (29%) were male. Of these persons, five were in their 50's and three were in their 60's.

(2) Five persons (20%) stated that they experienced problems during intercourse. Of these persons, two were female (one experienced pain and the other reduced libido).

Two males stated they could not achieve an erection and one male suffered premature ejaculation.

(3) None of the 24 persons (100%) experienced a change in marital status.

(4) Twenty-nine percent of the Middle aged group were males who did not have sexual intercourse with their wives. (This may explain the slightly higher scores achieved by the males in the marital role).

Clearly the group of young persons with an ostomy are more sexually active than the group of middle-aged persons with an ostomy. In addition males in the middle-age group experience more sexual problems than males in the younger group.
While the differences between the young adult and middle-age adult groups indicate that the middle-aged male demonstrates more sexual dysfunction, other variables must be considered:

(1) The entire young adult group had ileostomies, while the majority of the middle-aged group had colostomies. In addition six of the eight persons in the middle-aged group who did not engage in sexual intercourse had colostomies.

(2) While persons with colostomies are usually older than persons with ileostomies, previous studies indicate that other surgical variables may influence sexual activity. Burnham et al reported that ileostomists who did not experience rectal excision were more sexually active than ileostomists who did (Burnham et al, 1977, p. 673). Whether or not this group of ileostomists underwent rectal excision is not known. Wirsching et al noted that males having colostomies reported more decrease in sexual activity than males who underwent colonic resection of the rectum (Wirsching et al, 1975, pp. 245-56). This is an indication
that the type of surgery experienced by the persons with an ileostomy and a colostomy may be an equally or more important consideration than age of subject in relation to sexual activity and therefore in relation to the marital role.

In relation to the social-leisure role, and the two age groups tested in this role area, further comments are indicated. In that the youngest subject of this study was 20 years of age and the oldest subject was 89 years of age, an age range of 69 years was represented by the Hamilton Ostomy Association sample group. When a decision to subdivide the sample into age groups was made, three groups were used for the following reasons:

1. More than three groups would have been cumbersome,
2. More than three groups have resulted in overly small subsample sizes
3. Three groups served to divide the sample of 70 persons into age groups that were of at least a 20 year span.

While this rationale is reasonable, it lead to an overinclusion of psychosocial age groups, (i.e. Persons in their 20's were included in the same subgroup as persons in their 30's.) Both these ages represent a productive period of life, but the life activity patterns of each
group are clearly different. The 20 year old is likely to be beginning work, or attending university, and is attempting to achieve intimate relationships with persons outside his family. The person in his 30's is likely to be struggling for a promotion, and involved with a mortgage, a wife and a family. While social interaction is an important part of life for persons in their 30's, it is likely to be of greater concern to the younger group. Perhaps if the young adult group had included only persons up to age 30, an even greater difference in social functioning may have been evident.

Young Adults with Ostomies Versus Retired Adults with Ostomies

The results of this series of tests can be seen in row four of Table 16. The younger group demonstrated more overall social dysfunction and more impaired functioning than the retired age group, in the following role areas:

(1) Social-Leisure
(2) Extended Family
(3) Family Unit

Significance was indicated at alpha levels of 0.01, 0.005, 0.03, and 0.04 respectively. Clearly the Young Adult is experiencing more difficulties in their life-role relationships and activities. In relation to the Social-Leisure
Role, it is notable that the difference between the level of functioning of the Young Adult and the Middle-Age Adult is significant at 0.03, and the difference between the functioning of the Young Adult Group and the Retired Adult Group is significant at an alpha level of 0.005.

A comparison of the means achieved by the Young Adult Group and the Retired Adult Group, in the role of member of a nuclear family unit, indicated a significant difference in the level of functioning of these groups. The Young Adult Group demonstrated a significantly higher level of impairment in this role area. This conclusion must be considered with discretion, however, in view of the small sample size (N=6) of the Young Adult Group.

Although the small numbers of young persons who qualified as Young Adults weaken this series of tests, interesting and indicative results surface. This can be seen in the similarity of the mean average scores of the Retired Age Group to the mean average scores of the Colostomy Group. (see rows two and four of Table 16) In addition the roles that test significantly different in the Ileostomist versus Colostomate series of tests, are the same roles that test significantly different in the Young Adult versus the Retired Adult series of tests. For reasons of conjecture the mean average ages of those persons with an ileostomy and those persons with a
colostomy were calculated. The mean average age of the persons in the Ileostomy Group was 48.62 years, and the mean average age of the persons in the Colostomy Group was 68.97 years. Once again there is an indication that dysfunction increases as age decreases in nuclear and extended family relationships, in social-leisure relationships and activities and in overall social adjustment. However the levels of functioning may be effected by the type of ostomy, or perhaps being young and having an ileostomy may constitute a particularly stressful combination. Tests of correlation of these two variables are indicated.

**Middle-aged Persons with Ostomies Versus Retired Persons with Ostomies**

As can be seen in row five of Table 16, there was no difference in the level of functioning of these two age groups in five of six role areas and in Overall Social Adjustment. A significant difference was noted in the life role of parent. This conclusion must be viewed tentatively, however, in lieu of the small numbers of persons (n=6 and n=9) who qualified in this role. Closer examination of the data does indicate a tendency that is similar to the parental role test of ileostomists versus persons with colostomies. (see page 107). Four of the six retired persons achieved a score of 1.00. These persons
are the same four persons tested in this role area, and commented upon page 107. The score of 1.00 was lower than any of the nine observations tested in the middle-aged group.

The scores of the Retired Group ranged from 1.00 to 1.75 and the mean average age of this group was 71 years. The scores of the Middle-Aged group ranged from 1.25 to 2.50, and the mean average age of this group was 48.8. It is interesting to note the similarities of the data of these age groups to the data of the parental group tested in the Ileostomy versus Colostomy series. Notable too, is while the data is similar, significance was concluded in this case. Further tests of the parental role in relation to age and type of ostomy are needed to explore the level of parental role functioning.

Persons with Ileostomies and Persons with Colostomies Versus a Comparative Group

Having made inferential tests of the variables, age, gender and status of ostomy, from data gained through the Hamilton Ostomy Association, a number of conclusions were made.

(1) It was apparent that persons with ileostomies were demonstrating more maladjustment than persons with colostomies.
(2) It was concluded that Young Adults with ostomies demonstrate a greater degree of impairment in several role areas, than retired persons with ostomies.

(3) It was noted that the colostomy group achieved mean average scores that were lower than the mean average scores of the Weissman Community Sample in four of five life role areas, as well as in Overall Social Adjustment (Weissman et al, 1978, p. 322).

In view of these observations, three questions were formulated.

(1) How did the level of functioning demonstrated by the persons with colostomies in this sample group compare with the level of functioning of Weissman's Community Sample?

(2) Was the impairment noted in the ileostomy group significantly different than the functioning of the Community Sample?

(3) Could the data published by Weissman et al be used to make a valid comparison?

In relation to question three, Weissman suggests that the data presented in the article, "Social Adjustment By Self-Report In A Community Sample and In Psychiatric Outpatients", can be used as norms in evaluative research (Weissman et al, 1978, p. 325). She further suggests that
these norms can be "used as a criteria "to detect areas of social dysfunction" (Weissman et al, 1978, p. 326). Edwards et al suggest that "the community norms of adjustment may be used as a relatively stable criterion against which treatment programs can be evaluated" (Weissman et al, 1978, p. 325). It was determined that inferential tests of the Hamilton sample and the Community sample would be appropriate for the following reasons:

(1) The reliability and validity of the SAS-SR test has been tested in previous research (Weissman, 1975, pp. 357-365).

(2) A detailed description of the Community Sample Group is available (Weissman et al, 1978, pp. 318 and 321).

(3) Both the Community Sample and the Hamilton Ostomy Association Sample were measured by the SAS-SR test.

(4) While such a comparison may not be ideal, it is advantageous to utilize this existing means of comparison.

Although the Community Sample Group has been described in the chapter on Methodology, it is reviewed here in terms of similarities and dissimilarities to the Hamilton Sample Group.
(1) Size. The Community Sample Group was much larger (N=482) than the Hamilton Ostomy Group (N=70).

(2) Age. Both groups included adults over 18 years of age. However the Hamilton Ostomy Group had a proportionately higher percentage of persons over 65 years (45%) than the Community Sample (21%).

(3) Sex of Subject. The Community Sample Group included a proportionately smaller percentage of males (42%) and a proportionately larger percentage of females (57%) than the Hamilton Ostomy Group. The Hamilton Group was composed of 55% males and 44% females.

(4) Religion. Sixty-three of the subjects in the Community Sample were Catholic and 27% were Protestant. This is in direct opposition to the Hamilton Ostomy Group wherein only 18% were Catholic, and 78% were Protestant.

(5) Socioeconomic Class Level. A majority of the persons' (67%) of the Comparative Sample Group were of the lower two class levels as measured by the Hollingshead Two-Factor Index of Social Position. Fifty-two percent of the Hamilton Ostomy Group reported a level of education at or beyond grade 13. Twenty-one percent of the Hamilton Group had attended university. In
addition 31% of the Hamilton Group reported an annual income of $20,000 and up. A further 11% earned at least $15,000. On the basis of income and level of education, the Hamilton Ostomy Group represents at least a middle-class socio-economic level.

(6) Nationality. While it is not reported, it is likely that a group from Connecticut are citizens of the United States. Seventy-eight percent of the Hamilton Sample were born in Canada.

(7) Race. Eighty-nine percent of the Community Sample were white and a further 10% were non-white. This study did not enquire as to the race of subject.

(8) City. The Community Sample was drawn from the city of New Haven, Connecticut, which has a population of 72,000. The Hamilton Ostomy Group was drawn from a city of more than half a million people. Both cities are university and industrial communities.

A series of non-directional t-tests were performed in the following manner:

(1) Ileostomy Sample versus Community Sample,

(2) Colostomy Sample versus Community Sample,

(3) Work role scores of the males of the Community Sample versus those of the males of the Hamilton Sample.
TABLE 20 - A Comparison of the Mean Averages Scored by Persons with Colostomies and Ileostomies, with the Mean Average Scores Achieved by a Community Sample

<table>
<thead>
<tr>
<th>Role Areas</th>
<th>Community Sample</th>
<th>Ileostomy Sample</th>
<th>Colostomy Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>X</td>
<td>S.D.</td>
</tr>
<tr>
<td>Work</td>
<td>399</td>
<td>1.40</td>
<td>.46</td>
</tr>
<tr>
<td>Social-Leisure</td>
<td>482</td>
<td>1.83</td>
<td>.52</td>
</tr>
<tr>
<td>Extended Family</td>
<td>475</td>
<td>1.34</td>
<td>.33</td>
</tr>
<tr>
<td>Marital</td>
<td>361</td>
<td>1.75</td>
<td>.48</td>
</tr>
<tr>
<td>Parental</td>
<td>276</td>
<td>1.40</td>
<td>.42</td>
</tr>
<tr>
<td>Family Unit</td>
<td>464</td>
<td>1.46</td>
<td>.58</td>
</tr>
<tr>
<td>Overall Social</td>
<td>482</td>
<td>1.59</td>
<td>.33</td>
</tr>
</tbody>
</table>

*Indicates Significance at an alpha level of 0.05
(4) Adjustment of the Middle-aged adult with an ostomy and the Retired adult with an ostomy.

A series of nondirectional t-tests were used to compare life role adjustment and overall social adjustment of (1) persons with ileostomies and (2) persons with colostomies, to the adjustment of subjects in a Community sample group designated to represent the norm. In relation to the group of persons having ileostomies, the following conclusions were made:

1. There appears to be no difference between the overall social adjustment of the group with ileostomies, and the overall social adjustment of the Community Sample.

2. No difference is indicated in the levels of functioning of persons with ileostomies and persons from the Community Sample, in the role areas of Work, Social-Leisure and Parent.

3. Persons with ileostomies seem to demonstrate a different level of functioning than persons in the Community Sample in the following roles:
   (1) The role of member of an extended family,
   (2) in the role of marriage as a spouse, and
   (3) in the role of member of a nuclear family unit.
Work role scores of the females of the Community Sample versus those of the females of the Hamilton Sample. (Tests of sexual status groups are reported in this chapter under the subheading, Males versus Females with Ostomies. The work role means in relation to these tests are presented in Table 17.) Table 20 lists the role means and overall adjustment scores for the three sample groups, (1) the Ileostomy Sample, (2) the Colostomy Sample and (3) the Community Sample. These sample groups will be discussed at this time, beginning with the overall adjustment scores.

Although the mean average score for overall social adjustment, of the ileostomy group is higher than the community sample, the difference is not statistically significant. Therefore we conclude that indications of overall dysfunction in the ileostomy sample appear to be of a minor nature. The difference between the mean scores of the community sample and the colostomy group, indicates that the colostomy group is the least impaired. Reference to Table 20, however, reports that only six (15%) of the colostomy group had children living in their home; therefore a majority of persons with colostomies were not assessed in this role and an accurate measure of total adjustment is not available.
The mean average scores of the ileostomy group were higher than those of the community group in all of the role areas that had to do with family relationships, thus indicating dysfunction in these relationships. The difference was statistically different in regards to membership in the nuclear family unit, the extended family, and the marital dyad. Thus it appears that persons with ileostomies may be experiencing a considerable amount of impairment in roles that pertain to the family.

The questions in each role area generally deal with,
(1) the subject's performance at expected tasks,
(2) friction in role related relationships,
(3) interpersonal relations, and
(4) subjective feelings and satisfactions (Weissman et al, 1978, p. 319). The family role dysfunction of persons with ostomies, therefore, will involve one or more of these components. The person with an ileostomy may be experiencing difficulty with tasks that are his responsibility. He may experience friction or hostility in interactions with his spouse, children, parents, and so forth. He may not enjoy the love, satisfaction, respect, et cetera of family members, or perhaps he may not be able to demonstrate these feelings toward members of his family.

The persons with colostomies appear to be dealing more effectively than the community norm in family related
areas. The mean score for the marital role, however, indicates a degree of impairment in the marital relationship. This slight impairment may be in relation to sexual dysfunction. Both groups with ostomies appear to be well adjusted in work related activities and relationships and social-leisure activities and relationships.
Summary

The analysis of quantitative data was presented in this chapter. The quantitative data consisted of the mean average scores achieved by the research sample and the New Haven normative sample, as measured by the Social Adjustment Scale-Self Report version. These mean average scores were used to test the levels of role functioning and overall social adjustment of various groups on a number of variables, (1) gender, (2) type of ostomy, and (3) age. The findings were:

1. Females with ostomies demonstrate a more impaired level of functioning in a work role area than males with ostomies do.

2. There is no significant difference between the functioning of women with ostomies, in the work role area, as measured in this study by the SAS-SR test, and the functioning of women in a community sample, as measured by Weissman et al, with the SAS-SR test.

3. There is minimal difference in the level of functioning of males with ostomies and females with ostomies in (1) the social-leisure role, (2) in the extended family role, (3) in the marital role, as a spouse, (4) in the parental role, (5) or as a member of the family unit.
4. Females with ostomies demonstrate a level of overall social adjustment that is similar to a level demonstrated by males with ostomies.

5. There is little difference between the level of functioning of persons with ileostomies and persons with colostomies, in the work role, the marital role as a spouse, and the parental role areas.

6. Persons with ileostomies demonstrate strongly significant impairment in the social-leisure, extended family and family unit roles than persons with colostomies do.

7. Persons with ileostomies demonstrate more mal-adjustment on the overall, than persons with colostomies.

8. Young adults (from 18 to 40 years old, with ostomies inclusively) demonstrate a higher level of impairment than Middle-Age adults (from 41 to 65 years of age, inclusively) with ostomies in the life role area of Social-Leisure.

9. Young adults with ostomies do not demonstrate more impairment than Middle-aged adults with ostomies in the following roles: (1) Work, (2) Extended Family, (3) Marital, (4) Parental and (5) Family Unit.
10. Young adults with ostomies demonstrate more maladjustment than Retired adults (age 66 and up) with ostomies in Overall Social Adjustment.

11. Young adults with ostomies demonstrate significantly more maladjustment than Retired adults with ostomies in the Social-Leisure role.

12. Young adults with ostomies function at a significantly lower level than Retired adults with ostomies in the family roles of Extended and Nuclear Family Unit.

13. There is no significant difference in the levels of functioning of Young adults and Retired adults with ostomies in the roles of (1) Work, (2) Marriage and (3) Parent.

14. Middle-aged adults with ostomies appear to demonstrate more maladjustment than Retired adults with ostomies in the Parental role.

15. Middle-aged and Retired adults with ostomies function at a similar level in the roles of (1) Work, (2) Social-Leisure, (3) Extended Family, (4) Marriage, and (5) Member of a Nuclear Family Unit.

16. There is no difference between the Overall Social
Adjustment of the Middle-aged adult with an ostomy and the Retired adult with an ostomy.

A series of nondirectional t-tests were used to compare life role adjustment and overall social adjustment of (1) persons with ileostomies and (2) persons with colostomies, to the adjustment of subjects in a Community sample group designated to represent the norm. In relation to the group of persons having ileostomies, the following conclusions were made:

1. There appears to be no difference between the overall social adjustment of the group with ileostomies, and the overall social adjustment of the Community Sample.

2. No difference is indicated in the levels of functioning of persons with ileostomies and persons from the Community Sample, in the role areas of Work, Social-Leisure and Parent.

3. Persons with ileostomies seem to demonstrate a different level of functioning than persons in the Community Sample in the following roles:
   (1) The role of member of an extended family,
   (2) in the role of marriage as a spouse, and
   (3) in the role of member of a nuclear family unit.
In relation to the group of persons having colostomies the following conclusions were made:

1. No difference is indicated in the level of functioning of persons who have colostomies, and persons from the Community Sample, in the following areas, (1) The work role, (2) the role of member of an extended family, (3) the role of marriage, as a spouse, (4) the role of parent, and (5) the role of member of a nuclear family unit.

2. Persons with colostomies appear to demonstrate a different level of functioning than persons from the Community Sample, in the life role area of Social-Leisure.

3. A significant difference in the functioning of the persons with colostomies, and the persons from the Community Sample is indicated in terms of Overall Social Adjustment.
CHAPTER VI

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

The purpose of this study was to describe the characteristics, and assess and describe the postconvalescent level of social adjustment of persons with permanent ostomies. It was hoped that indications of maladjustment could be traced to specific life areas and populations, thereby making it possible to identify persons-at-risk before maladjustment occurs. At this point indications for social work intervention could be considered.

Sample

The sample was drawn from members of the Hamilton and District Ostomy Association, Hamilton, Ontario, and included 70 subjects over eighteen years of age. Of these, 40 persons had colostomies and 30 persons had ile-ostomies. For a brief description of the sample, see Table 21.

Community Sample

An existing normative sample group was used in this study for comparative purposes. This sample was drawn randomly from the population of 72,000 persons in New Haven, Connecticut for purposes of a longitudinal study. It was composed of 482 persons over the age of
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>39</td>
<td>44.28%</td>
</tr>
<tr>
<td>Female</td>
<td>31</td>
<td>55.71%</td>
</tr>
<tr>
<td><strong>Type of Ostomy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ileostomy</td>
<td>30</td>
<td>42.85%</td>
</tr>
<tr>
<td>Colostomy</td>
<td>40</td>
<td>57.14%</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>37</td>
<td>52.85%</td>
</tr>
<tr>
<td>Ulcerative Colitis</td>
<td>25</td>
<td>35.71%</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>11.42%</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 41</td>
<td>11</td>
<td>15.71%</td>
</tr>
<tr>
<td>Under 66</td>
<td>27</td>
<td>38.57%</td>
</tr>
<tr>
<td>66 and older</td>
<td>32</td>
<td>45.71%</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protestant</td>
<td>55</td>
<td>78.57%</td>
</tr>
<tr>
<td>Catholic</td>
<td>13</td>
<td>18.57%</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>2.85%</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under $5000</td>
<td>9</td>
<td>12.8%</td>
</tr>
<tr>
<td>$5,000 - $9,999</td>
<td>12</td>
<td>17.1%</td>
</tr>
<tr>
<td>$10,000 - $14,999</td>
<td>11</td>
<td>15.7%</td>
</tr>
<tr>
<td>$15,000 - $19,999</td>
<td>8</td>
<td>11.4%</td>
</tr>
<tr>
<td>$20,000 and up</td>
<td>22</td>
<td>31.4%</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>26</td>
<td>37.14%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4</td>
<td>5.71%</td>
</tr>
<tr>
<td>On Sick Leave</td>
<td>1</td>
<td>1.42%</td>
</tr>
<tr>
<td>Part Time</td>
<td>9</td>
<td>11.42%</td>
</tr>
<tr>
<td>Full Time</td>
<td>15</td>
<td>21.42%</td>
</tr>
</tbody>
</table>
18, who were interviewed three times over a period of nine years. It was noted that the group was not significantly different in the three interviews, and they are therefore, considered relatively stable for purposes of comparison.

Representativeness Of The Sample

In regard to the sample used in this study, there is cause to consider whether or not it is representative of the Hamilton branch of the United Ostomy Association, and the United Ostomy Association in general. If it is regarded as representative, the typical member would be a well-educated Protestant, of retirement age and with a relatively high income. In this case it would appear that ostomy surgery is a phenomenon of religion or of the middle class. Such a conclusion would be foolhardy. Perhaps the United Ostomy Association is not reaching persons of lower socioeconomic class, or persons of younger years. Only ten of the 70 subjects were under 40 years of age.

In considering representativeness of the sample, those members who did not respond to the questionnaire must be considered as well. Was the questionnaire too difficult for them? If so, persons with lesser education may have been discouraged from answering. Did its length, or content require a certain level of adjustment to have the emotional capability to fill it out? If so, persons with exaggerated
dysfunction would not have been included in the sample. Membership in a self help group of this type is likely to attract persons who are of a middle class socioeconomic level. If this is the case the sample can be considered representative of membership in the United Ostomy Association.

Summary of Conclusions

Tests of the scores of subgroups within the sample indicated two groups that demonstrated social maladjustment. These groups were the young adult and the ileostomy groups. In terms of overall social adjustment, the scores of both groups were substantially higher than those of the colostomy and retired adult groups, thus indicating a more impaired level of overall social adjustment. The colostomy group, however, demonstrated a level of social adjustment that was superior to that of the normative sample. Consequently, while the ileostomy group appeared more impaired than the colostomy group, its level of social adjustment was consistent with that of the normative sample. Hence it must be concluded that the ileostomy group achieved scores that indicated an acceptable level of adjustment.

In regards to the work role area, there was no impairment indicated in relation to age or type of stoma. However, the females in the sample demonstrated more
impairment than the male in the work role area. This difference was consistent with a previous study, wherein females of a normative sample demonstrated lesser adjustment than males of the sample, in a work role area (Weissman et al, 1980, p. 323).

In tests of the scores achieved in the social-leisure role, the young adult group and the ileostomy group appeared to function at lower levels than the colostomy group and the retired age group. However, again the scores of the colostomy group were significantly different, and lower than the normative sample, indicating a superior level of functioning. Again the scores of the ileostomy group were similar to those of the normative community group. Thus the social-leisure functioning of persons with ileostomies did not indicate impairment.

In regards to extended and nuclear family unit functioning, tests of the scores of the young adult group and the ileostomy group versus those of the retired and colostomy groups respectively, indicated impairment of the young adults and persons with ileostomies. The ileostomy group was compared with the community normative sample, and the ileostomy group was concluded to be dysfunctional in the roles of extended family member and family unit member. The ileostomy group also demonstrated impairment in the marital role, when tested against the normative sample. In addition, while the difference between the scores of the
colostomy group and the comparative group is not statistically different, the scores do suggest a degree of dysfunction of persons with colostomies in the role of marriage. In addition to conclusions made in relation to the SAS-SR test, the following conclusions were drawn:

(1) Male sexual dysfunction is a common response to ostomy surgery, and this dysfunction most often involves erectile dysfunction. Advanced age is more likely to be a contributing factor to male impotence than the type of ostomy the male has.

(2) Persons with ostomies tend to perceive their stoma as a lifesaving and acceptable phenomenon, but the stoma is regarded as separate from their 'self'. Consequently, negative body image is a common response to ostomy surgery.

(3) The majority of ostomy patients receive counselling in relation to their surgery, and are most often counselled by enterostomal therapists or members of the United Ostomy Association. Counselling is seldom received before surgery.

In the Methodology chapter, the writer stated that two purposes of the study were: (1) to identify characteristics of populations likely to be in need of intervention, and, (2) to determine what life role areas social maladjustment is likely to involve. These purposes were
accomplished with the following findings:

(1) Persons with ostomies, who demonstrate social maladjustment, and are likely to be in need of intervention, are young adults and persons with ileostomies. This maladjustment occurs in family related roles, e.g. the extended family, the nuclear family unit, and the marital dyad.

(2) While the retired adult does not demonstrate maladjustment in the marital role per se, the older married male tends to experience dysfunction in the sexual aspect of marriage.

Implications for Social Work

This study has been carried out as part of the requirement for a master's degree in social work. The subjects of the study were persons with ostomies, and yet these persons are rarely referred to the social worker. How then, does the ostomy patient concern social work? The answer to this question can be understood in terms of the consequences of ostomy surgery for the patient and his family. According to the review of the literature, formation of a stoma, and surgical alteration of the natural process of elimination, precipitates intense psychological stress for the patient and his family. As a result the social and familial relation-
ships of the ostomy patient are severely strained, and
the healthy social adjustment of the patient is in
jeopardy (Sutherland et al, 1952, p. 868).

At the present time, the care and concern of the
ostomy patient is considered a medical responsibility.
However, the current trend toward patient care involves
interdisciplinary teamwork. In addition, the medical
field and its accrediting bodies, have recognized the
importance of the psychological and social needs of the
patient in his recovery and rehabilitation. More and
more the social service department is becoming an integral
part of the hospital community as a holistic medical
approach develops. Burn patients, cardiac patients,
dying patients, the families of the patients, and so forth
are being referred to social workers, to offset the
psychosocial consequences of illness or surgery.

This study clearly indicates that ostomy surgery
has ramifications far beyond the physical state of the
patient, and indeed, far beyond the confines of the
hospital. The expertise of medicine lies in diagnosis,
treatment, surgery, and nursing. The expertise of social
work lies in the field of human relationships, of human
emotions, needs, disappointments, hopes and crises.
Consideration of both these areas is fundamental to the
basic care of the ostomy patient. Once the ostomy patient
has become well enough to return home, he faces an entirely
new set of stresses. He must make a social adjustment,
a simple term for a complex task.

According to Weissman, social adjustment is the "interplay between the individual and the social environment", and it involves functioning in a number of roles (Weissman, 1975, p. 357). The 'social' in social work refers to human relationships. The 'social' in social work refers to human relationships as well. Where the patient is required to make social adjustments, the social worker has the expertise to facilitate the process.

Consider this definition of social work:

Social work seeks to enhance the social functioning of individuals, singly and in groups, by activities focused upon their social relationships which constitute the interaction between man and his environment. These activities can be grouped into three functions: restoration of impaired capacity, provision of individual and social resources, and prevention of social dysfunction (Skidmore and Thackeray, 1976, p. 5)

Whether the ostomy patient is in hospital or has returned home, if he is having difficulties in social, family or marital relationships, these difficulties lie within the area of skill of the social worker, who depending upon his own area of specialization, is trained to carry out individual, group or family therapy.

Should social work become involved with the person with an ostomy? According to the Curriculum Study, "The goal of social work is the enhancement of social functioning wherever the need for such enhancement is
either socially or individually perceived" (Skidmore and Thackeray, 1976, p. 6). The person with an ostomy appears to have such a need. Social work must recognize its own commitment.

Recommendations for Further Research

1. This study clearly showed that persons under the age of forty-one, and persons with ileostomies demonstrate impaired functioning in family role areas. However, in that a person with an ileostomy is usually relatively young, and a person with a colostomy is usually of advanced age, it is unclear whether impairment is a result of age or type of ostomy. Consequently the researcher strongly recommends a further study of persons with ileostomies and colostomies, who are of young and retired ages. The sample group should include matched elements of sufficient numbers.

General Recommendations

1. The Hamilton and District Ostomy Association should examine its current policies and activities to discern if and why persons under forty years, non Protestants, and persons of a lower socioeconomic class are underrepresented in the association.
The medical care team should refer the ostomy patient to the social service department of the hospital, before surgery if at all possible, or otherwise.

Persons who have ostomies and are experiencing sexual difficulties are encouraged to see their physician. Depending on his assessment of their physical state, they may wish to seek out a professional sex therapist. Persons in Ontario can be directed to a sex therapist in their area by contacting:

Sex Therapists Registered by Board of Examiners in Sexual Therapy and Counselling, in Ontario, 271 Russell Hill Road, Toronto, Ontario, M4V 2T5

Persons in the United States can be directed to a reputable sex therapist by contacting:

American Association of Sex Educators, Counselors and Therapists, Suite 2700, Number One Wacker Drive, Chicago, Illinois, 60601

This researcher wishes to make two recommendations directly to the persons who took part in this study. (i) If you are experiencing sexual dysfunction, there is a reputable source of help within your own city. I urge you to contact:
Human Sexuality Clinic,
McMaster University Medical Center,
Box 2000, Station A,
Hamilton, Ontario,
L8N 3Z5

Telephone: 525-9140, Extension 2765

This clinic requires referral by a physician
and the cost is covered by O.H.I.P.  (ii) If
you are experiencing problems in social, family,
or marital relationships, help is available at
many agencies, two of which are listed here.

Family Service Association,
350 King Street, East,
Suite 201,
Hamilton, Ontario,
L8N 3Y3

Telephone: 523-5640

Chedoke Child and Family Center,
Sanitorium Road,
Chedoke-McMaster Hospitals,
Hamilton, Ontario

Telephone: 387-1330

Summary

In this chapter the study was briefly described,
the conclusions of the research were presented, and the
implications of the conclusions to the social work
profession were discusses. Recommendations were made,
(1) for further research, (2) to health care professions,
(3) to the subjects of this study, and (4) to ostomy
patients in general.
BIBLIOGRAPHY

Journal Articles

Babb, Richard R., M.D.; and Kieraldo, John H., M.D.
"Sexual Dysfunction After Abdominoperineal
Resection", Digestive Diseases, Vol. 22, No. 12,

Baird, Nine and Corbin, Dale, "Colostomy Problems:
The Patient's Viewpoint", Journal of the Kansas

Burnham, W.R., Lennard-Jones, J.E., and Brook, B.N.,
Sexual Problems Among Married Ileostómists",

Dericks, Virginia C., R.N., M.A.; and Donovan, Constance T.,
R.N., M.S.N., "The Ostomy Patient Really Needs You",

Dlin, Barney M., M.D.; Perlm, Abraham, M.D., and Ringold,
Evelyn, "Psychosexual Response to Ileostomy and

Dlin, Barney M., "Emotional Aspects of Colostomy and
Ileostomy", In Emotional Factors in Gastro-
intestinal Illness, A.E. Lindner, American

Druss, R.G., M.D.; O'Connor, John F., M.D.; Prudden,
John F., M.D., Med. Sci. D.; and Stern, Lenore O.


Frager, Stanley R.; Penninger, Joyce I.; Moore, Sara B.; "Sexual Rehabilitation of the Male Ostomy Patient, Unpublished paper.


United Ostomy Association, Inc., Los Angeles, California.


Weissman, Myrna M., Ph.D.; Bothwell, Sallye, Ma Ed., "Assessment of Social Adjustment by Patient Self


Wirsching, Michael; Druner, H.U.; and Herrmann P., "Results of Psychosocial Adjustment to Long-Term Colostomy", Psychotherapy and Psychosomatics, Vol. 26, 1975, pp. 245-56.


Books


Selltiz, Claire; Wrightsman, Lawrence S., and Cook, Stuart W., Research Methods in Social Relations,


Brochures


**News Article**


**Government Documents**

Canada. Almanac and Directory, Susan Walters, Editor,
APPENDIX A
To our knowledge there aren't any researched statistics available regarding the number of the ostomy population.

We estimate that there are 1,500,000 ostomates in North America today and that 65% are colostomates, 20% are ileostomates and 15% are urostomates (urinary diversion).

The American Cancer Society estimates that 101,000 ostomy surgeries are done annually for all causes except paraplegia and birth defects. Including these two causes, there are perhaps 110,000 ostomy surgeries done annually. This figure does not take into consideration how many of these procedures are temporary or a mortality rate. The same percentages of types of ostomies as above would apply to the annual figure.

Since there are many reasons for ostomy surgery, the ratio of male to female ostomates would probably be the same as the male-female ratio in the general population census.

We use a basis that one of every 200 persons is an ostomate to determine how many ostomates would be in a defined area.

We regret that there isn't more definite information available. Let us know if we can be of any further service.
The University of Windsor has requested that we participate in a Research Project which is being conducted by Mrs. Janet Towell, a graduate student in the School of Social Work at that University.

Mrs. Towell is now working for her Master's Degree and has had a long standing interest in Ostomates' problems. During her many years of work as a Registered Nursing Assistant, she developed a great concern for the social and emotional needs of Ostomy patients. As part of her academic requirement, and because of her concern for Ostomates, she has chosen as her research project, "The Indications for Social Work Involvement With Ostomates."

Professor Patricia Taylor (Mrs. Towell's Faculty Advisor at Windsor University) has asked for our co-operation and assistance. She requests that each member of our Association complete a questionnaire related to the research being carried out by Mrs. Towell. Both Prof. Taylor and Mrs. Towell have assured me that "Confidentiality will be guaranteed and that the questionnaires will be seen only by the researchers. No names, addresses, or other identifying information will be used in the reports."

The questionnaires will be mailed out within the next month or so. Although participation is voluntary on the part of each member, I urge every one of you to complete the questionnaire and return it promptly.

I am convinced that the knowledge gained by research such as this will ultimately be of great benefit to all Ostomates and that we should do everything we can to encourage it.

If you have any questions about this project, please feel free to telephone me. -- But above all, please support it.

Claude Campbell

---

In our February News Bulletin we mentioned the Research Project which is now being conducted at the University of Windsor, "The Indications for Social Work Involvement With Ostomates." Within the next week or so every member of the Hamilton and District Ostomy Association will receive a questionnaire. The results of this questionnaire will be analyzed by computer and correlated with other similar projects. We feel sure that the final result will assist us in our efforts to convince the Government that the purchase of Ostomy supplies should be covered by O.H.I.P.

You are, therefore, earnestly requested to complete this questionnaire and return it to Windsor in the envelope provided just as soon as you possibly can.

APPENDIX B
Dear Member of The Hamilton Ostomy Association,

Not enough information is available about persons who have an ostomy. As a result, ostomates may not be receiving appropriate or sufficient help.

I am a graduate student of Social Work at the University of Windsor, and I am presently undertaking a research study regarding the concerns and feelings of persons with an ostomy. Reference to this study was made in your February News Bulletin by your President, Mr. A. Claude Campbell.

As a person who has experienced an ostomy, you are in a special position to contribute a great deal to our knowledge of the concerns of persons who have a stoma. You will find a questionnaire enclosed. On a pretext, it was found to take about 45 minutes to complete. I realize this is asking a lot of you, but I believe the length of the questionnaire is necessary for this to be a valid study.

Your replies will be strictly confidential and will not be seen by anyone other than myself. The enclosed, self-addressed envelope will ensure your privacy.

If any one of the supplied answers do not fit exactly, choose the answer that is closest to it. Each question usually has only one answer. There are no right or wrong answers. Once you have completed the questionnaire, please return it to me as soon as it is convenient for you.

If you have any difficulty understanding the questions, you may telephone my home at 519-945-6011. Thank you for your kind assistance.

Yours truly,

Janet Towell, R.A., R.S.W.
QUESTIONNAIRE
SECTION I

(1) 1. Age ______

(2) 2. Sex: 1. Female ______

2. Male ______

(3) 3. Marital Status: 1. Single ______

2. Separated ______

3. Divorced ______

4. Widow/Widower ______

5. Married ______

6. Common Law ______

(4) 4. After ostomy surgery did your marital status:

1. Remain the same? ______

2. Change? (Explain how)__________

(5) 5. Type of Ostomy: 1. Ileostomy ______

3. Colostomy ______

3. Other (Please specify)__________


2. Temporary ______

(7) 7. Diagnoses that lead to Ostomy:

1. Ulcerative Colitis ______

2. Crohn's Disease ______

3. Birth Defect ______

4. Cancer ______

5. Trauma (i.e. Accident or Combat Injury) ______

6. Other (Please specify)__________

7. Don't Know ______

(8) 8. Period of time that has passed since original stoma was created:

______ years or ______ months.

(9) 9. What is your general state of health?

1. Poor ______

2. Fair ______

3. Good ______

4. Excellent ______

(10) 10. Please describe your highest level of education:

1. Grade 8 or less ______

2. Grade 9 or 10 ______

3. Grade 11 or 12 ______

4. Grade 13 ______

5. Vocational Training ______

6. Community College ______

7. Some University ______

8. University Degree ______

9. Postgraduate degree ______

10. Other ______

(11) 11. Country of Birth:

1. Canada ______

2. Britain ______

3. United States ______

4. Ukraine ______

5. Italy ______

6. Other ______ (Please State) ______

(12) 12. How many family members live in your household? ______

(13) 13. Religion:

1. Protestant ______

2. Catholic ______

3. Jewish ______

4. Other ______ (Please state) ______
EMPLOYMENT:

14. Occupation or Profession

15. Employment Status: (The year before ostomy surgery.)
   1. Retired
   2. Unemployed
   3. On sick leave
   4. Part-time
   5. Full-time

16. Employment Status: (At present time.)
   1. Retired
   2. Unemployed
   3. On sick leave
   4. Part-time
   5. Full-time

17. If you are working, are you employed in the occupation listed in question 14?
   Yes ___  No ___

18. If you are working in an occupation other than that listed in question 14, please state present occupational role.

19. If you are retired, did you retire as a result of ostomy surgery?
   Yes ___  No ___
   Explain if you wish.

EMOTIONAL SUPPORT:

20. Did you receive any counselling in relation to your stoma?
   1. Yes ___  2. No ___

Note: The next five questions may have more than one answer. If your answer to question 20 is yes, please answer questions 21 to 25. If the answer is no, please go on to question 26.

21. Did this counselling give you the chance to discuss any feelings or worries regarding:
   1. Future surgery
   2. Irrigation
   3. Appliances
   4. Future pregnancy
   5. Attractiveness to opposite sex?
   6. Sexual problems
   7. Employment
   8. Intestinal noises, gas or odor
   9. Fears of dependency
   10. Fears of dying
   11. Acceptance of you as an ostomate by friends
   12. Return to previous athletic activities
   13. Feelings regarding whether or not to reveal ostomy status to friends, employer
   14. Feelings regarding whether to let your spouse, children and close family members see your stoma
   1. Yes ___  2. No ___

22. Did you receive counselling in relation to your stoma?
   1. Before ostomy surgery
   2. After ostomy surgery
   3. Post convalescence (10 or more weeks) after surgery

   1. Yes ___  2. No ___
(23) 23. Was the person who counselled you in regard to your stoma a:
1. Member of the clergy? ________
2. Surgeon? ________
3. Physician? ________
4. Social Worker? ________
5. Enterostomal Therapist? ________
6. Nurse? ________
7. Member of an Ostomy Association? ________

(24) 24. What best describes your stoma?
1. Embarrassing ________
2. Easily hurt or damaged ________
3. Inconvenient ________
4. Nuisance ________
5. Acceptable ________
6. Tolerable ________
7. Life saving ________
8. Serves its purpose ________
9. Destroys femininity/masculinity ________
10. Other ________

(25) 25. Below is a list of bad feelings a person can have about their body. Please check (X) which feeling BEST describes your own body since having ostomy surgery.

1. Weak ________
2. Ashamed ________
3. Freak ________
4. Dirty ________
5. Guilty ________
6. Unattractive ________
7. Angry ________
8. Sad ________
9. Not a full man or woman ________
10. Other ________ (Please state.) ________

SECTION II

I am interested in finding out how you have been doing in the LAST TWO WEEKS. I would like you to answer some questions about your work, spare time and your family life. There are no right or wrong answers to these questions.

Circle the answer that best describes how you have been in the LAST TWO WEEKS.

(26) 26. What best describes your primary work role?
1. Employed outside home ________
2. Housework ________
3. Student ________

Note: The next 19 questions concern the above work categories. Please answer the questions listed under YOUR PRIMARY WORK ROLE.

CATEGORY A: WORK OUTSIDE THE HOME

Note: Answer the next six questions if you are employed outside the home. Otherwise move on to question 7.

Circle the answer that best describes how you have been in the LAST TWO WEEKS.

(27) 1. How many days did you miss from work in the last two weeks? (Do not include any days of scheduled vacation.)
1. No days missed
2. One day missed
3. I missed about half the time
4. I missed more than half the time but did make at least one day
5. I did not work any days
6. On vacation all of the last two weeks.
Note: If you have not worked any days in the last two weeks, go on to Question 19.

(28) 2. Have you been able to do your work in the last two weeks?
   1. I did my work very well.
   2. I did my work well but had some minor problems.
   3. I needed help with my work and did not do well about half the time.
   4. I did my work poorly most of the time.
   5. I did my work poorly all the time.

(29) 3. Have you been ashamed of how you do your work in the last two weeks?
   1. I never felt ashamed.
   2. Once or twice I felt a little ashamed.
   3. About half the time I felt ashamed.
   4. I felt ashamed most of the time.
   5. I felt ashamed all the time.

(30) 4. Have you had any arguments with people at work in the last two weeks?
   1. I had no arguments and got along very well.
   2. I usually got along well but had minor arguments.
   3. I had more than one argument.
   4. I had many arguments.
   5. I was constantly in arguments.

(31) 5. Have you felt upset, worried, or uncomfortable while doing your work during the last two weeks?
   1. I never felt upset.
   2. Once or twice I felt upset.
   3. About half the time I felt upset.
   4. I felt upset most of the time.
   5. I felt upset all of the time.

(32) 6. Have you found your work interesting these last two weeks?
   1. My work was almost always interesting.
   2. Once or twice my work was not interesting.
   3. About half the time my work was uninteresting.
   4. Most of the time my work was uninteresting.
   5. My work was always uninteresting.

CATEGORY H: WORK AT HOME (HOUSWORK)

Note: Persons whose primary work role is housework only answer questions 7-12. Other persons go on to question 13.

Circle the answer that best describes how you have been in the last two weeks.

(33) 7. How many days did you do some housework during the last two weeks?
   1. Every day.
   2. I did the housework almost every day.
   3. I did the housework about half the time.
   4. I usually did not do the housework.
   5. I was completely unable to do the housework.
   6. I was away from home all the last two weeks.

(34) 8. During the last two weeks, have you kept up with your housework? This includes cooking, cleaning, laundry, grocery shopping and errands.
   1. I did my work very well.
   2. I did my work well but had some minor problems.
   3. I needed help with my work and did not do it about half the time.
   4. I did my work poorly most of the time.
   5. I did my work poorly all the time.
9. Have you been ashamed of how you did your housework during the last two weeks?
   1. I never felt ashamed.
   2. Once or twice I felt a little ashamed.
   3. About half the time I felt ashamed.
   4. I felt ashamed most of the time.
   5. I felt ashamed all of the time.

10. Have you had any arguments with salespeople, tradesmen or neighbors in the last two weeks?
    1. I had no arguments and got along very well.
    2. I usually got along well, but had minor arguments.
    3. I had more than one argument.
    4. I had many arguments.
    5. I was constantly in arguments.

11. Have you felt upset while doing your housework during the last two weeks?
    1. I never felt upset.
    2. Once or twice I felt upset.
    3. Half the time I felt upset.
    4. I felt upset most of the time.
    5. I felt upset all of the time.

12. Have you found your housework interesting these last two weeks?
    1. My work was almost always interesting.
    2. Once or twice my work was not interesting.
    3. Half the time my work was uninteresting.
    4. Most of the time my work was uninteresting.
    5. My work was always uninteresting.

CATEGORY C: STUDENT WORK ROLE

Persons whose primary work category is STUDENT answer questions 13-18. Otherwise go on to question 19.

Circle the answer that best describes how you have been in the last two weeks.

13. How many days of classes did you miss in the last two weeks? (Do not include as days missed any days of scheduled vacations.)
   1. No days missed.
   2. A few days missed.
   3. I missed about half the time.
   4. I missed more than half of the time but did make at least one day.
   5. I did not go to classes at all.
   6. I was on vacation all of the last two weeks.

14. Have you been able to keep up with your class work in the last two weeks?
    1. I did my work well.
    2. I did my work well but had minor problems.
    3. I needed help with my work and did not do well about half the time.
    4. I did my work poorly most of the time.
    5. I did my work poorly all of the time.

15. During the last two weeks, have you been ashamed of how you do your school work?
    1. I never felt ashamed.
    2. Once or twice I felt ashamed.
    3. About half the time I felt ashamed.
    4. I felt ashamed most of the time.
    5. I felt ashamed all of the time.
(42) 16. Have you had any arguments with people at school in the last two weeks?

1. I had no arguments and got along very well.
2. I usually got along well but had minor arguments.
3. I had more than one argument.
4. I had many arguments.
5. I was constantly in arguments.
6. Not applicable; I did not attend school.

(43) 17. Have you felt upset at school during the last two weeks?

1. I never felt upset.
2. Once or twice I felt upset.
3. Half the time I felt upset.
4. I felt upset most of the time.
5. I felt upset all of the time.
6. Not applicable; I did not attend school.

(44) 18. Have you found your school work interesting these last two weeks?

1. My work was almost always interesting.
2. Once or twice my work was not interesting.
3. Half the time my work was uninteresting.
4. Most of the time my work was uninteresting.
5. My work was always uninteresting.

SPARE TIME: Everyone answer questions 19-27.

(45) 19. How many friends have you seen or spoken to on the telephone in the last two weeks?

1. Nine or more friends.
2. Five to eight friends.
3. Two to four friends.
4. One friend.
5. No friends.

(46) 20. Have you been able to talk about your feelings and problems with at least one friend during the last two weeks?

1. I can always talk about my innermost feelings.
2. I usually can talk about my feelings.
3. About half the time I felt able to talk about my feelings.
4. I was usually not able to talk about my feelings.
5. I was never able to talk about my feelings.
6. Not applicable; I have no friends.

(47) 21. How many times in the last two weeks have you gone out socially with other people? For example, visited friends, gone to movies, bowling, church, restaurants, invited friends to your home?

1. More than three times.
2. Three times.
3. Twice.
4. Once.
5. None.

(48) 22. How much time have you spent on hobbies or spare time interests during the last two weeks? For example, bowling, sewing, gardening, sports, or reading?

1. I spent most of my spare time on hobbies every day.
2. I spent some spare time on hobbies some of the days.
3. I spent a little spare time on hobbies.
4. I usually did not spend any time on hobbies but did watch TV.
5. I did not spend any spare time on hobbies or watching TV.
(49) 23. Have you had any arguments with your friends in the last two weeks?
1. I had no arguments and got along very well.
2. I usually got along well but had minor arguments.
3. I had more than one argument.
4. I had many arguments.
5. I was constantly in arguments.
6. Not applicable; I have no friends.

(50) 24. If your feelings were hurt or offended by a friend during the last two weeks, how badly did you take it?
1. It did not affect me or it did not happen.
2. I got over it in a few hours.
3. I got over it in a few days.
4. I got over it in a week.
5. It will take me months to recover.
6. Not applicable; I have no friends.

(51) 25. Have you felt shy or uncomfortable with people in the last two weeks?
1. I always felt comfortable.
2. Sometimes I felt uncomfortable but could relax after a while.
3. About half the time I felt uncomfortable.
4. I usually felt uncomfortable.
5. I always felt uncomfortable.
6. Not applicable; I have no friends.

(52) 26. Have you felt lonely and wished for more friends during the last two weeks?
1. I have not felt lonely.
2. I have felt lonely a few times.
3. About half the time I felt lonely.
4. I usually felt lonely.
5. I always felt lonely and wished for more friends.

(53) 27. Have you felt bored in your spare time during the last two weeks?
1. I never felt bored.
2. I usually did not feel bored.
3. About half the time I felt bored.
4. Most of the time I felt bored.
5. I was constantly bored.

Note: Persons who are single, separated or divorced, please answer Questions 28 and 29. Other people go on to Question 30.

(54) 28. How many times have you been with a date these last two weeks?
1. More than three times.
2. Three times.
3. Twice.
4. Once.
5. Never.

(55) 29. Have you been interested in dating during the last two weeks? If you have not dated, would you have liked to?
1. I was always interested in dating.
2. Most of the time I was interested.
3. About half the time I was interested.
4. Most of the time I was not interested.
5. I was completely uninterested.
FAMILY

Answer questions 30-35 about your parents, brothers, sisters, in-laws, and children NOT LIVING AT HOME. Have you been in contact with any of these relatives in the past two weeks? If yes, please answer Questions 30-35. If no, go on to Question 36.

Circle the answer that best describes how you have been in the LAST TWO WEEKS.

(56) 30. Have you had any arguments with your relatives in the last two weeks?
1. We always got along very well.
2. We usually got along well but had some minor arguments.
3. I had more than one argument with at least one relative.
4. I had many arguments.
5. I was constantly in arguments.

(57) 31. Have you been able to talk about your feelings and problems with at least one of your relatives in the last two weeks?
1. I can always talk about my feelings with at least one relative.
2. I usually can talk about my feelings.
3. About half the time I felt able to talk about my feelings.
4. I usually was not able to talk about my feelings.
5. I was never able to talk about my feelings.

(58) 32. Have you avoided contacts with your relatives these last two weeks?
1. I have contacted relatives regularly.
2. I have contacted a relative at least once.
3. I have waited for my relatives to contact me.
4. I avoided my relatives, but they contacted me.
5. I have had no contacts with any relatives.

(59) 33. Did you depend on your relatives for help, advice, money or friendship during the last two weeks?
1. I never need to depend on them.
2. I usually did not need to depend on them.
3. About half the time I needed to depend on them.
4. Most of the time I depend on them.
5. I depend completely on them.

(60) 34. Have you wanted to do the OPPOSITE of what your relatives wanted in order to make them angry during the last two weeks?
1. I never wanted to oppose them.
2. Once or twice I wanted to oppose them.
3. About half the time I wanted to oppose them.
4. Most of the time I wanted to oppose them.
5. I always oppose them.

(61) 35. Have you been worried about things happening to your relatives without good reason in the last two weeks?
1. I have not worried without reason.
2. Once or twice I worried.
3. About half the time I worried.
4. Most of the time I worried.
5. I have worried the entire time.
6. Not applicable; my relatives are no longer living.
EVERYONE answer Questions 36 and 37, even if your relatives are not living.

(62) 36. During the last two weeks, have you been thinking that you have let any of your relatives down or have been unfair to them at any time?

1. I did not feel that I let them down at all.
2. I usually did not feel that I let them down.
3. About half the time I felt that I let them down.
4. Most of the time I have felt that I let them down.
5. I always felt that I let them down.

(63) 37. During the last two weeks, have you been thinking that any of your relatives have let you down or have been unfair to you at any time?

1. I never felt that they let me down.
2. I felt that they usually did not let me down.
3. About half the time they felt they let me down.
4. I usually have felt that they let me down.
5. I am very bitter that they let me down.

Are you living with your spouse or living with a person of the opposite sex in a permanent relationship? If the answer is yes, please answer Questions 38 to 46. If the answer is no, go on to Question 47.

(64) 38. Have you had open arguments with your partner in the last two weeks?

1. We had no arguments and we got along well.
2. We usually got along well but had minor arguments.
3. We had more than one argument.
4. We had many arguments.
5. We were constantly in arguments.

(65) 39. Have you been able to talk about your feelings and problems with your partner during the last two weeks?

1. I could always talk freely about my feelings.
2. I usually could talk about my feelings.
3. About half the time I felt able to talk about my feelings.
4. I usually was not able to talk about my feelings.
5. I was never able to talk about my feelings.

(66) 40. Have you been demanding to have your own way at home during the last two weeks?

1. I never insist on having my own way.
2. I hardly ever insist on having my own way.
3. About half the time I insist on having my own way.
4. I usually insist on having my own way.
5. I always insist on having my own way.

(67) 41. Have you been bossed around by your partner during the last two weeks?

1. Almost never.
2. Once in a while.
3. About half the time.
4. Most of the time.
5. Always.

(68) 42. How much have you felt dependent on your partner these last two weeks?

1. I was independent.
2. I was usually independent.
3. I was somewhat independent.
4. I was usually dependent.
5. I depended on my partner for everything.
(69) 43. How have you felt about your partner during the last two weeks?
1. I always felt affection.
2. I usually felt affection.
3. About half the time I felt dislike and half the time affection.
4. I usually felt dislike.
5. I always felt dislike.

(70) 44. How many times have you and your partner had intercourse?
1. More than twice a week.
2. Once or twice a week.
3. Once every two weeks.
4. Less than every two weeks but at least once in the last month.
5. Not at all in a month or longer.

(71) 45. How many times did you and your partner usually have intercourse BEFORE OSTOMY SURGERY?
1. More than twice a week.
2. Once or twice a week.
3. Once every two weeks.
4. Less than every two weeks but at least once in a month.
5. Not at all in a month or longer.

(72) 45. Have you had any problems during intercourse, such as pain in the LAST TWO WEEKS?
1. None.
2. Once or twice.
3. About half the time.
4. Most of the time.
5. Always.
6. Not applicable; no intercourse in the last month.

(73) 46. Which of the descriptions best fits problems you have had during intercourse in the last two weeks?
1. Pain during intercourse.
2. Fear of embarrassment during intercourse.
3. Fear of pain or physical damage during intercourse.
4. No interest.
5. Premature ejaculation (coming too soon).
6. Unable to have an erection.
7. No problems.

(74) 46. How have you felt about intercourse during the last two weeks, even if you and your partner have not engaged in intercourse during this time?
1. I always enjoyed it.
2. I usually enjoyed it.
3. About half the time I did and half the time I did not enjoy it.
4. I usually did not enjoy it.
5. I never enjoyed it.

CHILDREN

Have you had unmarried children, stepchildren or foster children living at home during the last two weeks? If yes, answer Questions 47 to 50. If no, go on to Question 51.

(75) 47. Have you been interested in what your children are doing? Friends, school, play or hobbies during the last two weeks?
1. I was always interested and actively involved.
2. I was usually interested and involved.
3. About half the time interested and half the time not interested.
4. I usually was disinterested.
5. I was always disinterested.
(76) 48. Have you been able to talk and listen to your children during the last two weeks? Include only children over the age of 2.

1. I was always able to communicate with them.
2. I usually was able to communicate with them.
3. About half the time I could communicate.
4. I was not able to communicate.
5. I was completely unable to communicate.
6. Not applicable; no children over the age of 2.

(77) 49. How have you been getting along with the children during the last two weeks?

1. I had no arguments and got along very well.
2. I usually got along well but had minor arguments.
3. I had more than one argument.
4. I had many arguments.
5. I was constantly in arguments with them.

(78) 50. How have you felt toward your children these last two weeks?

1. I always felt affection.
2. I mostly felt affection.
3. About half the time I felt affection.
4. Most of the time I did not feel affection.
5. I never felt affection toward them.

FAMILY UNIT

Have you ever been married, ever lived with a person of the opposite sex, or ever had children? If the answer is yes, please answer Questions 51 to 53. If the answer is no, go on to Question 54.

(79) 51. Have you worried about your partner or any of your children without any reason during the last two weeks, even if you are not living together now?

1. I never worried.
2. Once or twice I worried.
3. About half the time I worried.
4. Most of the time I worried.
5. I always worried.
6. Not applicable; partner and children are not living.

Answer Questions 52 and 53 even if your partner and children are not living.

(80) 52. During the last two weeks have you been thinking that you have let down your partner or any of your children at any time.

1. I did not feel I let them down at all.
2. I usually did not feel that I let them down.
3. About half the time I felt I let them down.
4. Most of the time I have felt that I let them down.
5. I let them down completely.

(81) 53. During the last two weeks, have you been thinking that your partner or any of your children have let you down at any time?

1. I never felt that they let me down.
2. I felt that they usually did not let me down.
3. About half the time I felt they let me down.
4. I usually felt they let me down.
5. I felt bitter that they let me down.
FINANCIAL: Everyone please answer Question 54.

(82) 54. Have you had enough money to take care of your own and your family's financial needs during the last two weeks?

1. I had enough money for needs.
2. I usually had enough money with minor problems.
3. About half the time I did not have enough money but did not have to borrow money.
4. I usually did not have enough money and had to borrow from others.
5. I had great financial difficulty.

(83) Please indicate your total income for the last year. (Excluding monies earned by children under 18).

1. Under $5,000 ________
2. $5,000 to $9,999 ________
3. $10,000 to $14,999 ________
4. $15,000 to $19,999 ________
5. $20,000 and up ________

SECTION III

Note: This information is being gathered for the purposes of A. Claude Campbell of The Hamilton Ostomy Association, and will not be used in this research.

(84) 1. I have Supplementary Medical Insurance in addition to OHIP.

(1) Yes ________
(2) No ________

(85) 2. If the answer to Question 1 is yes, please state name of supplementary medical insurance.

(1) Blue Cross ________
(2) Westinghouse ________
(3) Prudential and Gamble ________
(4) Firestone ________
(5) Other (Please specify) ________

(86) 3. The estimated annual cost of non-prescription products required for care and maintenance of your stoma (i.e. appliances and materials such as karaya, stomahesive, solvents, tape and deodorants) is:

(1) $100.00 to $199.00 ________
(2) $200.00 to $299.00 ________
(3) $300.00 to $399.00 ________
(4) Other (Please specify) ________

(87) 4. The expense checked in Question 3 (above) is paid for by:

(1) Workmen's Compensation ________
(2) Provincial Disability ________
(3) Department of Veterans Affairs ________
(4) Supplementary Medical Insurance ________
(5) Self ________
(6) Other (Please specify) ________
VITA

Janet Miller Towell was born in Lambton County on June 20, 1939. She attended Wallaceburg District High School in Wallaceburg, Ontario, and the Hamilton School for Nursing Assistants, Hamilton, Ontario.

In the past Mrs. Towell has worked as a registered nursing assistant at Brantford General Hospital, Brantford, Ontario, Norfolk General Hospital, Simcoe, Ontario, and Sarnia General Hospital, Sarnia, Ontario.

Mrs. Towell returned to school in 1976, and received a B.A. in Psychology in 1978, and an Honours B.S.W. in 1980.

Mrs. Towell has two sons, Robert and Gregory, who are presently in grades XII and XIII, and a daughter, Bonita who is in her fourth year at McMaster University, Hamilton.

At the present time Mrs. Towell is employed with the Canadian National Institute For The Blind in Sarnia. She hopes to eventually work with medical-surgical patients in a hospital setting. Mrs. Towell expects to receive an M.S.W. in October, 1981.