

**OSTOMATES:
DIAGNOSIS, SURGERY AND REHABILITATION
A SYMBOLIC INTERACTIONIST PERSPECTIVE
ON AN ILLUSTRATION OF
SPOILED IDENTITY**

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DIAGNOSIS, SURGERY AND REHABILITATION
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ON AN ILLUSTRATION OF
SPOILED IDENTITY

A DISSERTATION
PRESENTED TO
THE FACULTY OF THE DEPARTMENT OF SOCIOLOGY
THE UNIVERSITY OF STIRLING

In Partial Fulfillment
of the Requirements for the Degree

Doctor of Philosophy

by
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July, 1978

ACKNOWLEDGEMENTS

This research could not, I am sure, have been undertaken in some Sociology departments. I am therefore grateful to Professor Duncan Timms and the Sociology Department of the University of Stirling for allowing me the intellectual freedom to proceed in this endeavour. I would further like to acknowledge the criticisms of Professor Timms, Professor S. Mitchell and Professor F. M. Martin from the Department of Social Administration of the University of Glasgow. Their concise criticisms and evaluations were valued in the presentation of this document. A special debt of gratitude is owed to Professor Robert Drass who constantly pressured me to continue the project and for his insightful comments and evaluations. I am also grateful to Dr. Maxwell Flood who encouraged me to obtain a Ph.D. and who also informed me of the existing Stirling program.

I would also like to express my thanks to those who have been patient, good natured and helpful beyond reasonable expectations in xeroxing countless copies and typing field notes as well as the final draft. A special thanks is extended to Miss Sandra St. Lewis who typed the first draft from tape and to Ms. Maureen Killoran who typed the final draft.

I must also extend my gratitude to the Ostomy Associations in Kitchener-Waterloo, Cambridge, Hamilton and Toronto for the carte blanche treatment they gave me for the conduct of this research and for the numerous small favours and conveniences they provided, as well as the degree of trust they placed in me. My appreciation extends to the osto-

mates, whose hospitality, openness and sensitivity provided me with the insight which enabled me to complete this project. The project could not have been completed without their assistance. I learned not only what is reported in these pages, but a great deal about myself from these individuals. One patient who has died since I research this paper provided me with ongoing inspiration.

In addition, I must acknowledge the surgeons, general practitioners, nurses, stoma therapists, psychiatrists, psychologists and social workers who provided valuable insight and perspectives.

It is impossible for me to adequately acknowledge the debt I owe to all who assisted me. However, this work is mine and so I would like to state above all else, it is for my parents, Adam and Sharon Nagler, and this for reasons best known to them and to me.

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Mark Nagler

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TABLE OF CONTENTS

	PAGE
ACKNOWLEDGEMENTS	ii
COPYRIGHT	iv
TABLE OF CONTENTS	v
LIST OF FIGURES	xiii
INTRODUCTION	1
CHAPTER 1	4
GENERAL THEORETICAL PERSPECTIVE	4
PREFACE	4
OVERVIEW	5
THE EARLY SYMBOLIC INTERACTIONISTS	7
COOLEY	10
MEAD	12
THOMAS	17
CONTEMPORARY SYMBOLIC INTERACTIONISTS	20
Deviance	22
Spoiled Identity	23
EMPIRICAL STUDIES OF SPOILED IDENTITY	30
CONCLUSIONS AND SUMMARY	44
REFERENCES	52

TABLE OF CONTENTS - continued

	PAGE
CHAPTER II	
STIGMATIZED DISABILITY AND THE OSTOMATE	55
INTRODUCTION	55
Characteristics of Illness - Non- Stigmatizing, Chronic and Stigmatizing	60
The Effect of Stigmatized Illness on the Interactants	66
THE OSTOMATE: A CLASS OF STIGMATIZED DEVIANT	67
THE INFLUENCE OF THE NORTH AMERICAN ETHIC OF CLEANLINESS ON OSTOMATES	75
SUMMARY AND CONCLUSIONS	85
FOOTNOTES	86
REFERENCES	87
CHAPTER III	
METHODOLOGY	88
THE METHODOLOGY OF THE SYMBOLIC INTER- ACTIONISTS	89
METHODOLOGICAL ASSUMPTIONS AND ORGANI- ZATION OF THE DATA	95
DESCRIPTION OF THE SAMPLE	99
DATA COLLECTION TECHNIQUES AND ANALYSIS	102
CRITIQUE OF THE METHODOLOGY	114
SUMMARY	118
FOOTNOTES	119
REFERENCES	120

TABLE OF CONTENTS - continued

	PAGE
CHAPTER IV	
CAREER OF OSTOMATES	121
INTRODUCTION	121
THE CAREER OF OSTOMATES	124
Mr. Q.	130
THE MINOR SYMPTOMS PHASE	134
THE MAJOR SYMPTOMS PHASE	138
DIAGNOSIS LEADING UP TO SURGERY	140
THE FEAR OF CANCER, SURGERY AND THE PRE-OPERATIVE PERIOD	147
PSYCHOLOGICAL PREPARATION FOR SURGERY	156
POST SURGICAL PERIOD	160
Patient Responses and Reactions Following Surgery	160
Reaction to Stoma	165
Major Complications Following Ostomy Surgery	170
POST HOSPITAL PHASE	171
Changes in Body Self Image	171
FACTORS TO BE CONSIDERED IN PATIENT ADJUSTMENT	181
Type and Duration of Disease	181
Subsequent Hospitalization	184
Ostomy Management and Related Physical Problems	185

TABLE OF CONTENTS - continued

	PAGE
Sexual Implications of Surgery	194
Age and Sex	202
Effect on Employment Opportunities	204
SUMMARY AND CONCLUSIONS	208
FOOTNOTES	210
REFERENCES	211
 CHAPTER V	
NEW ROLE FORMATIONS: ROLES AND REACTIONS OF SIGNIFICANT OTHERS INVOLVED WITH THE OSTOMATE IN THE REHABILITATION PROCESS	213
The Role of the General Practitioner	216
The Role of the Surgeon	219
The Role of the Nurses	228
The Role of the Enterostomal Therapist	236
The Role of the Ostomy Association	241
The Role of the Family	252
The Role of Significant Peer Groups	264
CONCLUSION	267
FOOTNOTES	268
REFERENCES	271

TABLE OF CONTENTS - continued

	PAGE
CHAPTER VI	
NEW ROLE FORMATIONS: PATTERNS OF ADAPTATION	273
CONCLUSIONS	290
FOOTNOTES	293
REFERENCES	294
CHAPTER VII	
CONCLUSIONS	296
INTRODUCTION	296
Sample Characteristics	298
Self-Help Group Affiliations	298
The Stigma	299
RELEVANCE OF THE STUDY TO THE PROCESSES OF IDENTITY FORMATION	301
THEORETICAL IMPLICATIONS OF THE STUDY	304
Career of Renegotiation and Factors in Adjustment of Ostomates	304
Importance of Age and Renegotiation	307
Importance of Family and Peer Group in Renegotiation	308
Importance of Medical and Paramedical Personnel in Renegotiation	309
The Labelling Process	311

TABLE OF CONTENTS - continued

	PAGE
The Concept of Victim	314
Legitimacy and Renegotiation	315
Awareness and Identity Renegotiation	317
Acceptance and Adjustment to a Deviant Identity	323
IMPLICATIONS FOR FUTURE RESEARCH ON THE STUDY OF IDENTITY RENEGOTIATION FOR INVOLUNTARY DEVIANTS	329
FOOTNOTES	330
REFERENCES	332
APPENDICES	
APPENDIX A	
RECOMMENDATIONS	335
ISSUES AND OBSERVATIONS	335
1. Pre and Post Operative Counselling	336
2. Advantages of Family Counselling	342
3. Post-Surgical Psychiatric Difficulties	343
4. Sex Counselling	343
5. Influence of Other Ostomates	345
6. Post Surgical Problems	345
7. Ostomate Identification	346
8. Ostomy Team Formation and Function	347
9. The Role of the Surgeon	348

TABLE OF CONTENTS - continued

	PAGE
10. The Role of the Referring Physician	349
11. Post Operative Care	350
12. The Importance of Training in Waste Evacuation	351
13. Problems Associated with Appliances	354
14. Medical - Paramedical Communications Problems	355
APPENDIX B THE HISTORY OF OSTOMY SURGERY	358
APPENDIX C TYPES OF OSTOMIES	364
APPENDIX D DIAGNOSIS	381
APPENDIX E THE HOSPITAL PHASE PHYSIOLOGICAL PREPARATION FOR SURGERY	382
APPENDIX F FACTORS ASSOCIATED WITH STIGMATIZED AND NON-STIGMATIZED AFFLICTIONS	383
APPENDIX G OSTOMY SURGERY	385
APPENDIX H MAJOR COMPLICATIONS FOLLOWING OSTOMY SURGERY	389
Prosthetic Problems	391
APPENDIX I GLOSSARY	394

TABLE OF CONTENTS - continued

	PAGE
APPENDIX J PATIENT QUESTIONNAIRE	409
FOOTNOTES TO APPENDICES	416
BIBLIOGRAPHY	417

LIST OF FIGURES

		PAGE
Figure 1	THE INTESTINAL TRACT	365
Figure 2	SIGMOID COLOSTOMY	366
Figure 3	DESCENDING COLOSTOMY	367
Figure 4	TRANSVERSE COLOSTOMY	368
Figure 5	DOUBLE BARREL COLOSTOMY	369
Figure 6	CECOSTOMY OR ASCENDING COLOSTOMY	370
Figure 7	LOOP COLOSTOMY	371
Figure 8	THE ILEOSTOMY	372
Figure 9	THE URINARY TRACT	373
Figure 10	CUTANEOUS OR BILATERAL URETEROSTOMY	374
Figure 11	ILEAL CONDUITS OR ILEAL BLADDER	375
Figure 12	NEPHROSTOMY (Back View)	376
Figure 13	VESICOSTOMY	377
Figure 14	TRANSURETER OSTOMY	378
Figure 15	DOUBLE BARREL URETEROSTOMY	379
Figure 16	LOOP URETEROSTOMY	380

INTRODUCTION

This investigation examines from a symbolic interactionist perspective, a case of spoiled identity - a segment of the physically disabled who find themselves subject to ostomatic status. Spoiled identity evolves when a person has had, or believes that he has had, the characteristics which normally define his presence in day to day interaction compromised. In these situations, the person is perceived by himself and/or others as possessing characteristics which are often negatively defined. Spoiled identity, as defined by self or others, often serves to create barriers in interaction between the bearer of the spoiled identity and various members of society.

Ostomatic condition befalls those who are subject to infections and/or injuries which make it difficult if not impossible for the kidneys and/or bowel to function normally. As a result bodily wastes are channelled through a surgically created opening on the side of the abdomen, the wastes are collected in an appliance, and then manually disposed of by the victim.

From a broad sociological perspective this investigation is one that focuses upon identity. Identity has been an important sociological concern that had its beginnings with theorists such as Cooley, Mead, Thomas and Znaniecki and Blumer. This tradition has been continued by the work of contemporary sociologists such as Becker, Goffman, Davis, Roth, Scott and Glaser and Strauss. The study of ostomates is similar to those done by researchers with polio victims (Davis, 1963) or those studies of mental patients (Goffman, 1963). Research on

ostomates is part of the sociological tradition which analyzes the patterns by which people with spoiled identity cope with the social meaning and consequences of being subjected to an instantaneous disability. This spoiled identity is often viewed and labelled by others in negative terms. The project investigates the ramifications of having ostomatic status and examines the reactions of the patients to their altered physical and social status. The research also examines the consequences of being defined as a victim of spoiled identity. The chain of medical, social and psychological events set in motion by being defined as an ostomate provides the basis for increasing our understanding of how those afflicted with spoiled identity encounter reality. It will illuminate the processes by which identities are formed and developed into new identities through encounters with families, medical and paramedical personnel, as well as significant others. The study suggests strategies which could be used in attempting to maximize the potentiality of rehabilitation for those subject to the stigma of being disabled.

Chapter One provides the theoretical and methodological perspective adopted for the study calling upon symbolic interactionists' traditions of Mead (1934), Cooley (1922), and Thomas and Znaniecki (1918); and the more contemporary works of Blumer (1962), Goffman (1961, 1963), Becker (1963), Davis (1963, 1967) and Scott (1967) on deviance and spoiled identity. Chapter Two discusses ostomies as stigmatized conditions. It presents a discussion of the factors involved when a victim of spoiled identity endeavours to come to terms with his new identity. Chapter Three provides an examination of the empirical basis and methodology used in the investigation.

Chapter Four focuses on the career of ostomates. Chapter Five provides an analysis of the roles and reactions of others involved in the treatment, adjustment and renegotiation of those afflicted with ostomatic conditions. Chapter Six focuses on the patterns of adaptation illustrated by ostomates to spoiled identity.

The concluding chapter discusses the relevant implications for identity formation and spoiled identity through the experiences of ostomates - how and why those with spoiled identity endeavour to come to terms with their altered identities.

CHAPTER I

GENERAL THEORETICAL PERSPECTIVE

PREFACE

In this chapter we will set out the relevance of the early symbolic interactionists' work to our study of spoiled identity. We will show how the work of the contemporary symbolic interactionists, in their studies of deviance and spoiled identity, adds to the body of literature on identity formation. And we will discuss the processes whereby identity is renegotiated when one is afflicted with a disability that is negatively evaluated by society, that is, stigmatized.

OVERVIEW

The establishment of an identity, a set of self-other recognizable statuses, is a central dimension of all social and social-psychological organization. In identity formation and maintenance is found the dynamic processes that make organized social behaviour possible, the basis for individual motivation and commitment to participate in a society, and the mechanisms for continuity and change within a social system. It is in this context of sociological importance that the earliest 'modern' sociological writers such as Cooley, Mead, Thomas and Znaniecki, Weber, Marx, Durkheim, Simmel and Blumer devoted much of their efforts. In this thesis, within this tradition, it is attempted to add more information and insight into the nature of general sociological processes by focusing on certain aspects of identity formation, renegotiation and reformation.

A strategy of analysis that has been consistently productive for understanding the 'normal' or organized aspects of society is the analysis of deviance and social disorganization. The logic has been that by looking at the obviously 'different', non-conforming behaviours and disorganized or unorganized states of social systems, some parameters can be identified about conformity, normal processes and organized behaviour. For the study of humans, contrast is a key scientific strategy, especially for sociologists. Thus, for example, when Thomas and Znaniecki (1918) studied the personal and social disorganization of uprooted Polish peasants, their concern was with trying to identify in what social context would their identities be normal, could be normal, or could be adaptive. Again, Parsons (1953), in his analysis

of the sick role and characterizing it as deviant, was hoping to identify the normal. Homans (1950), in his careful attention to the role of the deviant and the conditions of social disintegration, was attempting to show what conformity and the socially organized were. Merton (1945), perhaps, is the dominant person in this school of thought, in his well-known utilization of the work of Weber and Durkheim in his analysis of social structure and anomie. Studies in this tradition are multitudinous, but the sociological strategy is primarily the same.

Our work here is intended to fit in this tradition. We try to focus on identity formation and what happens to the identity (and the organizational context it is in) when identity is suddenly changed or threatened. Our theoretical and research approach primarily takes the symbolic interactionists' perspective. The style and analytic power of this approach seems best suited for the subject matter of our research.

THE EARLY SYMBOLIC INTERACTIONISTS

Those who led the early symbolic interactionists' perspective, Cooley, Mead, Thomas and their modern counterparts Goffman and Davis, have focused on the regularities in the formation, maintenance, patterning and break off of systematic behaviour. Early sociologists such as Durkheim, Weber, Cooley and Simmel conceived of groups as consisting of the interaction of human beings with one another. Weber, especially, was specific in outlining the framework of social action upon which he based his analyses. These early scholars could not avoid becoming concerned with the characteristics of the individual participants whose behaviour made up the patterns of interaction that they were describing.

In North America, the development of this kind of sociology became part of a more elusive, intellectual movement in which some of the implications of Darwin's theory of evolution are put to a new application and where reality is considered to be more changing than static. Pragmatists like William James and John Dewey as well as George Herbert Mead endeavoured to develop a new way of looking at man in society. Instead of regarding perception and cognition as attributes of substance and mind, they looked upon perception and cognition as types of behaviour. Their focus of attention was not preoccupation with certain types of behaviour, but rather an investigation centred on the regular ways that changes occur and develop.

In order to study social behaviour, early social-psychologists and sociologists regarded the social group as consisting of inter-

acting persons, and the various patterns of interaction were viewed as collective adjustments to life conditions. Behaviour, then, became influenced by patterns of socialization and the various ways by which individuals encountered crises. Thus, sociologists began to focus on the central problem of socialization: how do human infants, born helpless and undeveloped, acquire the capacity for participating in organized groups? For Cooley, Robert Park (1950), and W. I. Thomas, the study of personality development became one of the major sub-fields of sociology. This branch of sociology does not pretend concern with all of the things man does; rather, the intention is focused only upon those regularities in human behaviour that arise out of the fact that men are participants in a social group. Therefore, many studies such as those done by Cooley, Mead and Thomas focus on regularities of behaviour and how these regularities develop and maintain themselves in forms of personal and social identity.

According to Cooley (1922), all human beings have certain properties in common which enable strangers to identify themselves as being quite similar. This provides the basis for learning about the peculiarities of one another's customs and institutions. It is generally agreed that all men are of the same biological species in spite of superficial variations in appearances, different distributions of blood types and differential immunity to disease. Beyond this, there is very little agreement about what is typical of all human beings over and above their common biological nature. The symbolic interactionists directed their investigations towards the discovery of the common attributes that evolve as a consequence of

the degree and flexibility in behaviour which arises from man's ability to engage in symbolic communication. Man everywhere engages in some pattern of language and is capable of reflective thought. Hence, their behaviour is marked by foresight and planning. In addition to this, it was Cooley's contention that men are characterized by certain sentiments. "Indeed, it is through the detection of similar sentiments that role taking across cultural boundaries is accomplished" (Cooley, 1922:183).

COOLEY

Cooley contended that the sentiments which enabled men of diverse origins to identify with one another developed in intimate contacts with people whom each knows on a personal basis. He believed that the sentiments are universal because such intimate circles exist everywhere. Cliques, families, neighbourhood groups and juvenile gangs can be found in most societies. Man everywhere develops similar curiosities about one another - their emotional reactions, their secrets, their erratic preferences and peculiarities of their moral character. There are the same restraints and tensions, conflicting interests, cooperation to attain different aims, necessity of curbing aggressive tendencies, loyalty under conditions of duress and tests of courage in all primary groups. Everyone is confronted by authority figures of one sort or another and has learned to deal with them in some way (Cooley, 1922:183-185). Even Freud, although he learned a different vocabulary, also appreciated these facts and incorporated them into his theory of socialization. Freud's work is remarkably like that of Cooley, in spite of his emphasis on different kinds of sentiments.

Self conceptions, like most other meanings, are creatively reaffirmed from day to day in the interaction of people with one another. Each person develops some notion of the kind of person he must be from the regularity with which he finds himself addressed by others and with whom he has sustained association. Each man possesses notions of his physical appearance, of what he is expected to do, of

the deference he commands, and these arise through participation in groups. This is what led Cooley to describe man's sense of personal identity as a "looking glass self." Cooley suggested that: "One's conception of self is essentially a reflection of his attributes as they are mirrored in the society of which he is a part: he constructs the personifications and reactions of other people. If one is consistently treated as if he were peculiar, he tends to conceive of himself as odd and different" (1922:185). Cooley comes to grips with this phenomenon when he developed his theory of the looking glass self.

As we see ... our face, figure and dress in the glass and are interested in them because they are ours, and pleased or otherwise with them according as they do or do not answer to what we should like them to be; so in imagination we perceive in another's mind some thought of our appearance, manners, aims, deeds, character, friends and so on, and are variously affected by it.

A self idea of this sort seems to have three principal elements; the imagination of our appearance to the other person; the imagination of his judgment of that appearance; and some sort of self feeling, such as pride or mortification. The comparison with a looking glass hardly suggests the second element, the imagined judgment, which is quite essential (quoted in Lindesmith and Strauss, 1968:318).

MEAD

Another sociologist who concentrated on identity was G. H. Mead (1913, 1932, 1934) who maintained that each person forms a conception of himself by evaluating his subjective experiences from a collective standpoint. What a man regards himself to be should then be a reflection of what he believes others think of him, which is not necessarily what they actually do think. Mead contended, further, that men are able to form definite objects of themselves primarily through symbolic communication. In answering the question, if individuals act separately, how does cooperation occur, Mead suggested that mutual adjustment among independently acting individuals is facilitated by their ability to form perceptual objects of themselves through role-taking. A portion of the perceptual field of each participant becomes differentiated into what he experiences as himself, thus each person is able to form a self image. This enables each party to examine whatever he is about to do from the standpoint of the others involved in the situation. As an individual, he is being seen as being able to fix his own responsibility because he can imagine how he appears to others.

Personal responsibility within the confines of the game is fixed then by the actor's imagining of what others expect of him. The separate lines of action of the various participants fit together in a reciprocating fashion because each can take the role of the adjustment to the intentions and expectations imputed to them (Mead, 1932:176-195).

But self image is not completely stable, for as Mead argued, the most stable of individuals may find himself in an anxiety-prone situation when encountering individuals of higher status, influence

or power. Thus Mead proposed that the extent to which individuals are conscious of themselves varies from situation to situation, and this suggests that there may be identifiable conditions under which self images are formed.

Mead (1934) proposed that human beings are able to control themselves because of their capacity to act towards themselves in much the same manner as they act towards other people and as others act towards them. A person can berate himself, praise himself, make excuses to himself or indulge himself just as he can do these things to others. Thus, a man becomes conscious of himself as a distinct unit through role taking; he responds to his own activity as if he were someone else. He responds covertly to his own behaviour in the same way in which he expects others to respond overtly. The capacity to form self images makes self criticisms and self control possible. However, actors may not be able to exercise self control to the extent expected by varying segments of society. Mead's concept of self control refers to behaviour that is redirected in light of the manner in which it is imagined to appear from the standpoint of other people who are involved in a cooperative task. It is Mead's contention that only man is aware of the fact that it is he himself that has these experiences, therefore it appears that social control rests largely upon self control. What men are inclined to view in any situation is dependent upon the meanings with which they have entered a situation. What is being suggested is that the manner in which anyone perceives his social and physical environment depends upon the meaning that they as objects and individuals have for him, as well as upon what he is doing or what he is seen as.

What one is perceived as need not represent one's actual identity, as individuals are often erroneously labelled.

Under conditions of stabilized identity the planning and direction of overt behaviour becomes possible because men are able to respond to themselves in their imaginations; they can chart their course in such imaginative rehearsals by pretesting various kinds of action (Mead, 1913:374-389). Thus, one can see how individuals who become paraplegic, blind or disfigured often anticipate their patterns of interaction with others from their perceptions of the way in which similarly affected individuals are treated. Strain and anxiety are produced when the affected individuals desire and strive to maintain the patterns of interaction which they encountered before having their identities subject to the pressures, labelling and consequences of supposed and/or legitimate spoiled identity.

As a consequence of spoiled identity, self control is often compromised and the expectations of individuals' pattern of behaviour by others may be "renegotiated" in that significant others may expect alterations in the behaviour of the affected victims. Patterns of behaviour are often evolved from elicited hypotheses of what to expect. Thus, when one is encumbered by the difficulties associated with spoiled identity, one often expects to be accorded new patterns of acceptance and treatment. The ability to manipulate one's pattern of treatment is dependent upon a host of factors relating to one's primary group, one's identity, the extent of one's afflictions or perceived afflictions and a variety of other social and/or demographic variables which may or may not be present in particular situations.

Mead implied that the manner in which a man personifies himself is largely limited by the symbols that are available to him for describing and orienting his experiences.

The act of controlling one's self is itself a part of an ongoing social current; for as each individual adjusts in advance to the situation in which he is involved and reacts upon it, he makes more complex forms of cooperation possible. Precisely because each participant has incorporated into his own perspective the expectations of the others he is able to anticipate their responses and adjust to them in advance. The carrying out of such reactions to the self images on the part of all participants in a joint undertaking is what constitutes human society. (Shibutani, 1961:178-192).

Mead was concerned with the problem of the phenomena of the self. As it stands, the sense of self with its inevitable indication of a cognate sense of being different from others would appear to limit sociological analysis as such.

Mead meets the problem directly, by conceiving the self as itself a social phenomena. There are various ways of understanding his analysis. As we read it today, fortified by Freud and others, we have found it impossible to assess the full import of Mead's analysis. It is deeply inferred by the cardinal importance of communication, particularly of language (Naegele, 1961:154).

Mead maintained that it is not only language as such, but the way that language is used that describes or conveys images to others. Thus, one must be aware of the tone of voice utilized during conversation, for example. The phrase, "I wish he were dead" may suggest the actual desire to witness an individual's demise, but more often, it probably conveys a desire to avoid interaction with a particular individual.

According to Mead, we conceive of ourselves socially because in the company of others we have learned to think of ourselves as they think of us. Others think of us as they have learned to think of them-

selves, namely, as persons each of whom has a self. Mead argues that as we internalize the view of others, we become involved in a world of relations. However, maintaining the fact that the self is different from the audience, this behaviour is like a game which is an illustration of the situation out of which an organized personality arises. "He becomes something which can function in the organized whole, and thus tends to determine himself in the relationship with the group to which he belongs" (Mead, 1934:152-164).

Pitts (Naegele, 1961) suggested that implicit in Mead's thinking is the idea that the unit of the social system is not the individual, but the dyadic role expectation which involves expectations from self and the other; this is the social 'Me'.

The very organization of the self-conscious community is dependent upon individuals taking the attitude of other individuals. The development of this process, as I have indicated, is dependent upon getting the attitude of the group as distinct from that of a separate individual - getting what I have termed as generalized others. I have illustrated this by the ball game in which attitudes of a set of individuals are involved in a cooperative response in which the different roles involve each other. Insofar as man takes the attitude of one individual in the group he must take it in its relationship to the action of the other members of the group; and if he is fully to adjust himself, he would have to take the attitudes of all involved in the process. The degree, of course, to which he can do that is restrained by his capacity but still, in all intelligent processes, we are able sufficiently to take the roles of those involved in the activity to make our own action intelligent (Mead, 1934:253-257).

THOMAS

The orientation of Mead has been crystalized by Thomas in his writings concerning the understanding of the relationship between personality and social structure. Thomas made clear the distinction between personality, culture and social structure as independent but penetrating variables. According to Thomas (1951), personality provides the wishes to be satisfied and culture gives external objects their value. There are four wishes to be satisfied: 1) the desire for new experience; 2) the desire for security; 3) the desire for response and 4) the desire for recognition. According to Thomas:

The general pattern of behaviour which a given individual tends to follow is the basis of our judgment of his character. Our appreciation (positive or negative) of the character of the individual is based on his display of certain wishes as against others and on his modes of seeking their realization ... We may assume ... that an individual life cannot be called normal in which all four types of wishes are not satisfied in some measure and in some form (Thomas, in Volkart, 1951:121-144).

Thomas proposed that in endeavouring to satisfy the four desired there is established a moral code:

... which is a set of rules or behaviour norms regulating the expression of wishes, and which is built up by successive definitions of the situation. In practice the abuse arises first and the rule is made to prevent its re-occurrence. Morality is the generally accepted definition of the situation, whether expressed by public opinion and the unwritten law, in a legal code or in religious commandments and prohibitions (Thomas, in Volkart, 1951:121).

The definition of the situation is a process whereby a person explores the behaviour possibility of the situation by marking out the limitations which the situation imposes on his behaviour. The group from which the individual comes is important because the group products that we know as folkways, norms, mores and values are pre-

conditions for the definition of the situation.

Preliminary to any self determined act of behaviour there is always a ... definition of the situation ... gradually a whole life policy and the personality of the individual himself follows from a series of such definitions (Thomas in Volkart, 1951:144).

Martindale suggested that the most interesting of interhuman facts flow from different definitions of the situation. There is always a rivalry between the spontaneous definitions of the situation made by the member of an organized society, and the definition which society has provided for him.

Thomas's statement of the problem of sociology as one of tracing the influence of society and culture on the individual, and the individual on society and culture, parallels Cooley's theory and practice. For Cooley, too, had this problem in mind when he traced the effects of personal ideas upon social organizations, institutions, and public opinions (Martindale, 1960:34).

The most important work undertaken by Thomas was done in collaboration with Znaniecki and this represents their collective and perhaps their most worthwhile contribution to the symbolic interactionist perspective. The framework of their work was an analysis of the transformations of personality and social structure of the Polish peasant community in the course of their adjustment to North American society.

Rules and actions, taken ... with regard to the attitude provoked by them, are quite analagous to any other values - economic, artistic, scientific and religious ... The rules of behaviour, and the actions viewed as conforming or not with these rules, constitutes with regard to their objective significance a certain number of more or less connected and harmonious systems which can be generally called social institutions, and the totality of institutions found in a concrete social group constitutes the social organization of this group (Thomas and Znaniecki, 1918).

Sociologists in the tradition of Mead, Cooley, and Thomas and Znaniecki sought an explanation of the regularities in human behaviour which brought to the fore the development and explanation of the phenomenon of socialization. However, as is known, socialization in and of itself can seldom explain the interaction between those who are able to maintain their identity and those members of society who have been subject to some kind of phenomenon which required changes in their identity.

CONTEMPORARY SYMBOLIC INTERACTIONISTS

While early symbolic interactionists focused on the processes of identity formation and socialization as the mechanisms that made for regularities in society and produced social cohesion; the contemporary symbolic interactionists also tended to focus on identity formation but hoped to get at this process by attention to behaviour which broke the accepted norms of society. Many studies looked at devalued social positions which nevertheless were embedded in the social structure of society. This interest gave rise to volumes of literature on special subject areas such as crime and further developed the area of criminology, e.g. Shaw's *The Jackroller* (1931), Sutherland's *The Professional Thief* (1937); the literature that dealt with marginality and devalued social positions, e.g. Becker's studies of *The Jazz Musician* (1951), *The Marijuana User* (1953), *The "B" Girl* (1963), culminating in *The Outsider* (1963); and finally the group of studies that looked at the culture of whole groups which are devalued, e.g. Whyte's *Street Corner Society* (1955), and Cohen's *Delinquent Boys* (1955). The strategy was to examine positions or segments of society which were different from the 'normal' society in order to see more clearly the conditions and processes that were present in the development of identities for such divergent groups. This strategy also gave rise to a number of crisis studies with the hope that the processes could be examined as they were occurring, e.g. Cantril's *The Invasion from Mars* (1947) and Golding's *Lord of the Flies* (1954).

The strategy of studying the impact of crisis producing situations on the persons involved, as well as the impact of significant others,

gave rise to many studies of social categories that were of a social-psychological nature. Studies of the mentally ill (Goffman, 1961), the un-adjusted teenager (W. I. Thomas, 1951), the homosexual (Weinberg, 1974; Liznoff and Westley, 1956), divorce (W. J. Goode, 1956), the poor (Gans, 1962), the disillusioned (Bahr, 1973) or the unwed mother (Thomas, 1951) and more recently the aged (Townsend, 1971), were attempts to examine the impact of devalued positions under crisis in society on those persons in such positions.

More recently some of the contemporary symbolic interactionists commenced to look at devaluation of persons as a result not of social position or conditions, but because of physical impairment which made the person's previous identity problematic. Studies of deafness, blindness, amputation and polio examined the damage to the previous identity and focused on the new identity formation that resulted. The study of identity formation under conditions of physical impairment is the focus of the research reported in this study. The literature of deviance and spoiled identity is reviewed in the two subsections that follow.

Deviance

The deviance perspective can be summarized as follows. All of the studies dealing with devalued social positions and groups and those dealing with non-conforming groups or persons have come to be grouped under the area known as deviance, i.e. behaviour or situations that depart from socially accepted norms, or reflect violations of normative expectations - rule breaking behaviour. Howard Becker (1963) views deviance not as a property of an act itself, but rather as behaviour which violates someone's conception of the rule and is identified as doing so. The interest, then, is to understand how an individual comes to adopt a regular pattern of behaviour that is rule breaking. The link between occasional rule breaking (which everyone does at some times) and stable patterns of deviance is thought to be the labelling process (Lemert, 1967; Scheff, 1966; Goffman, 1963). The imputation of the label has implications for the identity of the labelled. Through principles of person perception (set out by the early symbolic interactionists, especially Cooley), people tend to see in others what they expect to see. A label defines these expectations. By suggesting that the individual behaviours are taken as documents or indicators of some underlying essential quality of the self, current and past behaviours of a person can be organized in terms of the label. Faced with the charge that he is some kind of different person (or not fully normal) the labelled person has two options - to attempt to fight the imputation of the label, or to accept it. Acceptance of the label implies living up to (or down to) the expectations of the labellers, e.g. being mentally ill,

being a criminal, being handicapped, being retarded, being old, etc.

Spoiled Identity

It is virtually axiomatic in the perspective of symbolic interactionism and role theory (Biddle and Thomas, 1966; Marshall, 1974) which underlies this approach to deviance, that if a person is induced or coerced into playing a role, he alters his self-concept, or his identity, in keeping with his behaviour. When the roles to be played are devalued and require radical changes from previous ones, the person's identity changes radically as well. The required change in identity under such conditions is termed spoiled identity. The person with spoiled identity must then develop, in some way, a new identity which is congruent with the label that is being applied. The physically disfigured or disabled are prime examples of the operation of this labelling process and the consequent acceptance of the label by many persons physically disfigured, since the disfigurement cannot be denied. The amputee for example must accept the label of disability, of a spoiled identity, since it is clear that he no longer is physically whole as he once was.

The early symbolic interactionists pointed to the social development of identity - the expectation of certain behaviour for given social categories and situations - and the process of forming a conception of self identity from the regularity with which one finds himself addressed by others and with whom he has sustained association. The later symbolic interactionists have tended to show what happens to social and personal identity when the regularity with which one is addressed, as

result of being unable to meet usual expectations in interactions, is discrediting or labelled as deviant. Studies by contemporary symbolic interactionists which focus on persons in devalued social positions or categories and pay closer attention to deviant identity formation can be grouped into an area of study referred to as 'spoiled identity'.

The term has come into use through Goffman's studies (1961, 1963), but it has never been explicitly defined nor has spoiled identity been recognized as an area of study as such. Goffman explains its meaning in terms of stigma and stigmatizing conditions. Stigma in the context of spoiled identity is used in the original Greek sense to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier. Goffman uses the term stigma to refer to an attribute that is deeply discrediting. It is a special kind of relationship, he says, between attributes and label, for an attribute that stigmatizes one individual can confirm the usualness of another and is therefore neither creditable nor discreditable as a thing in itself. Thus spoiled identity evolves when an actor has had or believes that he has had the attributes which normally define his presence in day to day interaction compromised so that he is perceived by himself and/or others as possessing attributes which are often negatively defined or labelled as devalued. The term stigma and its synonyms conceal a double perspective, Goffman reminds us:

Does the stigmatized individual assume his differentness is known about already, or is evident on the spot, or does he assume that it is neither known about by those present nor immediately perceivable by them? In the first case, one

deals with the plight of the discredited, in the second with that of the discreditable. This is an important distinction even though a particularly stigmatized individual is likely to have experiences with both situations (1963:3)

According to Goffman, we construct a stigma theory as an ideology to explain an individual's inferiority and account for the danger he is seen to represent.

The central feature of the stigmatized individual's situation in life can now be stated ... As far as the stigmatized individual is concerned, especially if he desires to regain normality, his goal becomes acceptance (1963:9).

This is the type of stigma that one is concerned with when one is discussing spoiled identity or what Goffman called 'abominations of the body', the various physical deformities. Those who are subject to the consequences of the stigma often find in various spheres that their life chances are reduced in terms of economic opportunities, social pursuits and general patterns of acceptability. Just because stigma is attributed or may be attributed to an individual or group by another individual or group does not necessarily mean that the designation of the stigma will have negative implications for the victim if he is able to disregard the stigma. One who has experienced severe facial deformities may continue to live the life patterns formerly observed, dismissing the negative implications which may be encountered through relationships with others (cf. F. C. Macgregor, 1951). Others may incorporate or be affected by the consequences of stigma. Those who becomes 'victims of stigma' may curtail their social contacts, withdraw, or in extreme cases commit suicide in order to alleviate the barriers encountered as a result of being designated as different and inferior.

For those subject to spoiled identity the type of acceptance one counters becomes problematic. Some 'handicapped' desire special treatment; others desire to be accepted without any discernable form of prejudice and/or special consideration.

Victims of stigma or potentially stigmatizing conditions encounter difficulty in accepting, maintaining and/or changing their personal identity. From Goffman's perspective, the difficulties involve 'stigma management'. Thus, an ex-inmate of a mental institution may not, for apparent reasons, make public his incarceration to new friends, employees and other social contacts. Those who are physically disabled are sometimes able to disguise their conditions, as is the case for many diabetics. Other victims of 'handicapped status' such as the blind and the deaf have no choice in making public their conditions, while other victims of disabilities, such as ostomates, often have a choice as to whether or not their condition should be made 'public'. Victims of mastectomies may choose not to disclose their discreditable characteristics in view of the fact that disclosure may often interfere with their acceptance by others. Some, however, possessing the same characteristics may offer disclosure as they believe in the dictum, "accept me as I am or not at all"; they are unconcerned and perhaps not even affected by those who fail to grant them acceptability. Those who decide not to disclose are subject to the consequences of "being found out". In many instances, being "found out" will place the victimized individual into the defined status of being dishonest as well as unacceptable, inadequate and perhaps even unclean. It is not only those with major disabilities who

are affected by these feelings, for, as Goffman (1963) pointed out:

The most fortunate of normals is likely to have his half hidden failing, and for every little failing there is a social occasion when it will look large, creating a shameful gap between virtual and actual social identity. Therefore, the occasionally precarious and the constantly precarious form a single continuum, their situation in life analyzable by the same framework ... The fully and visibly stigmatized in turn, must suffer the special indignity of knowing that they wear their situation on their sleeve, that almost anyone will be able to see into the heart of their predicament. It is implied, then, that it is not to the different that one should look for understanding our differentness, but to the ordinary. The question of social norms is certainly central, but the concern might be less for uncommon deviations from the ordinary than for ordinary deviations from the common... (1963:7-9)

Goffman went on to imply that anyone who fails to qualify in conformity to expected norms is seen as:

... unworthy, incomplete and inferior; at times he is likely to pass and at times he is likely to find himself being apologetic or aggressive concerning known-about aspects of himself he knows are probably seen as undesirable. The general identity values of a society may be fully entrenched nowhere, and yet they can cast some kind of shadow on the encounters encountered everywhere in daily living. (1963:7-9).

One's identity values are the outcome of one's perceptions of his or her self image, his or her perception of how others perceive one's characteristics and the extent to which both actor and audience interpret the effects of body compromises (stigma). Moreover, as Goffman observed:

The standards he has incorporated from the wider society equip him to be intimately allied to what others see as his failure, inevitably causing him if only for moments, to agree that he does indeed fall short of what he really ought to be...

Those who have dealings with him fail to accord him the respect and the regard which the uncontaminated aspects of his social identity have led them to anticipate extending and have led him to anticipate receiving; he echoes this denial by finding that some of his own attributes warrant it (Goffman, 1963:7-9).

The acquisition or possession of any status that is likely to be noticed as different makes an individual's acceptance a problem. Thus, some people tend to lose their sense of integrity which is bestowed as a consequence of belonging to a normal group. Often those who are afflicted by the criteria which may be attributed to mental or physical disabilities are forced to admit their own inferiority, in spite of the fact that many strive for normalcy. "A phantom acceptance is thus allowed to provide the base for a phantom normalcy" (Goffman, 1963:95).

Goffman concluded that by taking a concept such as deviance and using it to ask questions about impairments and their social consequences, we can better understand which of the facts most require deliberate change to improve the task of rehabilitation. In a study conducted by Farber (1968) on mental retardation in the family, the author cites Fred Davis's hypothesis that people try to ignore the effects of incompetence in interaction and tend to attribute role performance to situational factors.

In effect, persons interacting with an incompetent individual, apparently attempt to maintain the system of relationships as if there had been no role failure. At a certain point, however, this disavowal of problems becomes impossible. One problem for possible investigation is finding the point at which failure in the performance of role is no longer ignored, given different kinds of social situations. Labelling this role failure as deviance rather than as incompetence would determine the kind of action that would be taken (Davis, quoted in Farber, 1968:25).

The difficulties occurring for many who are defined as disabled as well as for other stigmatized individuals, stems from the fact that they too accept the deviant label often applied to them by the 'normals' and thus the whole process becomes even more insidious. When this is

the case, a disabled person may be open to attack from within as well as from without.

The above considerations about spoiled identity, relying primarily on Goffman's studies and the assumptions of the early symbolic interactionists, lead to a number of conclusions about how it develops, and the problematic nature of interactions with those possessing spoiled identity. The concept of spoiled identity developed out of an interest in persons who are seen as filling a marginal or devalued position in society and how they have come to be so categorized. Those who are subject to spoiled identity must be seen to possess (though do not necessarily have to possess) some characteristic or attribute or behaviour, which can be labelled as different from or prevents one from meeting the usual expectations of a given situation. Spoiled identity evolves when an actor in a situation has had or believes he has had the attributes which normally define his status compromised so that he is perceived by himself and/or others to possess attributes which are negatively defined or labelled as discreditable. Those subject to spoiled identity often find that their life chances are reduced in terms of economic opportunities, social pursuits, and general patterns of acceptance. The problematic nature of their acceptance by others in previously accepted situations often leads to the need for renegotiating a new identity, taking into account the discreditable attributes, so that they will again be acceptable in interactions with others.

EMPIRICAL STUDIES OF SPOILED IDENTITY

Davis and Roth among others, have extended the analysis of identity to focus on the factors leading to the reactions of those specifically and generally affected by spoiled identity. The contemporary symbolic interactionists have not only been concerned with the theoretical implications of identity and spoiled identity, but they have sought to actualize their theoretical concerns through empirical studies. Blumer (1962) has continued to explore the theoretical implications of symbolic interaction in endeavouring to account for the reactions of those imbedded in various segments of the social structure to emerging conditions. Davis, Glaser, Strauss, Goffman and Roth have endeavoured to illustrate the perceptions of affected individuals as a result of being subject to the conditions that produce spoiled identity.

In his work on polio victims, Fred Davis (1963) illustrated the effects of polio on the patient and his family in view of the fact that the individual so affected experiences extreme changes in life owing to the severity and consequences of this disease. He dealt with the crisis experience involved with the diagnosis of poliomyelitis. He reported that those afflicted with polio often experience a number of personality adjustments which in themselves may be adaptive or maladaptive - aggression, denial, compensation or disassociation.

The consequences of the effect of poliomyelitis upon the family illustrate the role performances and relationships that are changed as a result of this disease. Problems associated with redefinition of

self also often befall the patient. Regarding identity, a crucial situation evolves in terms of coming to grips with the awareness of a new and often imposed identity which comes into conflict with one's former self. The disabled person suddenly becomes aware that he is encompassed, in some instances for life, by the prospect of being subject to a disability which will curtail his activities. When a debilitating disease such as polio strikes children, Davis found that:

What was striking about the group of nine handicapped children, particularly the youngest, was how long it took them to become aware of either the physical or social implications of their situation ... The awareness of the children was no doubt influenced by other factors in addition to their lack of worldly experience ... the unqualified progress ideology of physiotherapy; the reluctance of doctors to give parents an unambiguous prognosis of the child's handicap; the parent's reluctance in turn to introduce the child to the social meanings of his handicap; and finally the tendency of many persons with whom the handicapped child comes in contact to, on the one hand, pretend not to notice his impairment while on the other hand acting in such a way as to show that they do (Davis, 1963:141-142).

Not only do most normals find it difficult to include the disabled or stigmatized in their own category of being but even the afflicted individuals tend to share the normal standards of evaluation and will therefore support the rejection of themselves.

In the works of Roth, Scott and Davis, one often encounters victims who adapt patterns of behaviour expected by some normal elements of society. In Scott's (1969) 'The Making of Blind Men', one encounters some newly blinded individuals who unnecessarily restrict their associations with sighted society and become totally involved with blind individuals and groups. These adaptations in part are assumed by

some as they accept the notion held by some sectors of sighted society that the blind should "keep to themselves". "Normals" often encounter anxiety in their relations with "abnormals": they may not know what types of interaction are expected; they may fear becoming incapacitated themselves, and they may harbour societally spawned discrimination and prejudice towards the disabled. Some patients act out a "self-fulfilling prophecy" based on definitions which they previous assimilated during their existence as "normals".

Polio patients, like tuberculosis victims, attempt to schedule their recoveries in terms of reaching significant sign posts, which can be defined in terms of attributes associated with getting well (Davis, 1974). The ability to schedule through sign posts, functions to build up and maintain patient morale. Therefore, polio treatment procedures, like those for tuberculosis patients for example, are of the "quintessence of the Protestant ideology of achievement in America, namely, slow, patient and regularly applied effort in pursuit of a long range goal (Davis, 1974). However, as is known, scheduling for tuberculosis patients, leprosy victims and ostomy patients becomes difficult owing to the fact that it is often impossible to forecast with any degree of accuracy the exact course of the impairment. One can establish in some incapacitating situations that the victim's difficulties stem not only from his physiological impairments, but also from lack of knowledge or awareness, stigma and the perceptions of others.

Davis analyzed the initial encounters between normal individuals and those who are visibly disabled in a paper entitled "Deviance

Disavowal" (1967). His findings illustrated that normal individuals seldom if ever grant normality in terms of their interaction to individuals who are different. Thus, a differential behaviour is often accorded to the disabled. Relations with normals often proceed under stressful conditions because of embarrassment, awkwardness, shock, concern, pity, revulsion and compassion which destroy the normal basis of interaction.

The visibly handicapped person (i.e. blindness, a hunched back, crippled limbs) has a tendency to become an exclusive focal point of interaction. It has a potential for inundating expressive boundaries. It is also discordant with other attributes of the handicapped person. Consequently, the handicapped person must manage this strange situation so as to ensure a quick return to such usable basis of social interactions as neighbours, fellow students, or people of the same age group (Davis, 1967).

Davis maintained that the handicapped person usually encounters three stages through which his interaction with others progresses. The first stage is labelled as fictional acceptance, where those involved in the interaction fail to acknowledge the existence of handicapped status. The second stage is facilitating normalized role taking, which is followed by the third stage where there is institutionalization of the normal relationship. In the course of these stages the handicapped person is seen as manipulating his acceptance towards the end point to where his handicapped status makes no difference. Obviously, it can be difficult if not impossible in many situations for a disabled individual to establish and/or maintain a set of so-called normalized relationships with others.

Therefore, those who find themselves in a disabling position are likely to encounter problematic interactional situations whereby it is difficult if not impossible to forecast with any degree of reliability the degree of acceptance granted to those affected by spoiled identity. In this situation, both normal persons and those defined to be different must work to keep the situation stable. By implication, although it is not at this point one of Davis's prime foci, he is also interested in the future encounters of interactants.

In this same study, Davis suggested that a recurring problem is the refusal of those who are labelled handicapped to concur with the verdict. Obviously, those who are subject to loss of a limb, for example, are regarded by others as physically incapacitated. However, it is difficult to draw the line in many instances as to how and under what conditions an individual should be subject to differential behaviour as a consequence of a physical disability. Should a medical student who loses a finger be prevented from becoming a student or should a one-eyed athlete be barred from competitive pursuits? Commenting on Davis's work, Glaser and Strauss suggested that:

Davis attempts to specify one class of structural conditions that permit the handicapped person to manage strained interaction. He begins his paper by referring to the genre of everyday intercourse which is characteristically face to face, not too prolonged but not too fleeting either, with a certain degree of intimacy, and ritualized to the extent that all know in general what to expect but not so ritualized as to preclude spontaneity at the slightly novel turn of events (Glaser and Strauss, 1967: 441-442).

This explicit detailing is not a mere backdrop, but an intrinsic part of the analysis of interaction in the presence of physical stigma.

The consequences of interaction (i.e. the satisfaction of both parties and the possibility of continuing a relationship) are left mainly implicit.

Strained interaction between those who are designated as normal and those who bear the marks of physical, psychological and social abnormalities or are at least deemed to possess these characteristics inevitably create conditions of strained interaction between the affected actor and his interacting counterparts. As the works of Davis, Roth and Glaser illustrate, the victims of the aforementioned conditions encounter social situations which often require that they renegotiate their images with their interacting counterparts. This process often produces anxiety as the interacting audiences and the victim of spoiled identity seldom have clear perceptions concerning what ought to take place in the structure of relationships between them.

Some victims of spoiled identity expect and/or require differential treatment based on the fact that the limitations imposed by their disabilities make it impossible for them to function at their former levels. When their interacting counterparts try to maintain previously existing patterns of relationships, they sometimes come to encounter the wrath of those with spoiled identity. Invariably there are other victims of spoiled identity who maintain that their acquired conditions should not in any way affect their acceptance by their interacting counterparts. However, some victims may discover that the patterns of treatment they encounter with their interacting others is often restructured as a consequence of the definitions and attitudes of their interacting counterparts. The victims of spoiled identity and their

interacting counterparts lack structured realities as to whether or not redefinition and renegotiation of the victim's identity and subsequent patterns of interaction is desired, necessary or wanted, at least from the perspective of the victim. On the other hand, various interacting counterparts of victims of spoiled identity endeavour to maintain existing patterns of relationships and in so doing, encounter the wrath of the victims of spoiled identity who desire to be accorded differential treatment, in spite of the fact that it may not be warranted by the condition which affects them.

Glaser and Strauss analyzed the interactional difficulties that inevitably affect some individuals who become victims of spoiled identity through crisis which may be of an instantaneous nature. When individuals are affected by spoiled identity, restructuring and renegotiation of one's identity and patterns of interaction may be desired if not indeed necessitated. The authors suggest that this restructuring and renegotiating of one's identity is a consequence of four awareness contexts. These four patterns of awareness are as follows: 1) open awareness; 2) closed awareness; 3) suspicion awareness and 4) pretence awareness (Glaser and Strauss, 1967:42).

In an open awareness situation, both actors or groups within a social environment are aware of each other's identity. In this situation from a medical perspective, for example, both the patient and the physician openly converse about imminent surgery and possible outcomes.

In a closed awareness situation utilizing the same example, the patient may not be aware of the serious implications suspected by the

physician. In this instance, when a surgeon is convinced that preliminary data illustrate that his patient is dying, is he entitled to proceed with surgery assuming that the outcome of the procedure is already known? In this closed awareness situation, it is assumed that the patient will have absolute trust in the surgeon and his role. His awareness of his possible fate does "not exist".

Suspicion awareness evolves in a modification of the closed awareness system, where the patient in this illustration may suspect that he is terminally ill, but may be reluctant for a number of reasons to confront the surgeon with these suspicions.

Finally, in the pretence awareness situation, both actors (doctor and patient) are aware of the full consequences of planned procedures, but pretend not to be.

In another work, Glaser and Strauss (1971) provide an important perspective for identity formation in their study, *Status Passage*. The concept of status passage was originally utilized by Arnold Van Gennep in his *Les Rites de Passage*, where status passage was identified as occurring through the acquisition of influence, power, or changed identity of sense of self. Glaser and Strauss identify the essential properties of status passage as the desirable or undesirable consequences of status change. These properties imply the inevitability of status change, the possibility of reversibility to normality, the responsibility for change, the knowledge of the consequences of status change, and the ability to control various agents.

During status passage, the patient often requires legitimation either in terms of group support or support by medical and paramedical

personnel. Another set of characteristics suggested by Glaser and Strauss include the clarity of signs of passage, which from the perspective of the study of disease, include recognition and early treatment of symptoms in order to be able to satisfactorily cope with the ramifications of disease. Many individuals with symptoms of cancer may not clearly recognize the symptoms or may, as often happens, choose to ignore the signs. This often results in severe consequences and sometimes even death. A potential patient experiencing vague and unclear symptoms often attempts to deal with them through dismissal or the use of home remedies in the belief that their symptoms will soon pass. Recognition of symptoms is also mediated by a patient's orientation to the medical system. Often, due to lack of finances, or the perceived abuse of medical facilities, individuals believe that they should not always seek medical assistance at the first signs of illness. This belief, as far as the case at hand is concerned, may have dire consequences.

Since becoming disabled may force drastic changes in one's identity, these changes would not be deemed to constitute a desirable passage unless the victim's surgery was regarded as a corrective procedure to eliminate death or pain.

Glaser and Strauss also perceived the importance of duration of the status passage. For some patients, becoming an ostomate for example, is an almost instantaneous reality; whereas for others, the long suffering associated with the more painful symptoms or family histories of disease may at least partially prepare patients for future ostomy status.

These criteria of status passage point to the direction and difficulties which a patient encounters on a journey from a state of normalcy, to one of sickness and finally to a condition of rehabilitation, cure or even death. Usually, when defining these stages, one postulates a tendency of cure. For the patient, cure of symptoms and painful conditions may render him back to normalcy, but also place him in a state of altered physical being. In effect, many of the previously referred-to authors were analyzing status passages.

Glaser and Strauss noted that:

Because there are several different properties of status passage these and other existing analyses of given status passages may easily be, and usually are, incomplete; with focus exclusively and on only one, two or three relevant properties of passage. The author may focus so steadily on the single property or two, that he sees no others and no exceptions; or as with Goffman's idealized (if negatively toned) depictions of a mental patient's moral career, readers may mistake his systematic analysis for the total truth ...

When ordinarily the recovery passage (from illness) is desirable for both the patient and the doctor, under certain conditions this passage is desirable only for the agent - neither the process nor the goal of the passage seem desirable to the passagee (patient) (Glaser and Strauss, 1971:103).

Many illustrations of status passage require the actor who has acquired real or supposed spoiled identity to deal with failure which involves an altered physical self marred by the negative consequences of prevailing concepts, prejudice and discrimination.

These avoidance reactions are often induced by a fear that direct contact with blind persons (or ostomates) may be contaminating, or that the stigmatized person will somehow inflict physical or psychic damage. Such reactions and fears are completely emotional and irrational in character (Scott, 1969:124-5)

Those who become victims of spoiled identity often resort to what Lindesmith and Strauss label as:

...defense mechanisms, security operations, and the like, the central idea being that the person heeds supposed threats to self-regard with characteristic modes of defense. Defence modes include among others, selective inattention, anxiety reduction, evasion of responsibility, rationalization pretence, and the disowning of undesirable qualities in one's self (1958).

Strauss and Goffman have studied types of rules that are implicit in the interactions though the participants may not be aware of them in spite of the fact that these rules affect interaction. In his paper entitled, "The Nature of Deference and Demeanor" (1956), Goffman suggested that researchers should be aware of the bizarre behaviour of mental patients or of the autistic behaviour noted among young children. Implicit in the behaviour of the mentally ill is the fact that they act according to common concepts of expected and/or appropriate behaviour in most instances.

The core of Goffman's position is that social regulations subtly govern interaction and make it the embodiment of social order; therefore, a complete picture of society must include these implicit, as well as the more explicit regulations (Lindesmith and Strauss, 1958:297).

In analyzing social interaction, Goffman maintained that the behaviour of individuals tends to be institutionalized in terms of the fact that during certain socially defined situations, an interactant of known or visible attributes can expect to be sustained in a particular 'face'. Lindesmith and Strauss suggested that: "When a person is 'out of face' the ordinary regulated interaction is out of balance: expressive events are being contributed to the encounter which cannot be readily woven into the expressive fabric of the occasions" (1958:297). Thus, the person may be embarrassed, shamed or confused and may show

these reactions. If he can control or conceal these reactions, he has 'poise'. In typical interaction, all participants share the responsibility of maintaining "face". In the course of interaction, expressive order is maintained with regulators that uphold the events so that behaviour is ordered and consistent as opposed to being erratic and inconsistent. Much of Goffman's work focused on stabilities of interaction. When individuals enter into interaction, they already stand in some kind of social relationship to others concerned, and they expect to stand in these relationships and maintain given relationships after a particular encounter ends. This, in effect, represents how social contact is maintained among people linked with wider society. Encounters among most individuals in normal social situations are patterned in an understandable way so that interaction amongst individuals and groups and interactions within groups takes place without disrupting the relationships of the participants. Therefore, the framework of interaction within a normal situation such as a teacher with students, or an actor in front of an audience is structured within an understandable and known context. Difficulties may develop however, when relationships among social interactants are changing. If relationships are in a process of change, the object will be able to bring the encounter to a satisfactory close without altering the expected course of development. This accommodative behaviour requires the socialization of all the participants. However, this view of interaction as being governed by existent norms and values as well as by explicit and implicit rules may be somewhat exaggerated in view of the fact that often, where disruptions

occur, satisfactory re-establishment of previously existent patterns of social interaction may be difficult if not impossible to effect. Thus, a president who is defined as a law breaker may find it difficult to re-establish the sets of relationships that were in force prior to the designation. Thus, one cannot assume that social relationships are enduring. Interactants, in order to maintain their relationships with others, often discover that the automatic operation or application of rules can insure stability. These rules designating stability evolve through tactics, strategies, assessments and actions of participants who are, in Goffman's terms, self-reflecting, self-referring and self-evaluating. Although Goffman does not explore the structural conditions from which various strategies are selected, work or fail, one may anticipate that those important tasks may be accomplished once the basis approach to interaction is grasped.

What this approach is not able to do, and is not designed to do, is to allow for the investigation of interaction that is more problematic, open ended and unstable. According to Blumer:

In modern society, with its increasing criss-crossing of lines of action, it is common for situations to arise in which the actions of participants are not previously regularized...While in more conventional situations ... little strain is placed on people in guiding and organizing their acts. However, many other situations may not be defined in a single way by the participating people ... Their lines of action do not fit together readily ... interpretations have to be developed and effective accommodation of the participants to one another has to be worked out. In the case of such undefined situations, it is necessary to trace and study the emerging process of definitions which is brought into play (1962:120-132).

In terms of socialization studies and in terms of studies of

organization such as bureaucracy, there is often the tendency to place too much emphasis on interaction as being patterned. Research in these areas often seeks to establish the rules and norms that are thought to regulate interaction. There are institutionalized forms of interaction such as the relationships between students and faculty, or between apprehended criminals and the legal system which is very institutionalized and in many situations resistant to change. Other patterns of interaction tend to be more open in nature in that the patterns of exchange are not by any means established but open to experimentation, negotiation, improvisation and bargaining. An individual who is subject to severe facial scarring, for example, seldom if ever is accorded the same patterns of acceptance as she or he obtained prior to the existence of the spoiled identity. Hence, emerging patterns are constantly being fashioned and are being discarded or modified to meet new situations and conditions. Central features of interaction are the re-assessments of self and of others. This re-assessment is a continuous process rather than a fixed or predetermined pattern; factors such as age, educational status, sex, religion and appearance can and indeed often do affect the interaction process over time. Initially, some individuals may be able to contend with the difficulties that evolve from the advent of spoiled identities but subsequent events such as those that arise from being excluded from certain groups or functions may lessen if not totally block some individuals' capacity to adjust to the consequences produced by having one's identity spoiled.

CONCLUSIONS AND SUMMARY

The major findings and implications of the research of the early and contemporary symbolic interactionists provide the basis for the perspective to be used in this study. Early symbolic interactionists such as Cooley with his perspective of the 'looking glass self', and Thomas's concept of 'the definition of the situation' illustrate that an actor's reactions to developmental conditions vary considerably. Contemporary symbolic interactionists have further demonstrated that actors respond to conditions associated with stigma-producing circumstances differently, depending on the variety of factors already mentioned. However, it has been demonstrated that there is a pattern to the responses of the stigmatized person, if one looks at the 'career of their responses'. As with those socially stigmatized, those persons afflicted with some physical disability and stigmatized by society, be they amputees, blind, deaf, or the mentally ill, show certain consistency of response from the time of the affliction until some form of rehabilitation is attempted or reached. There is firstly an attitude of denial - this cannot have happened to me or be happening to me. Then comes anger or resentment - why me, who's to blame, I won't cooperate. Next there may be a point where the victim will try to bargain with the medical personnel, try to find different diagnoses or treatments that will not be disfiguring or unacceptable; to the point where the treatment is performed or in some way the disfigurement is imposed on the person. After this step comes the recognition of the inevitability of the disfigurement, e.g. the operation or incarceration in an institution. Usually a depression sets in after the recognition of being different; there may be isolation

from others or even suicidal motives. The final step in the career for the victim is often the renegotiation to a new identity. If the attempt is successful it leads to a form of acceptance by self and others of a new status, as being disabled and perhaps assuming eligibility for rehabilitation. Davis's work suggests that several stages are involved in the process of gaining and maintaining a new acceptable identity through encounters with others. One first encounters some form of functional acceptance of the disability on the part of the other; second comes the facilitating by interacting counterparts of a more normalized role taking where each party tries to establish a basis on which to interact. Third comes the institutionalization or regularization of the new 'normalized' role relationships. The stages are to some extent conditioned by the age of the victim at disability. The third and fourth stages would not apply to conditions present from birth. However, when those young who have stigmatizing conditions come to recognize the stigma, they often follow the pattern outlined here.

For ostomates the same pattern of status passages is expected: 1) denial, 2) resentment, 3) bargaining, 4) imposition of disfigurement, 5) depression, 6) renegotiation of a new identity, and finally 7) acceptance of disability status and regularizing relationships, in their response to their new condition. This investigation is primarily concerned with ostomates as a case of spoiled identity. As such it will endeavour to illuminate the difficulties encountered by ostomates and attempt to demonstrate why some who are subject to ostomatic conditions inevitably find it difficult to adjust to their altered state, while the majority of

ostomates are able to successfully rehabilitate themselves. Specifically, this research is designed to illustrate how the ostomate learns to deal with his or her altered status and to assess the ramifications of surgery and the status of being an ostomate in determining one's total identity.

This research is intended to focus on a very basic problem of sociology, that is, the relation between an individual's identity, the identity he presents to the world, and the reactions, real and imagined, of others towards him. As we have said, the majority of actors establish their identity through interaction with others. As a consequence of socialization and one's achieved and ascribed status, one's identity is usually perceived to be continuous, consistent and in an established pattern fitting into what may be defined as an 'orderly career'. The orderly career comprises sets of expectations as to how actors will be treated in their relationships with others. Deviations from established patterns can cause spoiled identity. Victims of spoiled identity are seen as deviating from established expectations and hence many victims are subject to psychological and social anxieties which often serve to separate them from established patterns of sociability. The actor finds himself differentially treated by others as a consequence of characteristics believed to negatively influence his capacities to maintain established patterns of interaction and acceptability.

By focusing on deviations such as altered physical status as a result of surgery, we can observe how individuals often search for new identity. In viewing the process whereby a disabled individual attempts

to regain normality or become as rehabilitated as possible, the investigator is able to analyze the identity formation process.

In-depth interviewing allows the analyst to survey the consequences of spoiled identity for the victim as well as for his social interactants and by doing so, one is able to comprehend the process of renegotiating identity and the patterns of adjustment that invariably affect those who are subject to the consequences of having their identity compromised. The symbolic interactionist approach illuminates this process in all its richness. As such the ostomate phenomena provide an excellent illustration of what happens when 'normals' encounter a condition which results in a spoiled identity.

In the chapters that follow, a systematic account and analysis is attempted of the problems experienced by the victims of ostomatic status and their significant others from the time of symptom recognition to diagnosis, through treatment and adaptation. The relevance of the investigation goes beyond the specific patterning of events comprising ostomatic status. As Davis (1963) suggests:

... in the social vicissitudes caused by this particular disruptive experience, we are, perforce, inquiring into such generalized matters as the perception of sudden crisis by families, the effect on the family unit of prolonged hospitalization (or other separation from home) of a family member, problems in doctor-patient communication and the identity stresses arising from alterations in bodily self (1963:8).

The relevance is further refined by Myer who tries to show that from a sociological perspective, an examination of ostomy victims as a segment

of the physically disabled and/or handicapped is one that endeavours to examine their corporate life.

Basic to a study of disability is an understanding of the social meaning of its consequences for the individual. Because of his disability, an individual's roles are changed fundamentally. Not only are there behavioural changes, but there are also changes in the way the individual perceives himself and his role, and in the way he is perceived by others. Usually the disabled person is unable to meet the normal demands of his role and is exempted from his normal social responsibilities. He may not be held morally responsible for his condition but he is obligated to try to become rehabilitated if possible (1965:38).

Further, Scott draws the distinction between disability and illness. Both terminologies imply the acceptance of roles that are usually defined to be deviant, but they also refer to distinctly different phenomena. R. A. Scott (1969) draws the distinction for us:

Illness is a trait to which a non-stigmatized form of deviance is attributed; disability is a trait to which a stigmatized form of deviance is attributed. Illness is often curable; disabilities are ordinarily incurable, although they may be improvable. An ill person ordinarily returns to a non-deviant role; a disabled person remains in a deviant role. Rehabilitation, therefore, is not 'an aspect of healing'; nor is it ... the process of movement from disability towards health. Rehabilitation is the process of determining the form which deviance will take. It can be viewed as a socialization process, the purpose of which is to prepare a disabled person to play a type of deviant role.

Our investigation focuses on this distinction, made by Scott and others, by treating the adaptation of ostomates as responses to disability and the process of learning a deviant role. The findings of this research may suggest, to workers with the disabled, strategies which could be used in attempting to maximize the potential of those subject to the stigma of disability.

With regard to being 'handicapped' it is also useful to note that many individuals categorized as being physically or socially disabled are not 'handicapped' by their afflictions. Some are able to overcome their disabilities so that members of their interacting audiences may be unaware of the victim's conditions. 'Disguising' behaviour on behalf of the incapacitated may be seen in a positive light as being an alternative adaptation which will allow the disabled individual to be accepted without deference and/or stigma which is often accorded those defined as being physically disabled. In other instances, some patients make monumental efforts to overcome the disabling aspects of their afflictions, but are unable to do so owing to the extent of the physical limitations imposed by their conditions or the lack of availability or access to proper rehabilitation facilities. Others may refuse to attempt to achieve maximal rehabilitative status while some opt for gains as a consequence of their disability. The existence of a disability may produce a condition or conditions which are defined as handicapping, but a handicapped status need not always be a necessary and inevitable consequence of a disability.

Research on the disabled or potentially disabled reveals the multitude of orientations and difficulties experienced by the disabled in our society. It would be difficult if not utopian to expect to generate a 'grand' sociological perspective from which to base this type of research. This study will focus on osotomates as representatives of those who can be classified as suffering from conditions which are ascribed as stigmatizing by many segments of society, primarily from the

perspective of spoiled identity. The research will survey the patterns of adaptation utilized by ostomates in coping with their altered physical selves. It analyzes the renegotiation process that takes place when individuals become subject to the consequences of a condition that serves to spoil identity, at least in the eyes of some segments of their interacting environments. The project surveys the 'ostomate zeitgeist' surrounding the crisis reaction of those patients and their significant others in the course of developing, maintaining and/or limiting if not totally severing, patterns of social relationships. It also introduces and attempts to answer questions regarding the legitimacy of using ostomates as an example of the physically disabled who encounter a series of 'difficulties' in relating to the 'normal world'. And finally, it attempts to find patterns of adaptation in the response to disabling and stigmatizing conditions. In conclusion, the following outline portrays the approach of this study:

- (1) The reactions of actors to developmental conditions vary considerably (early symbolic interactionists, e.g. Cooley, Mead, Thomas).
- (2) Actors respond to stigma producing situations differently (contemporary symbolic interactionists, e.g. Goffman et al).
- (3) A pattern of responses emerges when one looks at the 'career of responses': denial, anger or resentment, bargaining, inevitability, depression, renegotiation of a new identity.
- (4) Renegotiation involves three stages: others' fictional acceptance of the disability, the 'normalization' of role taking, and institutionalization.

- (5) Illness involves now stigmatized deviance and eventual return to status quo ante (Scott).
- (6) Disability is stigmatized deviance and involves the assumption of a new role (Scott).
- (7) The study of ostomates is a study of the career of stomats' responses to a disability and the renegotiation of a new role. It is an attempt to study the corporate life of the stigmatized deviant (Myer).

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CHAPTER II

STIGMATIZED DISABILITY AND THE OSTOMATE

INTRODUCTION

Chapter II will focus on various types of disabilities and the reactions of patients and significant others to the consequences of being perceived as stigmatized by conditions which are viewed by many as producing spoiled identity. Many victims of relatively sudden diseases producing stigmata encounter considerable and unavoidable anxieties as consequences of their conditions. The conditions become a central organizing aspect of identity for many of the affected individuals and many of their interacting counterparts.

The social consequences of these conditions are often severe. Victims of spoiled identity often encounter patterns of alienation due to the detectable consequences of their impairments. Victims cannot exert much control over placement into a spoiled or stigmatized category as their incapacitated state is inevitably viewed by others as a disabling and handicapping condition which subsequently necessitates altered patterns of interaction.

The manner in which one copes with a disability depends on the extent of the disability, the stigma attached to the disability, the incapacities encountered as a result of the disability and whether the disability is of a congenital, developmental or instantaneous nature.

The first are those disabilities that have originated from congenital disorders where the impairment stems from pre and/or post-

natal factors. In many cases (i.e. cerebral palsy) it is very difficult to determine whether or not the injuries responsible for the disability occurred prior to or immediately after the birth of the child. The cause of these disabilities is generally an inadequate supply of oxygen to the brain some time during the prenatal gestation period, or during the birth or shortly after the delivery. Congenital disabilities may also involve physical deformities attributable to the effects of drugs such as thalidomide which are ingested during pregnancy. Disabilities such as epilepsy, blindness, deafness and limb deformities can also be inherited disorders.

Victims of these types of afflictions are often misdiagnosed. There have been many instances where victims of cerebral palsy have been diagnosed as mentally retarded even though, as intelligence tests subsequently revealed, these persons are usually of average or above average intelligence. Many cerebral palsy patients are able to live and function in relatively normal fashion within the community. Some cerebral palsied are mentally retarded but this is not a normal consequence of the affliction. These persons, as well as those suffering from congenital deafness, blindness or congenital deformity, usually encounter difficulties early in life in their adjustment to living in normal society. They are almost always stigmatized by the rest of society for being "different" and they are rarely treated as normal by most people coming into contact with them.

A second type of disability may be labelled as a developmental impairment in which an individual in a normal state is aware of the

fact that he will eventually be impaired due to a progressive illness which is impossible to arrest. Many persons with slowly deteriorating vision, hearing and motor functioning have known normalcy, but they are also aware that their physical and/or mental state(s) is gradually diminishing due to age or a progressive illness. People in this situation at least have advance indication of the difficulties they will face and because the impairment process is gradual they are more able to adapt over time to their slowly changing state. These persons are not totally free of difficulties because anxieties often develop from the knowledge that they sooner or later have to adjust to a major impairment. This type of disability may be more difficult to adjust to than a congenital disability because those experiencing birth defects have never known normalcy and so are forced to make their adjustments as they age. As a result, many of their adaptations are simply incorporated into their developing life pattern. On the other hand, persons suffering a developmental or progressive disability must change their life patterns to accommodate their altered body state; they must relinquish normal functioning and adopt new modes of response and behaviour in order to adjust. This type of disability, however, is usually thought to be easier to adapt to than the following type of impairment.

The third category of disability is classified as instantaneous. In this instance, normal body appearance and/or functions become unexpectedly and suddenly changed as a consequence of disease, accident or surgery. The victim is suddenly cast into a situation which requires him to make drastic alterations in his life patterns in order to adjust to an altered bodily state. In most cases, the acquisition of the altered

status is undirected and unwanted. It creates for the victim a series of difficulties and problems in the physical, psychological and social realms. This final type of disability is often interpreted as the most difficult one to adjust to primarily because of the suddenness with which it takes place. The victim has not had forewarning to physically and mentally prepare himself for the changes that have occurred. The sudden necessity of having to relinquish established habits, activities and normal life patterns is an awkward and anxious transition that takes time. Habits and sometimes taken-for-granted behaviours and necessary functions (e.g. use of public washroom facilities) have to be changed or lost altogether as adapting behaviours must be learned and incorporated into a new life pattern. Some people are able to make this transition and become "rehabilitated" while others encounter difficulty in coping with their altered status. The ease or difficulty with which one tries to retain a relative state of normalcy depends on many factors. These would include the type of impairment (i.e. polio, blindness, loss of limb, deafness), at what time in one's life the impairment occurs, the availability of rehabilitation services, acceptance or rejection by one's family and whether or not employment and sociability are changed.

The various patterns of adjustment that all those experiencing a disability must make range from positive and excellent responses to maladaptive and negative adjustments. A disability necessitates changes in behaviour, in emotions and in attitudes. Therefore, adjustment usually has to take place in the physical, psychological and social

realms of functioning. Not all patterns of adjustment are positive, and not all are achieved in each of the three areas of functioning. For example, a man who suddenly loses his sense of hearing may continue in his occupation, but may feel obligated to limit his social life because it is too difficult for him to maintain both sets of activities.

Many disabled persons are stigmatized by other societal members because they are not seen as normal but rather changed, and therefore, "different". However, some of them desire to be treated as normal. "Normal" functioning people tend to feel anxious and uncomfortable when in the presence of a handicapped or disabled person and they are often stifled and stilted in their relations with these persons.

Those who find themselves disabled utilize various modes in attempting to overcome their altered circumstances. Some use denial and/or escape. Others totally withdraw into organizations and associations of people similarly affected in order to avoid or lessen the difficulties experienced in social contacts with normal societal members.

Patients will often defer surgery as long as possible especially if the surgery results in conditions which are seen to spoil one's identity. As in the case of many cancers, the sudden discovery of a disease necessitates sudden and drastic surgery, the ramifications of which often serve to spoil the identity of the affected patient. In these instances, patients are under much pressure to readily submit to surgical procedures as delayed treatment often results in death. Patients faced with operable or supposed operable cancer conditions often maintain that ridding themselves of the malignant condition was of primary impor-

tance and that they were not aware of nor do not remember being informed as to the ramifications of surgery which subsequently may require the patient to make relatively drastic alterations in his pattern of living. There are also instances where the individual has suffered over a period of many years from painful conditions (i.e. ulcerative colitis) and has known that at some time in his life he will probably have to undergo ostomy surgery. In this instance, patients would fall into the second category of disabled persons.

In coping with spoiled identity, the disabled may or may not be able to regain "normalcy". However, their patterns of adaptation are attempts to establish relationships with society that will be workable.

Characteristics of Illness: Non-Stigmatizing, Chronic and Stigmatizing

A multitude of features are associated with illnesses and can be characterized as follows: disease and disability may be characterized as involuntary, unscheduled and undesirable conditions. Illness causes individuals to relinquish some control over their normal social activities and the extent of the incapacity varies directly to the extent of the loss of control. Most diseases are characterized by degrees of uncertainty, anxiety and ambiguity. These characteristics are hopefully resolved, or at least mitigated by diagnosis and treatment. When individuals are deemed ill, society is usually permitted to grant them a number of "dispositions" so that they are usually excused from normal obligations in terms of role performance.

Fabrega and Manning (1972) identify four basic dimensions:

1) the duration of the disease; 2) the possibility of the cure; 3) the degree of discomfort, incapacity and disability, and 4) the potential for self-degradation and self-stigmatization. When people conceive of disease and illness, they often perceive the concept in terms of relatively short-term afflictions which may be illustrated by outbreaks of measles, flu and mumps. However, according to Fabrega and Manning, afflictions must be seen as short-term acute, long-term non-stigmatized illness, long-term stigmatized illness or mental illness and are subject to characteristics which can be categorized according to 1) clarity of symptoms, 2) medical diagnosis, 3) medical treatment, 4) physician's role, 5) impact on self conception and 6) social consequences. This approach is detailed in the Appendix of this work.

Fabrega and Manning suggest that chronic illnesses may be divided into two types on the basis of the social consequences resulting from the labelling of the illness by society as stigmatizing or non-stigmatizing. Amongst elements of society there is ambiguity as to whether an affliction is of a stigmatizing nature. Venereal disease is considered stigmatizing while measles are considered non-stigmatizing. Facial scarring, ostomy conditions and many physical impairments are generally considered to be labelled somewhere in between the two above polarized examples. Diseases leading to stigmatized disability or long-term illness are those where physical impairments or functional handicaps are obvious, detectable and considered socially undesirable.

The consequences of this differential labelling are that although in both cases the character and conduct of the ill person is redefined in the light of the perceived consequences of the illness, in the first case the ill person has some genuine control over the impact of the disease episode on his identity and way of life, whereas in the latter he has much less control due to the coerced and stigmatizing identity attributed to him (Field, 1976:341).

Some illnesses are therefore considered non-stigmatizing whereas others are characterized as at least partially spoiling one's identity. Spoilage of one's identity evolves because the outward characteristics, incapacities or supposed characteristics override other attributes and become central in re-structuring the victim's identity in terms of his self conception, the conceptions of other individuals or groups and even the conceptions of both. The conception of self and of others need not concur as illustrated in Cooley's concept of the "looking glass self". However, when spoiled identity in the individual's conception emerges, what results is a re-structuring of the victim's identity.

This new identity is incorporated in and structured by the reactions of the person and others interacting with him towards the stigma. What results is the development of a new set of stable definitions of the person's conduct and character. By contrast, although the stigma of some mental illness is also all-encompassing, it has no apparent physical location. It is the person as a whole that is spoiled. (Field, 1976:341).

As many studies illustrate, it is not the existence of a condition per se, but the social implications of the incapacity which is often crucial in determining the patterns of interaction expected by and structured to individuals with perceived incapacities. One pattern of stigmatization is illustrated in MacGregor's (1951) study of facial deformities. Facial deformities often provide the basis

for the imputation of identities (or characteristics of the person) that lead to spoiled identity.

Some actors may not be handicapped because of their condition but because of the way they are perceived. A facial injury, the loss of a limb, or the knowledge of the fact that one has had venereal disease is often more of a social handicap than one of a physical nature. Being subject to a stigmatized affliction inevitably requires that the victim must adjust not only to the physical consequence of being impaired, but also to the social and psychological consequences of being perceived as a victim of spoiled identity. Afflicted individuals are often required to re-evaluate their self conception. One sociologically puzzling phenomenon is the apparent fact that similar individuals with similar afflictions often react differently. Some victims of spoiled identity regard their afflictions as being irrelevant in terms of their interaction with others and seek to maintain previously established patterns of interaction. In some instances, these patterns of interaction may be changed as the interactant's audience is not willing to grant legitimation owing to the perceived changes in the actor's identity. In these situations the affected individual may be inclined to ignore the differential behaviour to which he is subject and perhaps rationalize it in terms of the fact that those who wish to alter established patterns of interaction are not worth being involved with. Others, however, may be affected to a minimal or maximal extent as a consequence of their own perceptions of their stigmatizing condition and also by virtue of the fact that they encounter altered interactional

patterns. One of the problems which is confronted by individuals who are subject to physically incapacitating conditions is the emotional readjustment that they are sometimes forced to make in their subsequent adjustment. The social and emotional consequences of an affliction may be just as difficult if not more difficult for a victim to overcome.

According to David Field (1976:347), regardless of the source or the nature of the stigma, there are a number of common elements in the ways in which people come to grips with the problem it poses. These have been identified by Goffman (1963) in his general analysis of the problem and documented by studies of the reactions of people to a number of stigmatizing illnesses. The problems posed can be divided into three roughly sequential issues that must be resolved by the disabled and also by those regularly associating with them. The first is somehow to come to grips with the question of "Why me?" and to assess the inevitable changes that the illness creates. Next is the problem of assessing the extent of the interference with normal life and this is often accompanied by serious frustrations and emotional setbacks. Finally, there is the massive problem of constructing a new way of life. All this is not easy and is not addressed alone. One important source of aid is that of medical and other professionals. Their part in the reconstruction of the person's world is often central to the shape of the resulting solution to the basic questions, "Who am I now?" and "What can I do?".

For a victim of polio for example, in order to embark on a program of rehabilitation involving the possibility of achieving normality, the victim must be diagnosed and treated appropriately. Secondly, the patient must utilize the technical aids and equipment available in order to retrain affected limbs so as to regain patterns of normality. Inevitably, difficulty arises at this stage because some victims of diseases such as polio are unable to achieve normality in spite of the existence of the most sophisticated rehabilitation programs. Many individuals in this state must inevitably obtain special care and perhaps submit themselves to psychotherapy in order to alleviate the manifestations of the difficulties which their newly acquired identity forces them to face.

In most instances, those with some type of spoiled identity, by virtue of the nature of their condition, are excluded from the patterns of normal life. They are pressured to put maximum effort into achieving the highest degree of rehabilitation and normality possible.

According to David Field:

Little, however, has been achieved with regard to the social aspects of the problem, and it is clear that this aspect and particularly the problem of stigmatization needs to be addressed directly if the position of a great number of the disabled is to be improved. It is, however, exceedingly difficult to specify how to make an impact effectively in this area.

The common consequences of stigmatizing illness can be summed up under the consideration of how they relate to activity and to attitudes. In the area of activity, the physiological or functional incapacity will lead to some restriction and restructuring of activity. However, there will also be a contraction in areas of social activity which

is not directly attributable to the severity of the impairment but rather to the social construction of stigma. This curtailment results from the reluctance of others to interact with the individual, and also from the individual withdrawing from situations in which he might be rebuffed. In extreme cases the stigmatizing illness may result in almost complete social isolation of the individual. The attitudes which result are more variable in strength and impact. On one side there are the attitudes towards oneself as somehow 'spoiled' and inferior. These are often coupled with feelings of uncertainty and inadequacy. I suggest that to some extent these negative attitudes are held by most, if not all, stigmatized people in the period immediately following their illness and that for some they never disappear. However, a set of offsetting attitudes usually develop around such ideas as that the illness has somehow 'been a blessing in disguise' because it has led to the discovery of 'true values', 'real friends', 'hidden sources of strength' and the like (Voysey, 1975). Finally, there is a redefinition of the previously accepted world of normality as somehow deficient and so not as great a loss as originally had been thought. The common element in all these reactions is the attempt to minimize the sense of loss and to support a definition of the stigmatized person as, despite his stigma, a worthy person (1976:348).

The Effect of Stigmatized Illness on the Interactants

One further consequence is that diseases and disabilities affect not only the disabled but also their interactants. In some instances, those who are disabled may enjoy the advantages and even secondary gains as a consequence of being defined as different. A person with a speech impediment may always be agreed with because segments of his interacting audience believe that it is unfair and unwarranted to contradict a handicapped victim, in spite of the fact that the victim's opinions may not represent "the truth". Goffman (1963) labelled this pattern of treatment as "courtesy stigma".

THE OSTOMATE: A CLASS OF STIGMATIZED DEVIANT

Ostomies are becoming relatively common operations. "Ostomy" is a collective and generalized term used to refer to different types of bowel and urinary surgery. Common to all these surgical procedures is the creation of an artificial body opening, located on the abdomen and called a "stoma". This becomes the new body orifice replacing the anus and/or urethra from which body waste elimination occurs. The term stoma is derived from two Greek words, stomoun meaning "to provide an opening" and tome which refers to "a cutting operation" and hence stoma - "cutting an opening". This new opening in the body simply serves as a bypass to let the body function normally without a diseased bowel or bladder. The stoma may be created in order to divert the feces or the urine, or in special cases, both. The waste is then disposed of into a collecting device work on the outside of the body and called an appliance or "bag". This appliance is lightweight and often disposable. It is attached to the body in the frontal stomach region of the abdomen.

There are many types of ostomies. Perhaps the most familiar is the colostomy. The word colostomy originates from kolon, the original Greek word for "large intestine" and which has since been converted in English to colon. Colon and ostomy combined therefore become colostomy - "cutting a (new) opening for the colon". Colostomy surgery is required to remove cancerous tumours in the large bowel or to repair bowel injuries resulting from accident or congenital defects. Colostomies are used as a last measure to medically treat unmanageable cases of ulcerative colitis, diverticulitis or other inflammatory diseases.

The large intestine or colon has two functions: 1) to accumulate and store feces and 2) to absorb water and electrolytes (salts). A colostomy obviously reduces both these functions and therefore the nature of the fecal discharge and the management of it depend on how much of the colon is left after the operation. A colostomy is named for the section of the colon that is cut into, for a sigmoid, descending, transverse or ascending colostomy. These will be explained in more detail in following chapters and in the Appendix of this study.

Another common type of ostomy is the ileostomy, coming from the Latin term ileum which refers to the last and longest of the three sections of the small intestine. The ileum is the fifteen to twenty feet of small intestine farthest from the stomach. Ileum and ostomy combined become ileostomy - "cutting a (new) opening for the ileum). An ileostomy is usually performed for the same reasons as the colostomy, however, most ileostomies are used for the relief of ulcerative colitis which is a painful inflammatory disease that most often attacks adolescents and young adults. In many cases, the surgery may well have been elective because the doctor and his patient agreed that the ileostomy would permit the patient to live a more pain free and normal life. Ileostomy surgery involves the surgical removal of part of the ileum and the entire large intestine and rectum. As with a colostomy, the anus may be closed up and a stoma is created on the abdomen to take its place. The ileal stoma consists of a half-inch or more of small intestine which has been brought out through the abdominal wall and sewn (sutured) back onto itself. This stoma is usually in the lower right hand section

of the abdomen; it replaces the absent colon and rectum and provides a new exit for the feces. Because there is no longer a colon to absorb water or form stools, the ileostomy discharge is a liquid or semi-solid paste. This discharge flows constantly throughout the day and night. Although some types of colostomies do not require an appliance, the constant flow from an ileostomy of a discharge very rich in corrosive, digestive enzymes requires that the patient wear an appliance at all times.

A third type of ostomy is the urostomy which is a urinary diversion procedure used to divert the urine away from a diseased or defective bladder and out the stoma. This urinary bypass surgery can be necessary for many reasons. A child who is born with a birth (congenital) defect in the urinary tract which causes urine to back up into the kidneys and causes chronic infection usually needs a urinary ostomy to save his life. In adults, it is required if there is a cancer malignancy in the bladder and then the entire bladder has to be removed. It has been found in recent years that a urostomy is easier to manage and is socially preferable to people who suffer from a defective bladder caused by birth or spinal injury. In this instance, the nerves have been damaged so that the victim is left without any voluntary control over his bladder which causes him the indignity and skin problems of constant wetting. The operation is usually requested in this case.

The purpose of a urinary ostomy is to make the discharge of urine more convenient to manage. A few drops of urine flow from the stoma every ten to twenty seconds and because there are no voluntary

muscles in the stoma this flow cannot be stopped or started at will. It is therefore necessary to wear a drainage appliance or "external bladder" at all times in order to collect the urine. There are several types of urinary ostomies and these will be discussed in more detail in the Appendix.

To a layman, explained in this manner, this type of surgery appears to be relatively "simple". Ostomy surgery, however, involves many complications, both physical and emotional. The patient in one way or another must come into direct contact with his bodily wastes once the operation is performed, and hence, it requires to some degree the alteration of one's life patterns. It obviously necessitates some radical changes in order that a person might live a healthy life without a rectum or normal bladder function. The common concerns expressed by potential ostomates are: "Will I bulge?" "Will I smell?" "Will I make noises?" "Will I be a captive of the washroom?" "Will my diet be radically altered?" "Will I be a social outcast?" "Will I be able to stay married, or be married?" "Will my sexual functions be interfered with?" "Will I be able to resume various activities such as sports?"

From a physiological point of view, in the majority of cases, when age is not a factor, a normal life may be resumed after an ostomy operation. However, a consequence of an altered body image and the requirement to manage their own body wastes, is that various patients develop a myriad of physical, psychological and social problems. From a medical and physiological perspective, these patients are considered cured of their disease or affliction. They are not, however, easily psychologically rehabilitated from the consequences of their surgery. They

tend to encounter social stigma because they are "different" and their social adjustment to their spoiled identity is not an easy accomplishment. Being different is a consequence of the fact that they are perceived or detected as violating existing standards of cleanliness.

In studying ostomies, it soon becomes evident that it is difficult to systematize and present a precise depiction of this affliction because ostomates are afflicted in a variety of ways.

Difficulties occur because of the change which the surgery forces patients to make in terms of evacuating their bodily wastes, the pain of surgery, the complications which may result, the negative perceptions of many others towards ostomy status, the effects on one's identity as related particularly to sexuality and one's capacity to resume a near normal life in one's occupational, psychological and social spheres. Unlike many other disabling conditions, most ostomates will be physically involved for life with the manifestations of their altered conditions unless surgical resection becomes possible.

Some ostomates are negatively identified as a consequence of their uncontrolled gas emissions and this often serves to hinder sociability and in the process produces varying degrees of anxiety. Some ostomy victims encounter emotional difficulties in trying to rid themselves of some colitis associated symptoms. In colitis conditions, there appears to be a positive relationship between one's emotional state and particular disease pathologies.

It is evident that ostomates are aware of being different and

are often treated as being different in spite of the fact that differential treatment is not always necessary, deserved or desired. The labelling of an ostomate refers to lack of physical weakness, cleanliness, interrupted sexuality and non-acceptability because there has developed a negative folklore concerning ostomies following the same pattern as the negative folklore regarding the mentally ill. Ostomates have become stereotyped with a number of negative attributes and this stereotyping inevitably leads to consequences which may be relatively severe causing some victims to withdraw in varying degrees from societal participation. Some victims are inclined to accept the credibility of folklore or the opinions of others who deem ostomy status as unacceptable. Ostomy victims and mastectomates are often pressured, especially in North American society, to disguise their conditions. This pressure to disguise bodily changes stems from two main sources: 1) the individual himself and 2) the interactant's audience who may or may not hold views which are 'anti-ostomatic'.

During the early periods of this investigation, it was found that a large segment of the public were unaware of ostomatic status. A study surveying 40 fourth year Arts students at University of Waterloo was undertaken in 1976 by the author and it revealed that only three students were aware of what was represented by the status of being an ostomate. One of the students had a concise and accurate knowledge of the difficulties of being an ostomate as a consequence of the fact that his mother had been an ostomate for seven years; but the other two students mentioned that ostomates collected their wastes in a bag which had to be emptied

periodically and were unacceptable because they smelled, they were unable to have sex, and their longevity potential 'was probably impaired'. Thirty-one of the students in the survey, upon reflecting on the consequences of ostomy conditions, were inclined to feel that they could not live in a normal way with the condition. Twenty-seven maintained that if they were affected by an ostomy, they would consider a monastic lifestyle (i.e. becoming a nun, a hermit or remaining single), while five maintained that, in all likelihood, they would commit suicide.

Empirically, these opinions must be suspect because although their reactions indicated patterns of reactions to a specific condition, their responses had to be imagined because it is difficult to respond to imagined consequences. One must also recognize the fact that if this imaginative situation was placed before different age groups, the results may have been substantially altered. (The age range of the sample was 19 - 24.) It must also be recognized that fourth year university students are usually concerned in varying degrees with matters of intimacy, sexuality and parenthood, whereas a population of middle-aged or elderly individuals may be less concerned with these matters.

In studying ostomates as a collective group, one cannot be specific about the nature of the affliction. When a patient is suffering from whooping cough, for example, there is a precise explanation for his condition and how one must be treated while his condition is active. But for ostomates, even if the reason for the condition is known, it is difficult to ascertain the directives with which one should be treated. A complex set of social and impersonal factors, often of uncertain impact, and more likely to be seen as influential in his subsequent living patterns, obtain in the case of the ostomate.

To some extent, disease and disability must be seen as problematic, as they are subject to social definition at least in terms of the way an audience is inclined to view a particular subject. How audiences react to a particular handicap or disability is illustrated by Scott:

For example, Scott (1969, 1970) has shown how the attitudes of workers with the blind influence the adaptation made by blind people to their blindness. He found that in different societies there are differing conceptions of what blindness involved. In Sweden, blindness is seen as a technical handicap, and emphasis is placed largely on teaching the newly blind the mastery of the technical aids that will restore them to 'normal life.' in the United States of America most conceptions are psychologically-based and focus on helping the blind person to come to grips with his psychological problems, to accept his condition and to learn to live with it. In England, attention focuses on psychological factors and there is little technical instruction in such as unaided mobility. Rather, it seems that the emphasis is on generating cheerfulness in the face of adversity. Such differences in professional outlook obviously have a direct impact on the restructuring of life, for to receive help and aid from such professionals involves an acceptance of their definition of the situation. Scott concludes that: 'Gradually, over time, the behaviour of blind men comes to correspond with the assumptions and beliefs that blindness workers hold about blindness' (1969:119, and 1970:285).

That is, blindness per se is not sufficient to account for the behaviour and attitudes of blind people. (Field, 1976:361).

THE INFLUENCE OF THE NORTH AMERICAN ETHIC OF CLEANLINESS
ON OSTOMATES

A large majority of the ostomate population experience heightened states of anxiety due to the fact that the elimination of their bodily wastes must be "personally handled" as a result of their altered physiological condition.

The emotional reactions demonstrated by ostomy patients both at the time of the diagnosis and following surgery are best examined by keeping in mind the importance of body image and North American values of cleanliness. These two concepts are basic perceptions that are felt and acted upon unconsciously by ostomy victims. No discussion of the psychological responses to the surgery by both the patient and by those with whom he interacts is complete without discerning the significance of the roles of body image and cleanliness.

One of the human organism's earliest accomplishments is the control of waste elimination, a function which is surrounded by strong emotional components as a result of North American cultural values and body perceptions. An individual relinquishes these controls with varying degrees of anxiety. Objectively, having an ostomy appears, on the surface, to be a small price to pay for life itself. Nevertheless, all humans are creatures of their environment and lack of control of body waste is perceived as intolerable. Incontinence, through loss of this control, implies a return to infancy, a subsequent loss of self esteem and resulting depression which may result in suicide.

The idea of having to expel body waste through a stoma is repugnant to most people, even to many medical personnel. In North American society, this pattern of elimination evokes a sense of inadequacy, dirtiness and emotional exposure. To the victims, there is a destruction of masculinity and femininity. Whether one loses a limb, an eye, or a breast, all mutilative surgeries frighten and outrage the patient as he or she faces a compromised physique. No longer are they capable of coming close to society's ideal which is the "body beautiful"; their physical appearance has been robbed of its integrity.

...There are indications that the standards for physical integrity and perfection, as well as for beauty, are very strict in Anglo-Saxon countries especially among the middle classes, and any deviation from the highly admired state of perfection is punished by social stigmatization. Not only physical deformities or chronic invalidating illnesses, but also obesity (or even overweight), pimples, oily hair, 'bad' breath or sweating odours are considered intolerable and label the 'afflicted' individuals as deviants (Safilios-Rothschild, 1970:126-127).

In addition to the existing attitudes and beliefs towards ostomates, there is a concomitant social force which operates to their disfavour. This is the high social premium placed upon cleanliness in North America. In mass media advertising, there is an attempt to persuade the public that only one particular brand of soap, toothpaste or deodorant is "the one to buy". Pictures of individuals, men women and children, the idealized "American type" with attractive physiques, fresh looking skin, shapely small noses, clean teeth and the general perception of freshness are designed to stimulate the interest and approval of potential purchasers. The aim is to make buyers feel that by purchasing advertised products, they are somehow identified with the

attractiveness of those who appear in the advertisements. Hence, North American advertisements in the mass media inform, indeed, threaten us that we will never find a job, spouse or friends with the presence of odour or "sensual barriers" (such as ostomies). Mastectomies, ostomatic defects and other similar conditions are considered insurmountable social and economic barriers to success. At all costs, we are told we must appear and smell attractive. The thousands of beauty parlours, deodorants, movies and television programs with the emphasis on glamourization of external features are further commentaries on the fixation on physical beauty and cleanliness.

Within North American society, there is emphasis on cleanliness and this emphasis tends to filter down the class structure. For example, during the evening of March 21, 1976, during prime television viewing time between 9:00 p.m. and 11:00 p.m. on the CBS television network, there were twelve minutes of advertisements devoted to various brands of soaps, deodorants, mouth washes and perfumes. This pattern of advertising reflects an increased emphasis within North American society on bodily cleanliness. Seven of the eleven advertisements made it abundantly clear that those who are afflicted with an unfavourable body odour are less desirable and have less opportunities in social and economic pursuits. The following night on the ABC television network, during the same time period, there were fourteen advertisements devoted to the same market products. In view of the fact that the largest segments of the television audience are in the middle and lower classes, and in view of the fact that advertising time can be expensive (up

to \$1,000 a minute on CBS and ABC television networks), it can be assumed that there is a substantial market for these types of products in order to not only maintain personal cleanliness, but also perhaps to accept the dictum that "the successful person is the one who is clean and well groomed at all times". Thus, those who are unable to meet the standards of bodily cleanliness are held in low esteem.

Difficulties related to sexuality also serve to inhibit social acceptability of the ostomate. The ostomate and/or his interacting audiences tend to limit their associates as a consequence of the fact that the audiences generally believe that the ostomate is physically weak, socially unacceptable and unable to participate at the same level as so-called normals. Many ostomates encounter, at least initially, difficulties in managing their conditions and, as will be seen from the data, there is a tendency amongst many of them to accept the negative stereotypes of ostomates held by some segments of society.

With this generalized bias towards physical perfection, together with the profound social emphasis on cleanliness, those whose bodies appear to be imperfect find themselves beset by conditions which separate them from others. Subsequently, there may be serious resulting psychological consequences.

Other indignities or patterns of spoiled identity often plague the ostomate. One encounters frequent repetition of derogatory phrases about ostomates; "they are different"; "they smell"; "they are weak"; "they cannot have sex"; or "they are socially unacceptable".⁽¹⁾

Bowel function is an emotionally-charged subject in North America.

Acceptability and status are always accorded those who are defined as "being clean". The symbolic identification of cleanliness and presumed acceptability of the clean individual is taken for granted. Being defined as dirty indicates low status and places the individual concerned in the realm of the "unacceptable". Being seen as dirty, therefore, has ramifications that are physical, social and psychological in nature.

The degree to which an individual's self concept is determined by his physical appearance varies from person to person depending on the type of personality. According to C. Safilios-Rothschild (1970:98) there are three basic types of people and each has a certain mode of adaptation. The first is that which has always placed a great value on bodily attractiveness. People in this category who have suffered an ostomy may tend to view the stoma and appliance as a misfortune and disaster. Because some aspect of their lives has changed (i.e. body waste elimination), they will never adjust, or might adjust outwardly, but they will never develop an inner acceptance of their ostomy. They will always be met with more or less significant frustrations because they will never take into account their inescapable physical limitations and disability-determined restrictions. One 32-year-old person commented:

I used to enjoy going to the gym to work out. But the other fellows were making cracks about, 'What was that?' or 'My hernia never looked like that'. I quit going; I just couldn't stand the problems.

My biggest concern is will I get married? I didn't realize until after my operation that sex would be impossible. How can you marry a girl and tell her you will have to adopt? Who wants to look at a useless body? (2)

Another patient who was interviewed, who could be classified as falling into this first category, said:

I don't think I ever accepted my feelings or the change. I never accepted the idea. I didn't want it; I cried but it was either that or dying. (2)

A second group of people are able to change their values about their body image. These people continue to value their physique and their strength, but are able to accept the fact that their appearance has changed and their physical capacities are different, without being plunged into helplessness and despair.

They can still feel that they are 'worthwhile' persons who can go on living a meaningful and full life by capitalizing upon their unchanged capacities, physical and non-physical. They are able to change their values concerning the body whole and the body beautiful as well as health in general by enlarging them so as to encompass their present state of health as acceptable, although not ideal (Safilios-Rothschild, 1970:8).

A gentleman who reveals this position humourously stated:

"What can I do? I just have my asshole in the wrong place!" Another volunteer for this study commented:

What can you do when you grow old? I have wrinkles in my face. I can't run because of a heart condition, although I still do golf, and I limp because of arthritis. However, as far as my urostomy is concerned, at least no one can see it. I regard it as one more thing I have to look after because I am old. One thing that most people certainly do not realize, I certainly did not, and that is how wonderful it is to really be young. What can I do? I guess I'll just have to 'keep on trucking'! (2)

Regarding ostomies, O. Beahrs came to this conclusion:

Even though life with an ileostomy is not perfect in every way, and the patient is not considered normal in every respect

(but neither was he normal with the disease), the quality of life with an ileostomy is certainly acceptable and compatible with normal living for almost all (Beahrs, 1971:460-463).

For this study, it can be deduced that a large number of ostomates fall into the second category of people:

I found out after the operation that I didn't have any sexual problems at all. I can't really say that the operation interfered in any way with my life pattern. I move around more or less as I have always done. The operation really didn't affect me with my association with other people. I am particularly active; I spend much time bowling and doing other things.

Ever since the operation, I have come to appreciate life and enjoy every little thing before I would have certainly taken for granted. The past eleven years have been the happiest of my life. (2)

The third group of people are seen by Safilios-Rothschild as being able to "bring about the 'necessary' changes in body image all too easily and painlessly and even eagerly accept physical limitations and restrictions that could be overcome" (1970:). This type of disabled person usually makes no attempt to minimize the degree of disability and to use his remaining physical capacities to the maximum. By considering himself disabled, such a person no longer blames himself for his failures but instead blames his disability. For the ostomy patient, the ileostomy or colostomy then becomes a convenient hiding place behind which he can take shelter from the realities of the world.

This was the case of Mr. K., one of the volunteers for this study. Mrs. K. was concerned that her husband would become compulsive. She said, "He is constantly emptying his bag and washing his hands countless times during the day." Quite often he will ask her if he has an odour about him. Mrs. K. has never been able to notice any odour. Mr. K. left the hospital without being told how to care for

his appliance. Until a Victorian Order of Nurses Nurse visited him, he was confined to his bed and used only dressings. Mr. K. No longer visits friends; he keeps in touch with acquaintances by phone and occasionally a friend drops over, but he feels very uncomfortable when he is with other people. He has, in effect, withdrawn from the social world.(3)

In another interview, a woman commented:

My husband tells me to have my daughters keep the grandchildren away as he does not want to play with them fearing an accident. He no longer bowls or golfs, but it is very interesting to see him keep the garden. It was never like that before. He is shutting me out too, but what can I do?

We have been married too long now, in fact, my husband was never the out-going type to begin with and this gives him the convenient excuse to hide from people.

He also spends as much time gardening as he does in the wash-room. He joined the Ostomy Association and reads about every new appliance and additive that is distributed on the market. I believe that he has tried everything manufactured in the last seven years. (3)

Withdrawal from traditional social contacts is a mechanism often utilized by ostomates. A mother who was interviewed talked about her daughter's situation. She commented:

My daughter had her urostomy after a car accident and broke up with her boyfriend. For the last four years, she has had no social life. She says she is a 'freak'. In essence, she can do anything that she did before - swimming, golf and even tennis. But I believe it is the fear of sexual contact that is responsible for her not accepting or maintaining a relationship with a man. I have tried to direct her to obtain psychiatric help, or even just to go out and she tells me to 'go to hell, you don't know what it's like'.

For the last two years, I have just sat back and watched. It is heartbreaking: she spends hours and hours keeping herself clean. I'm sure she has ten different perfumes on her dresser. (4)

Related to concepts of body image and cleanliness is the shift from evacuation through an orifice in the rear of the body to elimination through one in the front. A study undertaken by Orbach and Tallent was focussed on this event.

Formerly, concepts concerned with an individual's own anus and the act of defecation were primarily based upon tactile sensations and extrapolations from observing other people and animals. Both the new aperture and the act of defecation can be directly observed with the construction of a colostomy and therefore provide a novel source of information to be incorporated into the perceived body (Orbach and Tallent, 1965:128).

It is obvious that a profound change is required to conceptualize the reversal of function from rear to front and obvious also that it is necessary for the patient to organize this new function and sight into his existing concept of body image. This includes coming to terms with the fact that all elimination will occur in the front of the body, not just urination as before. As well, colostomy and ileostomy patients are often required to acknowledge the existence of a substitute anus. This is illustrated in the following:

The most embarrassing time I ever had was when my husband saw my stoma for the first time. We had never discussed it and I still do not think he can accept it. I did regard my body as beautiful but now that has been destroyed. (2)

It is as if the ostomy patient were presenting a tabooed zone directly to others instead of hiding and "disowning" it by concealment in the rear. The motivations of hostility and defiance that are sometimes symbolically expressed through the act of defecation are now open to detection.

This shift is accompanied by the realization of a generalized concept of dirtiness in the front of the body and thus some patients

feel "reduced or transformed into the state of an animal", a reference which connotes an extremely negative image of the self as well as the loss of anal control. Orbach has stated that:

When taboos against touching the anal zone unless the hand is covered by a thick wad of toilet paper or viewing the fecal product existed, this largely excluded the incorporation of the zone and its function in the body concept. The requirements of irrigation result in a breach of the taboo against touching. The presence of the colostomy opening in the front of the body also makes it impossible not to view the fecal product as well as the evacuatory process itself. The substitute anus now must be viewed and touched due to its shift in body position. As a consequence, it has to be included in an altered body concept no matter how distorted the form of its inclusion may be unless a massive denial intervenes. (Orbach and Tallent, 1965:128).

When individuals have created self images based on normality, one finds that they usually encounter many difficulties in adjusting to spoiled identity especially if this identity is readily detectable. Some affected actors demonstrate reactions based on societal connotations of their conditions which may or may not be factual. Thus, the victim of spoiled identity often finds that the stigma attached to his real or supposed condition severely retards if not eliminates previous established structures of social interaction.

SUMMARY AND CONCLUSIONS

In the present material we have attempted to distinguish between stigmatized and non-stigmatized status, define the ostomate as stigmatized, illustrate how North American ideas on cleanliness aggravate the disvalued characteristics of ostomates, and outline the physical characteristics of the ostomatic condition. Chapter three outlines and justifies the methodological procedures utilized in this investigation.

FOOTNOTES

- (1) These remarks were made by individuals who have come into contact with ostomates; three individuals who have never come into contact with ostomates but had heard about them and 31 of the participants in the study who mentioned that they were perceived as being different in spite of the fact that many of them tried to alleviate or were not affected by the conditions often supposed to affect all ostomates.
- (2) Statement by ostomate, personal interview.
- (3) Statement by wife of an ostomate, personal interview.
- (4) Statement by mother of an ostomate, personal interview

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CHAPTER III

METHODOLOGY

Chapter III will focus on the methodological procedures utilized in this study. As such, commentary will focus on the relationships of symbolic interaction to the study, the nature and type of cases utilized in the research, as well as a profile of the case studies in which the samples are described in terms of age, sex, educational and occupational characteristics. This section will also include a brief description of the nature and types of ostomatic careers encountered by the subjects who volunteered for this study.

Finally, a description of the data collecting procedures is outlined. The nature and types of interviews and techniques utilized for gathering information will be illustrated along with an attempt to account for the refusals and difficulties encountered in the data collecting process.

THE METHODOLOGY OF THE SYMBOLIC INTERACTIONISTS

All sociologists are guided in their work by some view of man, both with regard to his nature and the way he operates as a social actor (Phillips, 1971:53).

This investigation endeavours to discern the patterns of relationships encountered by ostomates in their associations with various segments of the normal world. From a methodological viewpoint, the symbolic interactionist perspective has been utilized in order to explore the patterns by which those who are affected by ostomatic status encounter reality.

From a sociological perspective, the utilization of symbolic interactionist theory appears to be the most useful theoretical orientation to enlighten the subject matter at hand. Social interaction implies a strategy for understanding and for attempting to analyze the real social world. As such, the analyst is not restricted by the requirements of a theoretical model, assumptions or orientations which may lead him to manipulate his data to fit a conceptual scheme. As Blumer suggested, "If one resorts to this type of analysis one is not letting the empirical world dictate the research strategy" (1967:33).

The research process is two-fold. First, researchers must approach concrete situations and be prepared to observe and revise their observations as new impressions of the situation arise. Subsequently, as emphasized by Blumer, exploration must be followed by a process of inspection whereby researchers use their observations to dictate how scientific concepts are to be refined and incorporated into more abstract

and generic statements of relationships among concepts. Investigators must understand each actor's definition of the situation, the relationship of this definition to the objects perceived by actors in this situation, and the relationship of objects to specific others, groups and expectations in both the actor's immediate and remote social worlds. Thus, research used to build up abstract concepts and propositions of sociological theory would be connected to the empirical world of actors interpreting, evaluating, defining and mapping the behaviours that create, maintain or change patterns of social organization. The controversy over the symbolic interactionist position comes from the frequent denial that others' methodological strategies are important in the understanding of the process and structure of society. How is it possible to operationalize concepts such as the definition of the situation so that different investigators at different times and in different contexts can study the same phenomena?

The concepts of symbolic interactionist theory clearly reveal a methodology which permits direct examination of the empirical world. The data speaks for itself and is not subject to an alien methodology which makes assumptions and interpretations about the data. Blumer states:

The ambiguous nature of concepts is the basic deficiency in social science ... symbolic interactionism advocates a clear-cut strategy for building sociological theory. The emphasis on interpretative, evaluative definitions and mapping processes of actors has come to dictate that it is only through induction from these processes that sociological theories can be built. Deductive reasoning should be replaced by the inductive approach, because of the ever shifting nature of symbolic processes. The symbolic interactionist strategy is to induce generic statements, employing sensitizing concepts from the ongoing symbolic processes of individuals in concrete interaction situations. Such strategy keeps theorizing in tune with social reality. (1967:146-147).

In analyzing the various social roles to which the disabled are subject, one must investigate and seek to understand their perceived realities. One must attempt to utilize their definitions of various situations, their perceptions of the roles of the family, medical and paramedical personnel, liaisons with the economic world and the various other facets of their universe. In employing this focus one may be able to suggest strategies which may be used in attempting to maximize the potential of those subject to the stigma of being handicapped.

The time span from the initial considerations of topic through to the provisional considerations of the project, to the revision and final report, encompassed four years. An underlying assumption which has persisted throughout this period is the conviction that an understanding of actors in various social contexts is best gained when attention is paid to the actors and their definitions of particular situations. This has had, however, changing implications in terms of one's conception of both human action and interaction and sociological methodology.

Briefly stated, the operating assumption underlying this work has its roots in Verstehen sociology of Max Weber and the symbolic interactionist social psychology of George Herbert Mead. This frame of reference takes as a basic postulate the human capacity for constructing and showing meaning.

The key notion ... is that of autonomous man, able to realize his full potential and to create a truly human social order only when freed from external constraint. Society is thus the creation of its members; the product of their construction of

meaning and the action and relationships through which they attempt to impose meaning on their historical situations. Thus, while humans themselves socially construct the reality of their worlds through what has been called externalization, that social reality comes to be experienced as having a reality of its own, a reality that confronts the individual as an external and coercive fact. This is the process of objectivation (Weber, 1964:87-123).

In attempting to account for patterns of behaviour, sociologists often construct models that attempt to explain the various patterns of behaviour illustrated by individuals or groups subject to various patterns, pressures and restraints. Thus, Durkheim was able to account for patterns of suicide and Merton was able to account for patterns of deviant behaviour. Such explanations provide partial answers and/or descriptions of various behavioural adaptations which take place in specific universes. However, in many instances, it is difficult to specifically account for various patterns of behaviour.

I find that you psychologists and sociologists are always concerned with your so-called models. Models may be interesting and helpful to some but after twenty-five years in surgery I find it impossible to predict even after spending up to twenty hours with a patient, which ones will adapt to a surgery, especially if it is drastic such as an ostomy or a masectomy. Some patients adjust immediately and subsequently illustrate growing patterns of negative reactions. This generally takes place when they themselves can accept the surgery but their relatives, friends and acquaintances cannot. While others cannot accept this alteration in their physical make-up. In this type of surgery, there are a number of contingencies not encountered in many other common surgeries. In most surgeries you remove a growth or you repair damage which may even result in the loss of a limb and/or disfigurement. But in this type of surgery, you have another dimension. The patients themselves are required to handle their stoma and appliance. Some have problems with dexterity and others experience hardship in disposing of their wastes while some get into situations in which they spill their excretions. How can you predict which ones will even have more likelihood of regaining normal lives and which ones will not?

To be honest, I believe that many of us can predict that older patients who cannot comprehend the surgery will not adjust. In this situation, we are in a very difficult situation. But who can make a decision as to whether or not to hasten an individual's death? Accurately predicting the rates of adjustment or non-adjustment of ostomy patients would be equivalent to accurately predicting which people like and do not like lemon pie!

One important fact in the journey of science is not to be captivated by methodologies or systems. As you know, there are dozens of examples of how the utilization of methods of doing things have been responsible for interfering with the development of science. You know from our previous conversation that I being a surgeon consider myself as being a technical scientist. I often believe that there is no real thing as a 'social' scientist as you people tend to be captivated by your own methodology. (1)

This also tends to be the perspective of Blumer who, throughout his work, always challenges symbolic interactionists specifically and social scientists at large to continually draw conclusions pertaining to social reality by examining and re-examining data.

One additional theoretical perspective is important. It is assumed that social reality and legitimation is maintained primarily through the objectivation of language. Berger and Luckmann suggested that:

Language provides the fundamental superimposition of logic on the objectivated social world. The edifice of legitimation is based upon language, it uses language as its principal instrumentality (1966:64).

It is assumed that we can only know reality through the medium of language. Winch stated this as follows:

Our idea of what belongs to the realm of reality is given for us in the language that we use. The concepts we have settle for us the form of the experience we have of the world ... The world is for us what is presented through these concepts (1958:15).

Or, as Berger and Kellner stated:

If we know our world through language, then the most important vehicle of reality maintenance is conversation. The possibility and stability of the world as socially defined is dependent upon the strength and continuity of the significant relationships in which conversation about this world can be continually carried on (1954:31-32).

To put it a little differently, the reality of the world is sustained through conversation with significant others.

If one wishes to learn about legitimation, one should then concentrate on both language and conversation. As will be noted later, the nature of this particular research project prohibited the gathering of conversational data to the extent that could have been wished.

Hartnacks, in a summary statement which is applicable to whole sentences as well as to words, summarizes: "The meaning of a word is learned by discovering its use. And if its use has been learned, its meaning has been learned too" (1965:55).

Language is a tool which we can understand by asking to what use it is put. What role does it play in the life of those using it? One must, therefore, attempt to understand how language is used in order to understand its implied connotation. Therefore, one must be aware of the role language plays in the lives of those who use it.

METHODOLOGICAL ASSUMPTIONS AND ORGANIZATION OF THE DATA

The methodological assumptions must be seen in the context of the data that were recorded from the interviews used in this investigation. Much of the data that were required deal with that which is taken for granted (i.e. legitimated) by the respondents. How does one gather data about the "taken for granted"? This "taken for granted" is acted upon by inferences to internal states and actors' definitions are precarious when based on the observation of behaviour roles. Moreover, the "taken for granted" is little discussed, precluding the gathering of extensive global data concerning it.

In this work, there was extensive reliance upon verbal data. This emphasis was necessitated by the very nature of legitimation which, as indicated, is maintained primarily through conversation. It was necessary to interpret the reserve, facial expressions and exhibited anxious tensions which were observed in the course of many interviews. These must be regarded as "nonverbal" data. The interactionist assumption which would seem to be applicable has been stated by Denzin as follows:

Man learns his basic symbols, his concepts of self and the definitions he attaches to his social objects through interaction with others. Man simultaneously carries on conversation with himself and with his significant others. (1970:7).

Denzin further suggests that:

The investigator must simultaneously link man's symbols and conceptions of self with the social circles and relationships that furnish him with those symbols and conceptions.

Symbolic interaction dictates that methodologies should respect the character of empirical reality and adopt methodological procedures that encourage direct and unbiased examination (1970:17).

Once the data had been assembled, there remained the task of sorting through and organizing all the information. In order to make a thorough analysis of this material, it was necessary to organize the data into a schedule of sequential stages of events that followed one another in time.

In their attempt to bring some order and meaning to the bewildering complex of events, actions and feelings that characterize mass disasters ... social scientists have sought to break down the history of disasters into sequential stages (Chapman, 1954:51).

These stages were classified by Davis as follows:

These typically include predisaster, a quiescent stage in which the community is seen as going about its normal business; a warning or threat stage in which signs of the approaching disaster appear but are not always attended to; an impact stage in which the disaster strikes; a post-impact stage or inventory stage in which the extent of the damage and loss is assessed; and finally a long-term recovery stage in which the community attempts to repair the damage and replace its losses (1963:19).

Sequential stage analysis has a number of advantages. First, it allows the researcher to order his subject matter into understandable components, to relate these components to one another in a systematic way and, in general, to bestow a semblance of order on the chaos of contradictory reports and observations that usually emerge in this type of situation. According to Davis, there are also drawbacks to using sequential stage analysis:

In these varied advantages however lies the chief disadvantage of this approach; for the segmented description of the crisis experience tends to suggest that more order and coherence exists

than is usually the case in such situations. To the extent that confusion, vacillation, ambiguity, fortuitousness and the like, distinguish these occurrences from everyday social life - and they clearly do - the employment of this kind of analytical tool falls short of reality. However, neither sociology nor psychology has yet evolved a set of concepts and terminology that more adequately expresses the suddenness, rapidity and breadth of social and personal changes experienced in disaster situations (1956:19).

A crisis experience is faced by individuals and families when a person is confronted with prospective drastic surgery. One experiences the development of a crisis situation and reaction becomes difficult, especially if the individuals involved become familiar with the difficulties and the effects which follow the surgery. Regarding this, Davis suggested: "Basically, the same paradox of ordering reality versus the unreality of order, taunts the investigator who wishes somehow to describe objectively the course of events" (1956:21).

As Davis attempted to follow an order based on disaster research, it appears that the same type of approach is warranted in this study. Like Davis who designated the stages in order of their appearance, this study will similarly name the following ostomy ideology: 1) minor symptoms phase, 2) major symptoms phase, 3) diagnosis phase, 4) hospital phase - preoperative stage and postoperative reactions, 5) adjustment phase, disability and/or handicap self definition, and 6) achievement of normalcy.

In this study, the last two stages will comprise the major focus of the research. It appears that for some patients the surgical shock results in a long-term physical, social and emotional handicap.

For others, however, the consequences of surgery do not limit their life experiences as they choose to adapt in a more positive manner. The various factors influencing how one adapts to ostomatic status will be examined in order to better understand why some people adapt more successfully than others.

Symbolic interactionist inquiry requires research empathy as a crucial part of the investigation act. In social interactionist theory, the process of research in actuality is the process of social interaction as the researcher must take the role of those whom he is studying. This role playing requires the successful researcher to evolve a set of conceptual tools rather than prematurely structuring the social world that he is attempting to assess. The investigator must sensitize himself to the interactive process.

DESCRIPTION OF THE SAMPLE

The perspective used in this study was one similar to that utilized by Davis (1963) in his work on polio victims and by Roth (1963) in his work on tuberculosis patients. The structure of their investigations amplified the value of this perspective for the current research.

Thirty-five candidates who had undergone ostomy surgery were interviewed. Eighteen individuals had had their surgery within the last five years, while the remaining seventeen acquired their ostomies within the last ten years. One individual had undergone surgery thirty-one years ago.

The field work took place in three settings in Ontario, Canada: in Toronto, Hamilton and the Kitchener-Waterloo area which includes the three former municipalities of Galt, Hespler and Preston now collectively referred to as Cambridge, Ontario. These three regions were chosen for their close proximity, the types of hospitals present, and the fact that they had Ostomy Associations. (2)

The thirty-five cases in this study did not include all of the participants who volunteered for an interview. Nine individuals claimed that they wanted to participate but for various reasons withdrew. They had either moved to another city or decided that they really did not have the time. There were also some interviews in which the responses of the subjects were far too generalized to be useful.

The majority of ostomates interviewed were contacted directly

through the Ostomy Association in their area. These persons were thought to be the most active members in the organization, both in view of their deep concern for other ostomates and as a result of their own particular conditions. There were a number of people, however, who were not interviewed. There were four volunteers under the age of 18. It was felt that administration of the interview could arouse anxieties that were unnecessary. From talking to these youngsters, it was apparent that their greatest concern was the ridicule they suffered from their peer groups.

The participants in this study were Caucasian and of Canadian citizenship of first, second or third generation. Twenty of the subjects were male while the remaining fifteen were female. The age range was between 19 and 86 years of age. All of the volunteers except two, an Agnostic and a Jew, were from Protestant or Catholic backgrounds.

The volunteers were representative of the entire range of socioeconomic backgrounds. The sample included ten housewives, two executives, three students, three salesmen, thirteen blue collar workers and three retired subjects. Of the three students, one had completed four years of university. One executive had a Bachelor of Architecture degree and the other a Master of Business degree. Two of the housewives had graduated from secretarial courses. The remaining individuals had at least the equivalent of a junior high school diploma.

It was noted that there were no differences displayed in the types of problems and difficulties encountered or in the types of adjustments and adaptations that were made to the surgery. It appeared that class background and education did not influence how they reacted to being ostomates.

Twenty-two of those interviewed came from what could be called stable family backgrounds. It was difficult to gauge their family backgrounds in terms of normalcy. That is, some of the families of ostomates had experienced various difficulties that can be associated with family stress and/or disorganization prior to the advent of surgery. No doubt some of the difficulties in this regard were occasioned by the stress and pain experienced by the future ostomates, but in some instances it was evident that the problems were a result of factors other than those related to the ostomy patient. In seven instances, there was difficulty in assessing the stability of the family as the participants chose to gloss over this area of questioning. In three cases, the ostomate had lost his or her spouse before the interview took place as a consequence of "natural causes".

DATA COLLECTION TECHNIQUES AND ANALYSIS

In order to investigate the corporate nature of the career of the ostomate, data were gathered in several ways and analyzed according to the age at which the ostomatic status occurred. Age of ostomatic status differentiates sharply ostomate careers. We found that the total picture could be accomplished by interviewing the ostomate himself, the family, the medical and para-medical personnel, Ostomy Association members and other significant individuals with whom the ostomate established and maintained meaningful patterns of interaction. The description of the methodology that follows, its advantages and shortcomings, follows the notion of "career". It is around this notion that the data became organized and from which the methodology is best illustrated.

It was established that patients who make the transition from normalcy to ostomate status go through five relatively specific periods. These five periods can be regarded as constituting the significant stages of a patient's ostomy career. In sociology, the notion of career has been utilized not only to describe the work employment of individuals, but also to describe the sequence of events encountered by deviants and others in establishing new patterns of identity. Thus, for example, the professional criminal does not assume this status by acquiring a university degree, but rather he must successfully accomplish a number of "prerequisite tasks" which legitimize him in the eyes of those who define or recognize professional criminals. Many analysts have utilized the concept of deviance in describing those who are considered ill.

Being sick or ill can be considered as deviating from the "normal" stage of health. The stages which one undergoes in the transition from normalcy to the state of being ill, disabled and/or handicapped constitute the various phases of a patient's career. For ostomates, there are five significant career stages: the minor symptoms phase, the major symptoms phase, diagnosis phase, the hospital phase (which includes pre and post operative reactions) and the adjustment phase. One's response and reactions during these phases inevitably demonstrate the problems encountered for an ostomy patient in attempting to maintain or re-achieve patterns of normalcy. The last two stages - the hospital phase and the adjustment phase - are perhaps the most crucial stages in illustrating patient capacities to adapt to their ostomate status. This may involve a renegotiation of their identity with many of the individuals with whom they interact. As will be illustrated, renegotiation of status is not always required because some patients are able to contend readily with the requirements of ostomate status and hence this status does not in any way interfere with their life patterns. Others are able to disguise their conditions in order to escape detection.

The participant ostomates were grouped into categories according to age at which they first acquired ostomy status as their experiences tended to be similar. A separate category designated as instantaneous ostomates involved only those who acquired their conditions as a result of accidents which resulted in injuries demanding immediate ostomy surgery. (The rationale of these categories will be illustrated in the following chapter.)

Originally, research was attempted through general practitioners and surgeons, but as time progressed, the most valuable means of meeting ostomates was determined to be through the various Ostomy Associations. Patients referred to the study by physicians and surgeons were reluctant to participate. In the beginning, a series of thirty questionnaires and explanatory letters were mailed out to these ostomates who had been referred by the various general practitioners and surgeons. Only one of these was returned. It was obvious that this method of obtaining information was not going to be successful and it was, therefore, discarded. The impersonal nature of a questionnaire survey discouraged those to whom it was mailed from participating. The very nature and implication of being an ostomy victim is a very private matter and the detached and impartial tone of a questionnaire was, in all likelihood, too insensitive.

Of particular benefit in the early stages of this investigation were discussions with two social workers, one who had set up an Ostomy Association in Cambridge and another who had worked extensively with ostomates in Toronto in a rehabilitative capacity. The insights and explanations shared by these two people provided references which eventually led to the discovery of willing participants for this study.

A series of questions were designed and incorporated into an interview schedule. Five subjects volunteered and they were interviewed as a pre-test so that their data could be reviewed in order to look for "loopholes" in the interview schedule (i.e. information that was not obtained). Subsequently, the questions were revised so as to

widen their scope and make the schedule more complete. A final interview schedule was formulated and this appears in the Appendix.

It was found that the members of the Ostomy Associations, particularly the one in Cambridge, demonstrated great interest and cooperation in participating in this study. The participants volunteered their names through other individuals or at Ostomy Association meetings. Those persons who were contacted by phone for interviews, first received a letter providing a short summary of the project and asking them for their cooperation. In all instances, preliminary discussions were held with the directors or chairmen of these Ostomy organizations in order to give assurance that those who chose to participate could withdraw at any time and have the freedom to answer or to decline to reply to any questions to be asked.

This interview method provide to be exceptionally successful. For example, one man in the Hamilton Ostomy Association volunteered names of four of his friends who he telephoned before the initial contact; all four agreed to participate.

Aside from the ostomates themselves, it was deemed advantageous to interview, where possible, the family, relatives and friends of the participants. Husbands, wives, friends and a few relatives of the volunteers furnished excellent supporting material.

At the outset these interviews were intended to follow the interview schedule or questionnaire as a general perspective. It soon became apparent that referring to the questionnaire during the conversation was too formalized an approach and that the participants were very uncomfortable and ill-at-ease when the formal questionnaire was present. Therefore, the questions were memorized and the interviews were

conducted on a more informal basis. This proved to be a more successful approach. Once all the conversations had taken place, the data was systematically organized to correspond to the line of questioning in the original questionnaire.

The research project spanned four years and where possible the study was longitudinal in that the families and/or patients as well as significant others were visited periodically over the four year interval. In three instances where the patients encountered their medical problems at the commencement of this research, the participants and their families were visited at regular intervals. In other instances where the patient had been diagnosed and treated at various intervals in the past, only an initial visit and one or two subsequent consultations were required. In general, the original investigation encompassed a twenty-month period during which time repeated contact with patients, relatives, hospital personnel, casual associates, working contacts and significant others was made. During the revision of this project, seven of the original patients, six new subject patients and their associates such as family, medical and paramedical personnel were contacted.

The interviews were scheduled where possible with the natural course of the "disease" and its treatment. However, in view of the fact that fourteen of the patients had had their surgery up to ten years prior to the research, the exactitude of this process must be carefully considered. In two instances, the first interviews were conducted with the patient and his family prior to his admission to hospital and three

interviews were conducted while the patient was in the hospital following surgery. The remainder of the interviews were conducted when the patient had, at least from a medical point of view, recovered to the point where he could leave the hospital and again live within the confines of a home environment. The length of hospitalization ranged from two to eleven weeks. At least sixteen of the interviews were conducted with the spouse as well as the patient and in nine cases secondary persons such as family members, friends, co-workers and other associates were interviewed. The families who volunteered attempted to be very cooperative, especially when circumstances necessitated re-interviewing and subsequent re-checking of data.

The interviews took place in the home and University office of the researcher, in the homes of the participants, in restaurants and in lounges. One interview also took place after an Ostomy Association meeting in the waiting room of a local hospital where the association meetings are generally held. The interviews ranged in length of time from one hour and a half to seven hours. Most of the interviews averaged four to five hours.

The selection of open-ended but mainly schedule-type interviews were also conducted with hospital personnel, medical and para-medical personnel such as nurses, stoma therapists, social workers and psychiatric social workers, psychologists and psychiatrists. In addition, executive members of the various Ostomy organizations were consulted on several occasions. Each of these individuals in one way or another assumes the capacity of being able to "treat" patients in their pre

and postoperative experiences. These interviews were intended to elicit information concerning the patient's pre and postoperative psychological and physiological states, and the subsequent effects these states had on patterns of behaviour. Apart from the specific information they furnished on each patient, these interviews were a highly valuable source of data on the roles, behaviour and professional attitudes of the various classes of treatment personnel. They also illuminated the difficulties in communication among medical and paramedical personnel, patients' families and related associates. These broad types of interviews provided an overall picture of ostomates in their social and psychological worlds during the diagnosis, the immediate recovery phase, the convalescent period and their long-term social adjustments.

The research was explained to the participants as part of an ongoing investigation of individuals who were handicapped or disabled. They were told that the study was looking at two basic groups - those who had congenital afflictions and those whose disabilities resulted from other factors (instantaneous or progressive). It was illustrated to the participants that disabilities may not be handicaps and that the goal of the project was to endeavour to contrive a strategy or a series of strategies which would maximize the rehabilitative potential of, in this particular instance, ostomates. This explanation helped to alleviate some of the anxieties which the participants may have had and it also helped to give them a sense of sharing in a useful project which could contribute to the successful rehabilitation of

others similarly affected. Four of the subjects interviewed expressed the opinion that they thought that many research projects and investigations were only research for research's sake, such as dissertations, and that they did not wish to be a part of these undertakings. No mention was made of this study being done as part of a doctoral thesis, but it was mentioned that some of the data might be utilized in a dissertation.

Many of the patients interviewed tended to experience anxiety at some time during the interview. These fears and apprehensions appeared to have stemmed from the re-awakening of exceptionally unpleasant experiences and reluctance to discuss sexual matters or family instability. As one patient who was interviewed commented:

I had not thought about these issues for the last five months. I indulged in self pity and my friends and my wife became quite distant. The relationship involving sexual affairs with my wife, I have never discussed with anybody. This may be strange - the problem was not hers, but mine. I thought that I had become repulsive just because I was wearing the bag. I have only had spillage once, and I can now control my odour. Once we worked this out, things became much simpler. That is, we lived together as before. Other than that, somehow I don't think that it is necessary to discuss our sexuality. (3)

Most participants appeared to be understandably very shy and reserved about matters of sexual intimacy and how their ostomy had affected this. Some persons showed great reserve in talking about their personal relationships. Questions were phrased in ways designed to achieve maximum response from the participants.

One of the general practitioners expressed extreme reservations about sociologists and other non-medical persons becoming too involved

in medical topics. Four of the surgeons were also hesitant to discuss the role of the surgeon, their expectations and their functions as far as the total care of the ostomates are concerned. Three of these men were somewhat suspicious of the research and one wanted to know whether it was a form of "checking up" for an agency of the Federal or Provincial Governments. Their consensus was that the area under investigation was strictly a concern of the medical profession, and this was stated in cool and warning tones:

These days it seems sociologists, social workers and other other government personnel are getting involved in the medical profession. The influx can only be relevant in terms of the fact that they cannot possibly appreciate the difficulties, conditions and situations which we encounter. Therefore, my advice to you is to go and study something in sociology. (1)

The paramedical personnel interviewed were exceptionally cooperative. Among those who were consulted were two psychiatrists, one psychiatric social worker, two stoma therapists and several nurses.

One of the psychiatrists was well aware of the emotional difficulties faced by ostomates and he claimed that he thought the creation of a stoma team at particular centres where the surgery takes place would be invaluable, but felt that unfortunately in most areas it would be financially impossible. The other psychiatrist consulted had no idea of the problems faced by these patients and although we discussed concepts such as body image changes, he still appeared to feel very ill at ease during the interview.

The two stoma therapists interviewed proved to be very helpful. One had had an ostomy herself. These therapists related the case

studies of numerous patients whom they had treated during their careers. It was their counsel also that contributed to the belief that a sufficient number of individuals had been questioned in order to adequately demonstrate the patterns of adaptation illustrated by ostomy patients.

The nurses were also helpful. They outlined the problems they faced in trying to care for ostomates, especially during the difficult immediate postoperative period. Two of the older nurses expressed the opinion that they thought the surgeons were not really concerned with the overall welfare of their patients. One operating room nurse claimed that she had witnessed mistakes made during several ostomy surgeries, but she declined to elaborate.

Four volunteers, sociology and social work graduate students from three universities in Ontario, also assisted in the study by interviewing an additional twelve subjects. The data gathered by these persons was used to authenticate the data obtained by the methods outlined above.

In addition to the interview material, there were another thirteen case histories described by personal friends (i.e. non-ostomates). However, only passing reference was made to this information as the reports were purely descriptive and based on the impressions of the individuals who related this material.

There was also valuable information furnished by the United Ostomy Association Journal. This journal is a publication of the

Ostomy Association of North America. It functions to keep ostomates informed on the new surgical techniques, new appliances being developed, formation of new associations and also describes club members who are making successful adaptations. In general, it serves to keep the ostomate well informed and to remind him that he is not alone.

In summary, a variety of sociological and psychological techniques were employed for studying ostomates and those directly involved with them. From the data gathered, it was possible to compare reactions, to note changes over time and in general, to trace in developmental terms the adjustment of families to the altered life circumstances occasioned by ostomy surgery.

When a researcher begins to note that the adaptations and case studies he has found begin to sound similar, it is realized that perhaps the point has been reached when data gathering can be concluded and analysis commenced. The cases in the literature, those gathered by the researcher and the allied cases obtained by the graduate students, along with the comments of various surgeons, stoma therapists and nurses, demonstrated that enough information had been gathered after thirty-five interviews to adequately illustrate the various difficulties associated with ostomy surgery and its aftermath.

The process of analysis utilized Davis's approach and can best be described in his own terms:

This analysis can better be described as the final product of a long process of rumination that bridged several months of active participation in the formulation of the project research design and objectives, in the collection of data, and in the

preliminary evaluation of themes and trends contained therein. Throughout this period I formulated and reformulated, untold times, the basic questions to which I eventually applied the data. Only when these questions had crystallized sufficiently in my mind did I systematically go through the whole accumulation of project data choosing and discarding, excerpting and extracting, and comparing them for what light they would throw on the problems I had marked off for the study. (1963:185-186).

CRITIQUE OF THE METHODOLOGY

The difficulty of the interview method is that it is not possible to obtain certain vital information because it is not easy for the subjects to spontaneously verbalize their feelings on certain matters (e.g. sexuality). It was noted that certain individuals were able to quite adequately express their particular situations and they could be quite dramatic and vivid in their descriptions. However, there were other persons who, even though they had experienced many of the same problems and anxieties, due to either emotional distress or educational levels, could not adequately portray their circumstances. In all but four cases, the subjects were inhibited and reluctant to talk about the consequences of the surgery on their sexual lives, and yet this is considered by authorities to be a very important adjustment that invariably affects the ability of the individual to successfully adapt. It must be noted that this reservation is not likely to be just a personal reluctance, but for the most part may be attributed to society's long-standing Victorian taboos on sexuality. Therefore, the effect of the surgery on family stability and sexuality remained a personal concern that was not as adequately investigated as had been desired.

An attempt was made to use a tape recorder to record all interview sessions. In some cases, the appearance and/or running of the tape recorder inhibited the responses of the participants and therefore tape was not used during these interviews. In these cases, the

content of the interview was recorded on tape when the interview concluded. This was done only when the volunteers being interviewed expressed reservations about being recorded. It must be admitted that the human memory is not as proficient as the mechanical tape recorder. However, the majority of the participants did not object to the presence of the tape recorder.

The direct interview method and the technique of tape recording the sessions proved to be the most useful and fruitful methods. Using this type of interview process the information is not only obtained in terms of all that the subject says, but also how or in what manner he conveys it and this in itself is valuable in that it can lead one to make fairly accurate assumptions about the emotional impact the surgery has had on the subject. There is also another advantage: the research is not constricted by an exact format so that some areas of knowledge can be obtained that go beyond the scope of the formal questionnaire. This is precisely what happened in many cases and this additional information contributed to the final analysis of the data.

Twenty-four of the volunteers were members of Ostomy Associations. Four of the remaining subjects had been members of the Ostomy Associations and subsequently relinquished their memberships as they had learned to manage their conditions and they themselves were not interested or did not have the time to counsel other prospective or functioning ostomates. The remaining seven subjects did not belong to Ostomy Associations. Two of them in Cambridge, Ontario maintained that they did not know the association existed, or that they had heard about its

existence but never felt it necessary to contact the association. Another individual, an older man, was not interested in the organization at all. The other four participants of the sample maintained that they were functioning as well as could be expected as a result of the counselling they obtained from medical personnel and therefore did not need nor desire contact with the Association.

Admittedly, there were some difficulties encountered with the data. The small number of participants obviously raises questions as to the validity and legitimacy of the research. However, it must be noted that studies such as the one conducted by Davis (1963) (who based his analysis on a sample survey of only fourteen cases) do illustrate the fact that a satisfactory analysis can be undertaken with a relatively small sample. If one includes all the ostomates, their family members, general practitioners, surgeons, nurses, Ostomy Association members, they there were approximately eighty-two people interviewed during the course of this research.

Lastly, but not of least importance, was the financial factor underlying the study. The time, effort and costs in any research tend to place an upper limit on the extensiveness of study. The limited finances of this author and the fact that his own physical limitations made it necessary to employ several people to type the thesis and data notes many times over until the final draft was completed, have indeed prohibited him from attempting to extend his scope. It was hoped that grant support would have been received to help finance the project, but unfortunately government cutbacks and restrictions have limited

the amount of funds available for research. Thus, the costs were incurred personally by the author and this represented a limiting factor in the scope of the study.

SUMMARY

In summary, the careers of thirty-five ostomates were studied. Data were collected about their careers in the aforementioned ways and in the chapter that follows the data are organized around the notion of career.

FOOTNOTES

- (1) Statement by a medical doctor; personal interview.
- (2) Ostomy Associations are mutual benefit groups for ostomates.
A more detailed description and analysis of these clubs will be undertaken in the further chapters of this study.
- (3) Statement by ostomate; personal interview.

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CHAPTER IV

CAREER OF OSTOMATES

INTRODUCTION

The evolution from the state of normalcy to becoming an ostomate, acknowledging this state and adjusting to it is often a difficult transition. The patient's identity is not only altered in terms of a physical change, but he also becomes regarded as having succumbed to factors which are interpreted by many as producing spoiled identity. Spoiled identity, especially if it stems from a relatively sudden condition, is a shock and subsequent adjustments to one's altered self often then become problematic. In many instances, the development of an ostomatic condition tends to produce identity anomia in that the ostomate becomes subject to anxiety produced by a condition which often has stigmatized connotations and consequences in his subsequent interaction with others. The universe of conditions and situations encountered and interpreted by the patient who has become an ostomate are often instrumental in determining whether the patient can or cannot make a positive adjustment to his altered self. By positive adjustment, one insinuates that the patient constantly strives to regain as much normalcy as is possible. In other words, the patient attempts to resume a normal life.

Resuming a normal life often requires the ostomate and his significant others to develop redefinitions of self, of experience and in some instances, of activity. The study of the process of this redefinition of self becomes a study of the step-by-step stages encountered by the ostomate during his process of transition from a state of normalcy to

a state of becoming and living with the reality of being subjected to ostomatic status.

As the data will illustrate, a patient's identity is subject to anxiety as a result of the consequences, physical, psychological and social, in becoming an ostomate. In many instances, a patient's identity changes substantially as a result of the conditions imposed or accepted by him which is a consequence of his altered status. Thus, for some, because of the difficulties encountered in facing one's spoiled identity, redefinition and readjustment in terms of Cooley's perspective of the "looking glass self" inevitably produces positive and negative effects for those attempting to accept their altered status.

What follows is a sequential analysis of the stages experienced by those who become ostomates. However, not all those who become ostomates do so in the same manner. Hence, the legitimacy of categorizing ostomates in specific groups will be demonstrated. Following this description of ostomy categories and of the patient's career, there will be an assessment of some of the interrelating factors that affect a patient's subsequent pattern of adjustment. It appears that these subsequent patterns of adjustment are influenced by numerous factors including the duration and condition which led to ostomatic surgery, subsequent surgery and hospitalization and the effectiveness of counselling.

During the transition to ostomatic status, the patient encounters five stages defined as: 1) minor symptoms phase, 2) major symptoms phase, 3) diagnosis, 4) hospital phase (this involves pre-operative

stage and postoperative reactions) and 5) adjustment phase - the patient attempts to achieve a normalized status which involves some form of handicap-self definition. The adjustment to ostomatic status can be categorized in terms of the characteristics of the patient with regard to age, sex, the nature of the condition which necessitated the surgery and other related variables. These five stages constitute an ostomatic career.

THE CAREER OF OSTOMATES

In Chapter One we have noted that empirical regularities in identity formation may be found in the patterning or career that a person goes through in the formation of a new identity. In addition, previous research has indicated that careers in identity formation vary significantly with age at onset. Five stages of ostomate identity formation have been delineated and we have divided our data into five separate age groups. With these two givens in mind, in the analysis below we attempt to follow five stages in the career of ostomate identity formation and how people of different ages experience them. The first four stages of the career are analyzed in this Chapter. The most important stage (adjustment) is analyzed in Chapters Five and Six.

The notion of a career in sociology has not only been used to describe and analyze the stages encountered by individuals in their association with life pursuits, but has also been utilized to describe the stages encountered by actors as they pursue "careers" in deviant subcultures (Becker, 1963), and in states of adapting to the prison process (Goffman, 1961). Therefore, one can utilize the concept to analytically demonstrate the stages encountered by ostomates in their transition from a normal state through the processes involved in becoming a full-fledged ostomate.

These processes involve a number of stages through which most ostomates pass. From an empirical point of view, these stages appear to be valid, as ostomates encountering the various stages experience rela-

tively distinct sets of anxiety when endeavouring to adjust physically and emotionally to their altered selves.

The data illustrate how the final identity of ostomates is established. Ostomates who make the transition through the five stages interpret their experiences in a way which often provides them with the understanding to subsequently adjust to their altered status. However, not all of the groups of ostomates encounter these five stages, as some arrive at an ostomatic status through a series of events that are sudden or congenital in nature.

Age appears to be an important factor in the ability of ostomates to relate to their identity. Basically, the age groups can be separated into five distinct categories: 1) the congenital and youth, 2) adolescent, 3) early adulthood, 4) mature adulthood, 5) the aged. These five categories appear to orientate themselves as to their rehabilitative potential and unique concerns that appear to be relevant to their age categories in terms of the significance of their conditions in inhibiting their life chances.

Congenital ostomates and those seen in the youthful category demonstrate many of the same difficulties and concerns. Having acquired ostomatic status usually as a consequence of congenital problems and/or injuries, few, if any of this group have a distinct recollection of normalcy. These individuals often counter serious problems relating to acceptability. It has been found that those who become aware of their ostomatic status from an identity perspective during childhood, encounter much anxiety from the reaction of peers. Some of their difficulties are not alleviated because of the inability of parents to cope

with the social and psychological ramifications associated with being a young ostomate. The following interview was with a patient who has been an ostomate since childhood and has never known herself to be "normal". As Louise commented:

Having the diaper and not being normal was especially difficult when I was a child, I mean before I was an adolescent. Kids are extremely cruel. I don't remember how, but the word got out that I was still in diapers. I can't tell you what it was like ... I had a fear of children my own age, younger ones, and people who were not adults. They all made fun of me, they all laughed ... I had no friends. My mother and my aunt used to come to school every day at 11:00 a.m. and about 2:00 p.m. to change me before I was aged eleven and could do it by myself. There were horrible rumours circulating throughout the school as to what they really did to me. The most cruel, of course, was the fact that I had a penis. In other words, everybody thought that I was a freak.

After I started high school, I had more 'contacts' but never friends, as somehow I was always different. I know you are interested in what I do and what my problems are and I guess perhaps some of my problems relate to the fact, or stem from the fact that they're of my own doing, in other words, I am not an outgoing person, but am extremely shy and have chosen to live on my own. Perhaps it is because of my early experiences because things could have been otherwise. My parents never helped me. I was ashamed of what I was and my parents never even talked about my condition to me. Occasionally, from upstairs at night, I could hear them talking about me to other people and they would usually start out with the conversation by stating, 'Poor Louise'. (1)

The second interview was with an ostomate whose parents could not tolerate his ostomatic condition. This patient became an ostomate as a result of an accident when he was thirteen. He maintained:

I became an ostomate when I was thirteen years old as a result of having a piece of metal enter my abdomen when I fell down a ravine. My father couldn't tolerate me and never spoke to me about my condition. My mother had nothing to do with the situation either. I became, I guess you say, a freak, as far as they were concerned. I was in a position to manage the emptying of the bag myself. I talked to my friends of the accident and my condition, and they were very helpful, but I can never talk to my parents. (1)

The third patient interviewed had a tendency to withdraw and did not participate in childhood activities.

I do a lot of reading and am very familiar with what individuals do with the various stages of their life from a social point of view. My social life is pretty well being confined to being a fairly active member of a political group and to being active with the church. I have become in most areas, a social outcast. I am not certain whether it is the ostomy, my personality, or other people. During the time I was growing up, I did not have anybody my own age to play with, even my cousins thought I was a joke. Perhaps my parents didn't treat me the way they did intentionally. They were uneducated immigrants and, if you were familiar with their expectations, having a child such as I has proved to be almost intolerable in that I was unacceptable. (1)

The second group, those characterized as adolescents, encounter a series of additional difficulties. In addition to having experienced the difficulties often encountered as an ostomate in childhood, they are also plagued by the fears of not being accepted by members of the opposite sex as a consequence of the fact that they may be sexually damaged or at least be perceived as sexually incapacitated. Members of this category are concerned with the possibilities of dating, career selection, mate selection and social acceptability within "an adult framework".

The third category can be defined as young adults. These are individuals who are concerned and involved with difficulties associated with "family creation". Some ostomates in this category marry anybody who will accept them and consequently often appear to settle for individuals who would not be deemed suitable if they were "normal". One individual in the study married a man who was eighteen years older than she was and already had three children. Still other individuals in

this category refuse to settle for anybody and often remain single. Some decide that they are not going to be married in view of the fact that they believe that they themselves are unacceptable - at least in matters of sexuality. One nun briefly interviewed commented that if she had not had a urinary ostomy, she would never have donned the habit. Other individuals maintained that they had had opportunities to establish "serious romances" and perhaps even marital status, but for one reason or another, either they or their prospective mate could not accept the difficulties associated with being involved in an ostomatic-influenced sexual and/or marital relationship. For the four of those interviewed in this category, it was impossible to establish whether the difficulties encountered by individuals in their situation were results of the inabilities and difficulties that afflicted the ostomates concerned and/or the non-ostomatic partner in these relationships.

The fourth category are the mature adults who acquire their ostomatic status usually after their early thirties. The subjects interviewed in this category established marital status and families before the advent of their ostomatic conditions. Two of the three males and one of the females had parented offsprings after the onset of their condition. Patients in this category appear to be less concerned about sexual difficulties than those in the adolescent category. For two of the individuals, their sexual life was improved after submitting to surgery.

The final group of ostomates may be categorized as the aged. These individuals usually encounter few problems with regard to sexuality, as sexual activity is substantially decreased amongst individuals beyond the age of sixty-five. However, those in this group encounter many difficulties as a consequence of the advent of an ostomatic status in problems arising from difficulties associated with the physical management of their condition. The fact that physical dexterity amongst the elderly is often impaired, can be attributed to factors relating to the aging process and problems related to developing senility. Amongst this older group, one generally finds an increased concern related to the ability to keep clean but, unlike the other groups, they more often rely on others for the management of their condition. Two of the individuals interviewed in this category were widowers and chose to live alone because of the embarrassment encountered or anticipated by choosing to live with others.

People in these categories encounter a series of difficulties in arriving at their "identity structure" as a consequence of being subject to the consequences of being an ostomate, interpreted by most as being subject to a condition associated with spoiled identity. However, before embarking on a sequential analysis of the stages encountered by patients in their transition from the state of normalcy to ostomatic status, it is instructive to examine in detail the case of Mr. Q., as his experiences serve to illustrate the difficulties encountered by patients in their efforts to cope with the consequences of being an ostomate.

Mr. Q.'s case study was one of the most interesting. Except for one other patient in this study, Mr. Q. was the only individual who had considerable foreknowledge of a possible colostomy. His case history is indicative of the series of difficulties experienced by most ostomy patients, and hence a summary of his case is in order to illustrate the etiology of symptoms encountered by ostomates.

Mr. Q.

Mr. Q. had a history of familial polyposis. His mother died when he was twelve years old from rectal cancer and before death had a functioning colostomy. His only brother had also died of the same disease, but functioned with a colostomy during the last six months of his life. His eldest sister died of stomach cancer. Mr. Q. had definite recollections of the appliances his mother and brother had used, but he stressed that:

Many of my family have been very sick and have spent most of their time in hospital or at home. They were dying and orientation was not to learning to live with the appliance. (1)

His first symptoms were severe rectal bleeding at age twenty-five, and at this time a portion of Mr. Q's bowel and colon were partially removed but he still functioned as normal. He received his ileostomy in October, 1974, at the age of fifty-one. During the previous twenty-six years, he was kept under close surveillance and, "Every six months, I had to go to my doctor for a sigmoidscopy to check the size of both of my polyps". Frequently, they were snipped off and sent to the lab to check for malignancy. Mr. Q's children go

for a sigmoidscopy at the age of ten and then every three years. Recently his eldest son, age sixteen, went for the same type of surgery; although his case could not be investigated, the boy did not know that he was going to undergo surgery until the day he entered the hospital.

Mr. Q. claimed: "I always knew I would have an ileostomy, it was just a matter of when." During the summer of 1974, his physician said that he had no choice and the only recourse was to perform surgery.

Although I knew it was inevitable, I was still upset. It's not that I never knew it was coming, it's just a shock when you realize that it's really going to happen. I knew for twenty-six years, but you don't believe it until they give you a date. (1)

He was admitted to a Toronto hospital where he received a series of rectal examinations and enemas. "They measured me up and drew a diagram of my stomach where the stoma would be." He did not receive any pre-operative counselling. With regard to this, he commented, "The doctor told me I would have a bag on the side and he also mentioned that I may become impotent, that was all!"

On October 9, 1974, his rectum and bowel were removed and his anus closed. Mr. Q. complained that:

During the first two or three weeks I was in hospital, only two or three nurses knew the score and others openly admitted they knew nothing about the management of my appliance. Still others would come in once and would never come back. One got me so infuriated that I threw a glass of water at him and told him to get out of the room.(1)

On a Friday, the nurse informed him that there were no more ileostomy rings - someone had forgotten to order them. His bags then had to be held in place with surgical tape. Mr. Q. was very upset with this

because, "they knew that I was coming here for the past four months; couldn't they have arranged to have some on hand?" Over the weekend he was forced to put the tape-bag on alone and this was very unsatisfactory because the bag leaked continually and popped off whenever he moved. Naturally there was an odour "which was very upsetting and embarrassing to any of my visitors. My wife was especially upset as she knows I am a very clean person and I pride myself in this." He went on to say that "this error in the ordering of supplies was very damaging so soon after the operation."

Mr. Q's children were all told of his operation by both himself and his wife. His younger son first remarked, "Will Daddy have to wear diapers?" Later, he made the following joke, "Daddy has his own bag of tricks for Hallowe'en!"

Mr. Q's wife had so long to get used to the idea of a possible ileostomy that she fully accepted it. She said, "It's difficult to see someone have to go through this type of operation, but if you love your man, it does not make any difference."

Mr. Q's reactions to the operation could be called positive. His eldest daughter, a registered nurse, discussed the operation with him and his wife and also arranged for an ostomate to visit the family. Mr. Q. now regards himself in good health and "expects to live to a ripe old age."

This is just one of a number of cases studied for this research. Although the cases tend to report the same patterns of surgery, they differ considerably in their particulars. The descriptions encompass

a wide range and sequence of events, attitudes, thoughts and actions that characterize the unfolding of the crisis. Some . of the accounts given by the patients tended to be more or less dramatic, while others tended to be of a relatively undramatic nature.

What now follows is a sequential analysis of the stages encountered by ostomates in their transition from normalcy to the state of being an ostomate and their resulting patterns of adjustment to their altered physical beings.

THE MINOR SYMPTOMS PHASE

From the standpoint of the patient, and from the perspective of his peers, this initial stage is signified by a series of symptoms related to bowel or urinary difficulties. The symptoms are as follows: an abused stomach, headache, rapid heartbeat, nausea, diarrhea, fever, pain, gas, indigestion and blood in the stool. Other symptoms are gas distension in the stomach when the diaphragm exerts pressure on the heart. A digestive upset is sometimes confused with cardiovascular problems in many instances. If the cause of these symptoms is not removed, actual stomach distress can result, causing serious disease for which surgery may be the only answer.

These conditions occur relatively suddenly, but in most instances, appear to be a consequence of long-standing symptoms that have become more severe. Some patients, in order to relieve symptoms, resort to aspirins, 222's or 292's, along with other antidotes such as laxatives, enemas, tonics and, in one instance (in the case studies), to a faith healer. These persons usually wish to be confined to bed. They eventually call their family doctor and unfortunately, as with many pre-cancerous conditions, the symptoms may have been disregarded for so long that the disease (cancer) has progressed too far for surgical arrest.

My stomach was upset, I had diarrhea for days. I started taking aspirin and then thought perhaps my diarrhea continued because of the aspirin. I watched my diet, I cut down on fruits and other foods which I knew were not healthy. Still no relief came. Finally, after not having slept for two days and nights, my husband forced me to go to the G.P. (1)

I began to perspire and I had an upset stomach for three days. I thought it was a flu and stayed in bed, but nothing happened. I felt very weak and went back to school. Then I noticed my stool turned black. I became concerned and then I went to the health centre; they directed me to the specialist. (1)

A surgeon who was interviewed for this study commented:

I am sure I have seen twenty-five patients in the last three years who noted their symptoms early enough but failed to take adequate steps. When they come and it's too late, there is nothing that you can do. I realize that patients, in trying to be good patients, are put in an ambivalent situation. As we all know, health services are often overused and abused. In many instances, patients tend to dismiss minor symptoms in the belief that they will go away and are not major enough in terms of having to consult a doctor. Unfortunately, many patients who perceive these symptoms in this way, probably die because detection is delayed to the point where nothing can be done. (2)

Whatever the specific therapeutic path followed by individuals, their remedial measures, although appearing to be common sense, may retard, if not completely thwart, recovery.

At the first sign of symptoms, the majority of individuals did not realize or believe that they were ill - a very common reaction to illness and disease. Many of the patients had an excuse for their symptoms, e.g. "I ate the wrong food" or "I played too hard", "I've been working too hard. I need a holiday", "I need to relax". In several cases, the patient had previously been involved in some incident or mishap that accounted for his complaints: "I've had this difficulty for years." Other patients attributed their symptoms to an upset stomach or supposed hernia.

What one often finds in these situations is that the patient

becomes shocked with the realization that the characteristics that he or she had thought were minor, were in fact major symptoms of cancer. Their "definition of the situation" in Thomas's terminology, directs them to misperceive and consequently mistreat or ignore crucial symptoms.

Early ostomates, and those categorized as instantaneous ostomates as a consequence of the rapid onset of the difficulties, do not experience "early symptoms".

During the minor symptom stage, Mr. Evern commented:

I had had pain and all of the discomforts that we talked about earlier. We had already had three children and we did not want any more, but somehow as soon as I heard of the surgery, I felt that my wife would no longer want me.

For years, as a result of ulcerative colitis, we had not been able to participate in our former social life, which could be described as very active.

As soon as I realized that surgery was imminent, I became extremely depressed; I thought I would not be my own anymore. By this, I mean that I would not be a man. I could only think of the difficulties involved in 'being a man' and having to look after my stoma and the waste.

A month after surgery, I was living a normal life. I was not bothered by the pain. I had grown used to looking after my wastes and our life was socially more active than it was four years ago. (1)

Mr. Maddon commented:

There were really no early symptom signs that I was aware of that caused pain. After my stool had been black for four days, I went to see the doctor. (1)

Of those in the mature adult category (sixteen), eleven of them did not associate or were not aware of the fact that the conditions which they diagnosed as reaction to the flu, being 'out of sorts', were in actuality the first signs of the condition requiring ostomy surgery. Four individuals were aware of early signs in terms of the fact that ostomy status was a condition with which they were

familiar owing to the fact that it had befallen close friends or relatives. In these instances, those involved included Mr. Q., Mr. Howard and Mr. Freedson, who clearly recognized the symptoms. These patients were concerned about problems of acceptability and cleanliness, but by and large, as a consequence of foreknowledge, and being exposed to others with similar problems, they appeared to be capable of coping with the difficulties to be anticipated. The other twelve ostomates in the mature adult category were not aware of their impending fates, and did not associate the minor symptoms with any potentially serious conditions.

It is difficult to surmise the effect and extent of minor and major symptoms as far as the elderly or aged are concerned. Except for one elderly patient, the other three individuals dismissed minor symptoms as a consequence related to their advancing age.

Thus, as far as the early symptoms phase is concerned, only the sixteen mature adults, two of the early ostomates and one of those classified as belonging to the elderly group, recognized the symptoms as signs of impending ostomatic status.

THE MAJOR SYMPTOMS PHASE

This stage is analogous to Davis's warning stage and it sets the perspective for this second area of analysis. It is at this time that the individual begins to realize that the persistent cue of his symptoms warrants further investigation. The cues only now begin to be thought of as symptoms requiring medical attention.

I knew something was wrong. I lost fifteen pounds in less than two weeks. I had no energy to go to the gym. My stools were loose and they appeared black. (1)

Among the cases studied, a considerable variability of symptoms were experienced which caused the patient to visit his family physician.

I had lost a lot of weight; the doctor kept saying it was my nerves, but then I had diarrhea every day. I couldn't control it and I kept on losing weight until I was sent to the hospital for a full examination. (1)

Since none of the patients or their families were interviewed at the time of diagnosis, it was difficult to determine with certainty how much they knew prior to the diagnosis, and how much they had learned subsequently. The events, in many instances, became clouded or forgotten.

As is well known, many people, when afflicted by symptoms, tend to ignore them. Others seek medical advice at the first sign of any irregularity. Within society, there exists a number of orientations with regard to the utilization of medical facilities. On the one hand, there are groups of people who will readily use whatever medical facilities are available, while others maintain that facilities are overused and that one should not make use of them unless absolutely

necessary. In Great Britain and in Canada, government health programs provide for the financial security of patients. However, in the United States, there are no government sponsored health insurance plans, and as a result, many individuals disregard early symptoms because of the financial outlay required. Even though financial burdens from medical care do not exist in the former two countries, many citizens, for reasons previously described, fail to utilize existing facilities. Lack of early consultation in the case of some ostomates may have fatal consequences.

It is only on a conceptual basis that one may designate, as separate entities, minor and major symptoms. In other words, some may seek immediate medical attention at the earliest sign of difficulty while others will ignore the "syndrome" until major complications develop.

Ostomates who are categorized as congenital and/or presenting childhood disorders have no cause or do not remember their non-ostomatic status, as they do not recall with any clarity the difficulties associated with disorders leading up to surgery.

DIAGNOSIS LEADING UP TO SURGERY

The illness must be diagnosed and the cause of the condition determined in order to decide which operative procedure may be the most effective.

Usually, a general practitioner will refer the patient either to a gastroenterologist or to an internist, both of whom are specialists in digestive tract diagnosis and related symptoms. These specialists attempt to identify causes such as hereditary factors, the patient's habits over a long period of time, accidents, or early illnesses which may have contributed to the patient's condition. After completing the history and examining the patient, the specialist will decide on a schedule of diagnostic procedures which are often difficult and time consuming. Usually, the diagnosis results in a series of experiments or "educated guesses" as to what is wrong and, in fact, what prompts the need for ostomy surgery.

Early diagnosis may be difficult. Colon-rectum cancer strikes both males and females, and is only diagnosed through a most dreaded examination. "Embarrassment and fear of discomfort prevent many from submitting to proctoscopy" (Carbary, 1975:34). But the earlier this cancer can be detected, the less extensive and mutilating the surgery will be. A proctoscopy is routine, but the embarrassment and slight pain that one has to go through tend to make most people resistant to the idea of having a routine proctoscopic examination with their annual physical checkup. Yet, 75% of colonic cancers can be detected in this way (Carbary, 1975:34).

There is no question, however, that the fear of cancer of the rectum is prevalent because colon and rectal cancer are two of the most commonly diagnosed forms of malignant disease. If this is the diagnosis, surgery becomes compulsory and the operation results in at least a temporary but usually a permanent alternation in body waste evacuation.

Whatever the difficulties experienced by the patients, the consequences of the symptoms caused them to seek medical advice. Upon seeking advice, the diagnosis with the partial and/or complete disclosure to the patient of the extent and probable difficulties associated with becoming an ostomate serves to increase rather than alleviate their anxieties. The heightened anxiety stems from the consequence and fear of impending surgery and the fact that they will be required to participate, usually on a permanent basis, in the evacuation of their bodily wastes. These apprehensions cause some anxiety relating to their identity and acceptability by others.

Some patients refuse to accept the diagnosis and seek other medical opinions, while other patients accept the inevitable. In the cases where cancer is the precipitating factor in surgery, the patients readily accepted the diagnosis and treatment even though they experience much anxiety. For those who were diagnosed during adolescence, their major concerns centre on their acceptability, sexuality, attractiveness, marital potential and family establishment. As Miss Coning maintained:

I had my ileostomy when I was sixteen. At that time, I was completely shattered. I was a grade eleven student and I lost a year because of the time I was forced to miss during the school year. Missing school did not bother me so much as the fact that I lost my boyfriend, and in retrospect, I entered a shell. I changed schools. I not only changed schools but went from a public school into a private school. I was excused from all physical activity, that is, physical education, and never attended any social events. I am just coming out of my shell now. There were a number of problems as to why I went into my shell. It was a surgeon who told me what procedures would be followed. My parents were not even in the room during his explanation. This individual also told me that my condition would be temporary. Well, it's been temporary for the last eight years, in other words, it is permanent. He knew it was a permanent diagnosis at the time, but wanted to give me hope. From a psychological perspective, perhaps, in a doctor's interpretation, lying to patients is valid, and I must admit I can see that in giving a patient false hope, initially helps them to recover from surgery.

But, what of me now? I don't know what I will do. When I say I don't know what I will do, I mean I became a 'career woman' and I think my marital opportunities have been substantially diminished. I do not know whether I can have children or not. I have not had any sexual experience since I was fifteen. You must admit that people outfitted with a bag are not generally considered to be sexually attractive. I have avoided all these relationships, so I don't know. In any case, what this shows is that the way surgery is explained and its consequences, can have effects on the personality.

I was fairly active in school. I used to belong to a lot of organizations. I had a lot of friends, both male and female. Now, not even my parents are friends. (1)

Miss Coning's perspective is not representative of all ostomates who assume this status during the period of adolescence. As Miss Y maintained:

I had my ostomy when I was fifteen, and now I am twenty-nine and have five children. I have always managed to irrigate ... that was never much of a problem, and my husband always accepts me for what I am. I keep it sectionally clean and, to be quite honest, I think we have had an exceptionally active sexual life. I realize that the majority of ostomates probably experience much difficulty with regard to problems of a sexual nature, but if one is fortunate enough like I was to

have an understanding family and an understanding and sympathetic surgeon, I think this can do wonders as far as influencing those entering the world of the ostomy to adjust. I feel sorry for those who cannot enjoy a sexual life, but that has never been one of my problems. My only problem is that unfortunately, I cannot golf. The stretching when one swings always causes problems and that is unfortunate because members of my own family and my husband's family and my husband as well still spend a lot of time on the course. However, when it comes to swimming, running and other activities, I am as active as anybody else. The only time I had an accident in the last five years was when I was at a party and tried to do the limbo. (1)

Adolescent males experience the same type of difficulties, except that they have the advantage, at least in North American society, of being able to initiate relationships. According to Mr. Barny:

I had my surgery when I was ten years old. It was really unfortunate I became an ostomate as a result of having surgery for a wound that was caused when I fell on a spike. During the next four years I had a lot of difficulty. I hid from my friends, but when a fellow moved in next door whose nine-year-old daughter had been a wheel chair since birth, I began to realize that my situation wasn't so bad. I didn't start dating until I was nineteen and after the second or third date, if I felt anything towards the other individual, I explained my situation.

I started to explain my situation after a dating period some two years ago when I had taken out a girl four times and never made any 'advances'. She wanted to know if I was 'queer'.. Certainly, I do have problems, and I don't know if I will be able to have children, but my capacity to have an erection has not been impaired. (1)

Three females indicated that their dating opportunities were limited by their ostomatic status. One commented:

Those who have asked me out have never been aware of my condition. I did not tell my husband about my condition until we had been dating for two months. (1)

Hence, the data insinuate that single female ostomates experience more difficulties than their male counterparts as far as dating is concerned.

It is more difficult for females afflicted by this condition because, from a social perspective, they are expected to wait until they are "invited out".

Many of the difficulties encountered by ostomates emerge after the diagnosis stage, as many patients do not receive a clear, concise explanation of the difficulties encountered. There is debate as to whether or not patients should be aware of the full implications of surgery. In some jurisdictions like Ontario, Canada, it is legally required that a surgeon or any other medical personnel inform the patient of his exact predicament. It appears from the data collected that in spite of the legal dictum, seldom is this dictum obeyed. Only once in the last ten years has a surgeon been prosecuted for failing to comply.

Responses to diagnosis vary. Some patients refuse to believe the prescribed treatment and seek further medical consultation before undergoing surgery. As Mr. Benson stated:

I just could not believe the diagnosis. Perhaps it was just the conditions that were associated with the diagnosis that really concerned me. I was fully convinced that they had to be wrong about the procedures they had prescribed. I therefore went to two other doctors. The first doctor I encountered made exactly the same diagnosis within five minutes. I did not inform the second surgeon of the diagnosis that had been established by the previous two doctors, but after two examinations in his office, and a three hour one in the hospital, the diagnosis was the same. The only thing I lost was time and money. It is difficult to face up to surgery, especially this type of surgery. One usually views surgery as correcting faulty conditions, but in this particular situation, a faulty situation is remedied, but you are also placed in a faulty position as you cannot again re-establish normality. (1)

Twelve of the other sixteen mature adults and three of the elderly patients received consultation from more than one doctor. But as Mrs. Anderson stated:

I did not attempt to get any outside diagnosis. I knew my general practitioner and my surgeon had well established reputations. It is like death in a sort of way and other serious problems which one does not wish to face. It did not occur to me that the doctors were making a mistake. You know, mistakes always occur or often occur in inconsequential circumstances, but in expecting mistaken diagnosis for conditions such as those we have discussed, one is really not being realistic. Of course I understand that many individuals do not like being realistic in this situation. I guess it has to do with how one views life. (1)

Mrs. Nelson maintained:

The surgeon told me that I had nothing to worry about in the long run. He told me that initially I would experience much pain and I would have to become self-reliant in disposing of my own wastes, but this would be a temporary situation. It is a permanent situation and he probably knew about it all of the time but refused to tell me. It is hard being honest with oneself. Perhaps he honestly thought that my situation would be temporary but as I subsequently found out through the ostomy association, the majority of surgical procedures are permanent and perhaps he held the possibility of resection to me in order to raise my spirits which would inevitably help me through surgery. I have changed surgeons and doctors three times since. What I am looking for is honesty and perhaps just the type of family doctor treatment that one cannot encounter today. (1)

Nine of the mature adults maintained that they had been counselled by their physicians as to what to expect. Three maintained they were given what were probably false hopes or expectations by their physicians as to the possibility of resection and the remainder were not certain as to what information had been conveyed to them.

Mr. Simmons maintained:

When you are in a stressful situation like that, it is often difficult to recall what information was conveyed. Perhaps it

is like someone who has just seen a crime and is asked by the police to recall the characteristics of the criminal. One just cannot remember clearly in many instances and situations in which one was placed under stress. And you must remember the conditions which I faced were not instantaneous stress. It was instantaneous in the sense that I found out about my condition without having any prior knowledge as to what the conditions entailed, but I had to go on living with the knowledge and subsequently adjust to it. This becomes most difficult. It is more difficult and more excruciating than living with the knowledge that someone close to you is dying or indeed has died because sooner or later the pain of the loss goes away, but when you face the long term and sudden reality that you are going to be drastically different, it leaves you with a feeling of emptiness and you cannot just recall what other people, even surgeons, say. Have you ever been in a stressful situation and had the individuals attempting to counsel you, but somehow the information goes in one ear and out the other? That's what probably happened to me. These sorts of questions that you are raising somehow I have never really thought about. (1)

THE FEAR OF CANCER, SURGERY, AND THE PRE-OPERATIVE PERIOD

Attached to the diagnosis of bowel irregularities and ostomatic conditions is the fear of cancer and the anxieties faced over the prospect of an untimely death. In the public's eye, and therefore in the patient's mind, cancer and death are often synonymous. The prospect of, "Will I live? How will I contend with it?" is foremost in the patient's mind. The future of one's relationships with others causes one's loves, fears and guilt to come into focus.

In the mature adult category, nine of the sixteen patients were diagnosed as having malignant conditions necessitating surgery. At the time of surgery, seven of these individuals desired the surgery as it gave them hope of surviving cancer. According to patient Walmore:

What can one do when one has found out one has cancer? You always hear about it and somehow it always involves somebody else. My first concern and that of the doctor's as well was the fact that I had to have surgery immediately. I was diagnosed on a Wednesday morning and the following afternoon I had surgery. There was no question that something was wrong. I had been listless for a long time. I did not feel like doing my housework and in fact I did not feel like doing anything. I kept experiencing sharp pains in my lower pelvic region. I had had a kidney infection before, and this was a ramification of difficulties that some experience as a result of an infection acquired during intercourse. I had had this condition three or four times in five years and I really anticipated that the symptoms that I was experiencing was a result of the fact that I was experiencing a recurrence of the same difficulty. Unfortunately my interpretations of the symptoms were incorrect and after the condition persisted over a week and the pills did not work, I visited the doctor. He said I was fortunate because if I had waited another ten days or so, nothing could have been done. (1)

Mrs. Anderson commented:

I agreed with the doctor completely that I should have surgery right away. I don't know whether I was more concerned with

having the surgery or with becoming an ostomate. I really don't recall when you experience traumatic events like those in quick succession and when literally, your life is on the line; you opt for surgery right away. Believe it or not, I think I actually wanted the surgery. It is hard to clarify these thoughts because at the time I was literally panicstruck. I went home and I cried, but I did not have too long to cry because 24 hours later, I was an ostomate. I think the doctor told me what was entailed in becoming an ostomate. I really don't recall. In situations like that, I guess you just get mixed up. I really don't know because that was the first and only time that I was in a panic situation that really involved me personally to the effect that it was the first time that I thought about the reality of death. (1)

Mr. Howard commented:

My condition was really strange. I was experiencing difficulties relating to severe pain emitting from my bowel. They did what was to be an exploratory operation, but as soon as they sighted the malignancy, I became an ostomate. I guess I have always been a pessimist, and after they informed me that I might become an ostomate, I believed that this would be my fate, were you to experience my pain prior to surgery and if you attempt to be realistic. (1)

The fear of death generally convinces the patient to consent to surgery in spite of the fact that he will have to contend with the evacuative techniques that result. A woman maintained:

My doctor just told me that I needed to have an ileostomy done and there was no way out of it. I had to have it or I would die. I knew what that meant. I went kind of berserk and my first reaction was that I would not have anything like that done to me. I told my parents bluntly ... I was crying. I didn't tell anyone else. I guess that at the time, I simply refused to have the operation done and I tried to put it out of my mind.

It seems so long ago. I remember that the doctors claimed that the tests gave every indication of cancer. I was absolutely mortified! It wasn't the surgery that scared me, it was the prospect of death. I have never been a religious person and I kept asking why, why, why, ... why me? As soon as he mentioned the word cancer, I really felt I was dead.

Actually, I have gone through the experience twice, as I have gone through two operations: one, a mastectomy, and the other my colostomy. Perhaps they will carve me up until I die.

With the mastectomy, I was not worried about dying at all because I knew that I had detected it very early and I only had to have a partial mastectomy so that even my appearance would not be changed. The prospect of internal cancer ... that scared me because, as I said, I thought I would die. (1)

In some instances, the cancer may be too far advanced for surgery to do anything but possibly delay death. A surgeon who was interviewed commented:

What bothers me so much is the number of cancer deaths that I know I could have prevented had the patient recognized the early symptoms and sought professional help. These symptoms are usually minor and many patients refuse to seek medical help. One wonders why people refuse to seek medical help when in this country, it is almost usually free. (2)

It is not surprising that patients with provisional diagnosis of cancer enter the hospital with many fears. They are concerned with the prospect of surgery, with pain, with a changed body appearance and with being rejected. In addition, they fear that their disease may be inoperable or that it may re-occur even if surgery takes place. Two of the patients were reluctant to have surgery. Mrs. Benson commented:

I never had surgery. I was scared to death and somehow my first thought was that this was some reason I could not rationalize was God's will. I did not believe in surgery although I must hasten to add that I am not a Christian Scientist. I just sort of think that cancer is incurable. The people that I have known that have cancer had all died and I must admit that in retrospect, I gave up - at least mentally. I was conned. I think that is a fair way of putting it - by my husband, by my family doctor, by the surgeon and by a next door neighbour who happens to be a physiotherapist. They all said that I should undergo surgery. They did not make me believe in surgery, they just conned me into having it. (1)

Mrs. Lowen maintained:

Look, what can you do? Let's face it. I have had a long history of diseases and difficulties. I had had cancer once before and I thought it was spreading beyond control. As far as I was concerned, the only treatment I wanted was chemical or radiation therapy and even that is painful. As you can see, I have lost all my hair as a consequence of it anyway, but going through surgery again - that was too much. You ask me why? I recognize the signs, and I recognize the pain, and the doctors and the surgeons told me that I had no choice. Must be wonderful to die suddenly because when you are cut up like this, look at what they have done to my body. You become very depressed. The family is not a problem. My children and my husband accept me the way I am, but I am no longer a beautiful person. I think at least at one time I was. I am not trying to be vain, it's just that when these situations happen time after time after time, look what happens ... look at me. (1)

For cancer patients whose symptoms are of short duration, or who do not show any etiology of being ill, the cure may seem much worse than the complaint. Mrs. Terry expressed:

I came home from the doctor's crying. I had to have an operation. I would have done anything else, anything else, but I never had a choice. (1)

Since this woman has had the operation, she now confesses:

In retrospect, my feelings have somewhat changed. I am not depressed any more and I think it was the lesser of two evils. I only get depressed occasionally now. There was no time for counselling procedures at the time, and I had the operation on an emergency basis. The doctor told me I would live longer. No advice was given to me and I didn't know what I'd face when I went into the hospital and the difficulties in immediately recovering from the operation. My family was not asked to come in and talk about my situation and they didn't know anything. (1)

Most prospective ostomates express fears of: "What will happen to the relationship with my wife? My family?" "Will I be able to engage in sports?" "What will happen to me: I'll be a stinker!" "What will happen?" The more optimistic people maintain:

"Anything is better than dying of cancer!" "What's a bag!" (3)

Another participant commented:

... But we've been cleaning up barns all our lives, and cleaning up the house as well. Human waste is much easier to handle than animal waste. No problem!

Mrs. W. sobbed, "How could this be happening to me?" Her dreams of being a wife and a mother were being brutally crushed. This may be unrealistic, as most ostomates are able to bear children. Reactions like the latter indicate the prevalent cultural orientation in society towards the "body beautiful". Another woman, Mrs. Lymore, said: "They say I can hide it, but I'll have to wear baggy clothes. I won't be in shape unless I'm pregnant!" A nineteen-year-old male commented, "What am I going to do? Who's going to marry me? - I look like a freak!" (1)

Some people even go so far as to refuse to have surgery. One surgeon in the study exclaimed, "I've had four patients who refused to have the operation and as far as I know, within two years they were all dead." (2) A young ostomy victim expresses his fears in the following:

After I spent a week in UCLA Hospital, they decided that I needed surgery. I decided I didn't need surgery, so I left. Later on, I went to Orange County Medical Centre and checked in there ... I took all kinds of medicine, and at this point I decided I did need surgery. I would do anything that would help me because I was just fed up. I had accepted surgery for a long time until December 15. That's when I wanted to back out. I was so scared, I started to check out of the hospital that night. They notified security and security picked me up at the gate. I was kind of obvious ... that's when I barricaded my door. I was very scared. I didn't know what to expect. I had been told about the surgery by a member of the staff who came to see me. I always thought that ostomates were green people who were really wild... (Clark, 1968:)

Depression is a psychological reaction to all surgery and it tends to weaken the patient and make the entire procedure less attractive. Mr. Benson commented:

I met a patient in the hall who had had her colostomy two days before. Mine was scheduled in another three days. I was sick, I couldn't believe it - she smelled! I guess I was extremely upset too because I believe that males and females should be separated on the floor. I guess I was almost semi-hysterical before I was put to sleep. (1)

The advent of surgery presents further difficulties, as in other surgeries, tonsillectomy for example, the patient knows that he is going to be rid of a troublesome organ which is causing pain and difficulty and that after the operation he will experience normal life. This is not the case for ostomy patients. Mrs. Searce related the following:

I was in utter shock. I had never thought of a colostomy. I never knew anybody had these types of operations. I never thought that something like that could happen to anybody! I was shocked. I had to have an operation and it was my first operation, but I saw the x-ray and knew I had no choice. (1)

Blin and Perlman further illustrate this shock in the following:

For some, surgery represents a personal failure for either the patient or the physician or both. For some with bowel cancer, the surgery is an abrupt and shocking procedure required to save life. For most, it is a simple matter of life and death (1971:114).

Teenagers and young adults are generally concerned with problems of their future. They evolve anxieties related to dating, marriage and family life. Young females are particularly concerned with their capacity to bear offspring yet many female ostomates are able to bear children. Likewise, young males are concerned with the effect of surgery on potency. It is a fact that a complete colostomy or ileostomy includes parenal resection and the nerves are usually not

damaged as they are when the surgery is more encompassing as a colostomy for cancer of the rectum or a urinary ostomy in which the bladder is removed. Many ostomies do not render the male sexually impotent.

Seven participants believed that they had accurate foreknowledge concerning the consequences of the conditions that they would encounter after surgery. Thirteen of these patients complained they had very little prior understanding of the conditions that they would experience. Four subjects acquired their ostomatic conditions as a result of accidents which necessitated surgery and thus one would not expect them to be familiar with the consequences of ostomy surgery.

Data gathered from interviews with surgeons illustrate that some surgeons are reluctant to convey the full implications of surgery, especially to elderly patients, in the belief that these patients may be unable to cope with the immediate physical stress. Three surgeons maintained that they always conveyed the ramifications of surgery to their patients regardless of the age and physical condition of the individuals involved. As one surgeon commented:

It is always difficult to deal with older patients. No matter how precise you are in the descriptions of their conditions and the results of the surgery, they often confuse even the simplest matters. Therefore, you must realize that perhaps the majority of the patients who claim that they are not fully informed, probably were so informed, but their impressions of what may be happening to them force them to re-interpret much of the information they were given.

Admittedly, there are some surgeons who always convey to their patients the most positive future. For example, I know that some surgeons, even if there is only the faintest hope that resection can take place, will still inform their patient

that the ostomy is only temporary. I only hold out this slim possibility whenever it exists and, as you know, resection tends to be a firm possibility in probably less than twenty percent of these cases.

Our business is not public relations, but perhaps we should have been so trained, because in all honesty, whenever I deal with patients - be they ostomates, potential ostomates, or patients with some other condition requiring surgery - I find myself in a situation of not knowing the best way to convey the conditions which they may experience as a result of surgery, or as a result of non-treatment of a condition which I believe requires surgery. These difficulties are faced by most surgeons and all I can say is that it is unfortunate that in medical training, there are no programs that I am aware of which instruct medical students on the most efficient ways of conducting difficult face-to-face relations between themselves and patients. (2)

Twelve of the individuals claimed that they were not properly informed as to the consequences of ostomatic status, while the remaining twelve claimed to be informed. In examining the data, it appears that prior knowledge is not a factor in determining an individual's capacity to adjust. One must regard such findings with skepticism as most studies illustrate that patients who had prior knowledge of the reasons for surgery, and the consequences of surgery, were usually better able to cope with the ramifications of treatment.

One's definition of the situation becomes subject to ambivalence in view of the fact that some medical personnel, in the course of describing the required procedure, voice their personal concerns, skepticism and doubts regarding the consequences of surgery. Patients expect positive medical advice, even though such advice may occur in the "closed awareness" context, as many patients at least initially do not desire an awareness of the negative consequence of the procedures which they face (Glaser and Strauss, 1967:42). Many surgeons also believe (for a variety of reasons discussed in the next chapter)

that perhaps it is not always in the patient's best interest to be aware of the long-term consequences of surgery.

There is nothing so frightening as hearing a surgeon tell you that he has to perform an operation that he doesn't want to perform. When you are told that there is no way out, you just feel at a dead loss. I had a case of diverticulitis...(1)

A female cancer victim stated:

I have cancer; I want to live and it can be cured. I wish I could read some information. Have you ever gone to the library and tried to find out what a colostomy is? Have you ever tried to discuss it with your friends? Colostomies are like death - you can't get anyone to talk about it, and this time you really need them. (1)

In these situations, it is vital that the patient be given an opportunity to express his feelings. Another patient commented:

I had a number of examinations because I wasn't feeling well. The doctor came in and told me that I had cancer and that I had to have it removed and that would mean an operation on my abdomen. He said he was sorry, but that would be it. He would make the time and I would get a phone call when to report to the hospital. It was just the cold facts he told me. He said: 'You'll have an abdominal opening and you will have to use an appliance, your rectum will be closed up.' That was it!

I didn't get any counselling, but what was even worse was that it was never suggested that my wife be given any. I was treated as if I was alone, with nobody at all to sympathize with. It was very difficult for my wife; she could not get over it. Also, she felt that she was kind of left out of the whole thing. (1)

PSYCHOLOGICAL PREPARATION FOR SURGERY

Twenty-four of the patients, after having been informed of the need for ostomy surgery, encountered a wide variety of problems that stem from difficulties associated with disturbed eating and sleeping patterns, due to the presence of depression, pain and weakness which are common to patients about to undergo major surgery.

Twenty-four patients reported acute despair. It was during this time, and especially in the immediate postoperative period, that many contemplated suicide.

I thought that I had just begun to live. I had started my first year at the university. For the previous two or three years, I had felt uncomfortable. I was not sure what it was, but you know how things go, I just never reported it. In any case, I had to have a colostomy.

I remember lying awake at night in the hospital; I didn't know what to do. I cried, and males don't cry too often. I just broke down; I wanted to die. For someone who had never had sex, believing that I would never have sex, and in fact would be a freak, was just the situation at the time that I did not want to face. I thought that most of the beauty in life would be taken away from me. (1)

Prospective ostomy patients are therefore in need of acceptance, trust, and encouragement. One male patient who had his surgery seven years ago commented:

No one would talk to me about it. I mentioned it to my wife and I believe her first reaction was: 'How can we live with it? Do you think we will stay married?' (1)

What so often happens is that the cure itself tends to provoke crisis. In this instance it is interesting to note that the crisis can take place both before and after the surgery. Ostomates have to adjust physically, emotionally and socially to their altered

altered body state. This is not an easy task when they are given so little information, both prior to and following the operation. As one woman said:

When the surgeon came into my room, he just told me that I'd have to have the surgery. He did not tell me anything about my post-surgical experience. I realized before preliminary surgery that in all likelihood this would probably happen, but I still never had a chance to discuss and really find out what was involved in terms of the fact of how I would be affected after surgery. As a matter of fact, the immediate post-surgical phase was completely side-tracked. The discussion that I remembered was how I would have to look after myself later on and entailed an explanation of the difficulties I might encounter in irrigating. But, my hospital life, so to speak, was not discussed. (1)

Of the twenty-four patients who recalled their ostomy operations, only nine claimed to be aware of the full ramifications of their prescribed surgeries.

My urologist thought I should have an operation. They didn't explain it well to me compared to what I found out afterwards. They just told me that I will be urinating from my abdomen, but I had no idea that I would have a little red 'bud' sitting on top, and the appliances and all that.

I was bluntly told by a specialist that I had cancer, that it had to be removed and that I would have an opening in my abdomen. The doctor mentioned that I would have to have a bag on my side; I didn't know it would be there for the rest of my life. (1)

Severe difficulties initially tend to be encountered by those who become instantaneous ostomates. Those who become ostomates as a result of sudden injury, inevitably are unaware of the consequences befalling those subject to ostomy status. For some patients in this situation, the sudden shock of being severely injured, the possibility of imminent death and the pain encountered during the early

stages of post-surgical consciousness serve to almost nullify the fact that one has become an ostomate. According to Mr. Barren:

For the first five days, I was worried about living. I didn't want to go to sleep and my only sleep occurred after I was given an injection. I remember trying to breathe looking at other people in the room. To be honest with you, I don't even remember the pain. I know that I was in difficulty. The third person whom I saw was the minister, and I thought I was getting the last rights. I couldn't even talk. I didn't really know whether or not I was alive.

It was a fantastic situation to be in - in retrospect. I was in pain, I thought I was dying, and I couldn't even communicate. It was not until five days after the operation that I knew, or it was conveyed to me, that I was an ostomate. I didn't really care what I was, as long as I was living, and I was really worried. You think of so many things - your wife, family, obligations, but living becomes the most important thing and being an ostomate in that particular situation seems relatively insignificant. As you know, I was in the hospital for six months. And it's funny, I really don't recall the difficulties of my experience in first learning what was involved in being an ostomate. When I was informed much later on that the other four individuals in the car had died, my ostomy never presented a problem to me. (1)

For Mr. Benson, becoming an ostomate occurred as a result of an accident during surgery for another difficulty:

In my case, I became an ostomate as a result of a surgical mistake. They say it only happens to one in thousands, but what had happened after internal surgery, I experienced much pain and infection had set in. They opened me up again three days after my first operation, and the following day, all of a sudden I became an ostomate. That was a real shock because I had never heard of the word, let alone known the condition. My first reaction to this situation was one of non-belief. This just cannot happen. Surely they can fix you. This is another expectation of surgery. That is, when you have an ulcer, or an appendix, or any other difficulty, surgically it is treated and you are all right again. This was not the case for me. I harboured a lot of resentment after my experience. I managed to get a settlement of \$35,000 but that isn't much when you are in a situation like I am in. Of course, you go on living, but it creates a lot of difficult situations, socially especially. I try and disguise my condition as much as possible because people resent you when you are like this. (1)

Emotional trauma on learning of the intended surgery can be devastating. In the case of severe ulcerative colitis, for example, the general practitioner is often emotionally involved in what he considers his failure to cure the patient medically, and his negative thinking may be very obvious to the patient. One family gastrologist interviewed during this study said: "I never want to perform this operation: I will resort to anything short of surgery if at all possible." (2)

Only a few years ago, the decision to establish an ileostomy for the management of the inflammatory and neoplastic conditions of the colon was a most serious one for the physician and the surgeon to make, and it was one that produced great anxiety in the patient. It was commonly held that an ileostomy was merely the exchange of one disease for another, ulcerative colitis for ileostomy dysfunction, with prolonged periods of hospitalization and incapacity. (Beahrs, 1971:460).

Since 1970, ostomatic surgery has tended to become accepted procedure for the alleviating of difficulties relating to gastroenteriology. The surgery has become professionalized with the accumulation of personnel such as the surgeon, stoma therapist and other paramedical personnel, along with organizations such as the International Ostomy Association, which endeavour to counsel pre and postoperative patients in making satisfactory adjustment to the difficulties which the experience. (Beahrs, 1971)

POST SURGICAL PERIOD

Patients encounter a variety of anxieties related to surgery and its effects, the reaction of significant others, and the fact that it is often difficult, at least from the patient's perspective, to obtain a detailed explanation of the pending surgery and its consequences. During the immediate post-surgical stage, many patients experience the severe difficulties associated with being an ostomate, which include spillage, the uncontrolled emission of gas and the disturbing sounds associated with the condition. Their initial reactions range from revulsion to alienation and in some instances, contemplation of suicide. It is also during this stage that the majority of ostomates commence a renegotiation period in which they attempt to maintain and/or renegotiate their identity with self and significant others. There are a few ostomates, however, who do not pass through this difficult renegotiation period, as they maintain:

This is what I am and if people don't like it, it's not my problem, it's theirs. This operation enabled me to live and I will do anything to live, anytime, even compromising other people's standards. (1)

Most ostomates from the immediate post-surgical period onwards find themselves involved in renegotiating their identity as they find it difficult to maintain normalcy while being an ostomate.

Patient Responses and Reactions Following Surgery

The following is an account of an ostomy patient's reactions to her surgery.

The lights blurred as I opened my eyes. Completely dis-oriented, I slowly focused on my surroundings. Then the facts came flowing into my mind: ulcerative colitis, hospitalization, toxic megacolon, emergency surgery, ileostomy. Ileostomy! Surely this was a bad dream ... I lifted the covers and there was the bag on my side covering a large purple protuberance. It was true!

Depression settled in like a fog, separating me from the figures who came in and out of the room. I closed my eyes. Nurses came in to check my IV, nasogastric tube or perineal drainage and talked about me, thinking I could not hear them.

... Days and nights blended together. I was aware of my husband's presence and occasionally of my mother's, grateful to have loved ones with me. Still the fact of the mutilating surgery had to be faced. 'You are a nurse,' I was told, 'it will be easy for you.' I'm still a human being who is scared to death. I'm afraid my husband won't love me, my teenage children will reject me, and I'll smell bad and offend my friends - Help me!

... Your idea of a normal life is different from mine, I thought. I'll never wear tight clothes again, I'll have a restricted diet, and how will I manage the care? Everyone who comes in takes care of it differently ...

As the days went by, I lived through a myriad of complications. The perineal wound was unbelievably painful. The word 'sit' disappeared from my vocabulary. I tried to be civil, but was irritated by everything. I could not cough - the pain was too great. I hated the nurses who made me get up - I felt they had no idea of the supreme effort it cost me. When I had to wait for my light to be answered, I was sure it was because my stoma disgusted the nurses. My roommate called me 'Stinky'.

Once the ileostomy began to function, it functioned continuously ... The ileostomy drainage got on my skin which quickly became excoriated. Every time I moved in bed, the bag leaked. Flatus poured out freely, making so much noise, visitors could hear it even through the bed clothes. My life is over, I thought. I cannot live this way. I cried every night thinking no one would hear. (1)

These were the reactions of a young woman who had to have an ileostomy. Her background as a delivery room nurse had not prepared her for this turn of events in her life. She subsequently trained to become a stoma therapist so that she could help others through this difficult stage.

A fifty-year-old patient, married with four children, who prided himself on his physical prowess, was told before his operation

that he would be totally able to manage his colostomy. However, several days after the surgery, when the nurses reminded him that he must not be too upset by the emission of odour, he reacted with extreme despair and shock. He later commented: "If I had known about these odours coming out of that opening, I would have killed myself." He then threatened to do so, and psychiatric aid was immediately summoned. Consultation with his attending physician revealed that this man had suicidal depression in the past, but that this information had not been conveyed to the surgeon before the operation.

Relating her feelings in the immediate post-operative period, Miss Coning, an adolescent patient, commented:

I was surprised when I woke up with the pain. The pain was absolutely beyond description. I was not aware of the odours, difficulties or anything else. I just did not believe the pain. I believed I passed out, but in retrospect, I was probably given sedatives. I don't remember people around me for the first three or four days after surgery, and after that, my problems came from the fact that the nurses and orderlies were convinced of the fact that I had to walk around. They said I could not stay in bed any longer - and that was really painful. My first dreads were not of the changing of my appliances, but the fear of being pushed around and being forced to walk up and down the hall, even in my room. I was not really concerned about the state of being an ostomate until four or five days after surgery. (1)

The reactions of the mature adults to hospitalization were similar. None of the adolescent ostomates contemplated suicide immediately after surgery. Seven of the mature adults began to consider this alternative during their immediate post-surgical period.

According to Mrs. Framson:

I was all set to check out (commit suicide) when my friends from the cooperative came to see me. I was just so embarrassed

and so were they. You know, when you want to see people and talk to them and no one knows what to say - it's an incredible experience. I began to think that I was an animal, but one who shouldn't be on a farm - an animal who should be done away with. (1)

For the elderly patients, the consequences of surgery appeared to be even more severe. Like the other groups, they experienced much pain and tended to be upset by the fact that they could not talk of their conditions with anyone. According to Mr. K.:

When you are old and sick, you feel helpless, especially after surgery. You just don't know what to do. Sometimes I think I would have been better off dead, but I'm sure that will come shortly anyhow. (1)

Most patients (seventeen out of twenty-four) informed the researcher that they had no previous awareness as to the harsh difficulties they would face during the immediate post-surgical period. According to the wife of Mr. K., an elderly patient, he was kept on drugs for days and as a result has no recollection of the first nine days after surgery. Eighteen of the twenty-four patients maintained that they lost track of time and this, perhaps, indicates that they were heavily sedated. According to Mr. Jenkins:

When I woke up, I didn't experience any pain at all, or perhaps there was pain, I don't remember. Although I do remember the fact that the smell was incredible. My urine was spilling and there were no nurses around. The covers were soaked and it was just a very bad situation. I don't remember being cleaned up. My next level of awareness was meeting my family for the first time. There was a strange quietness. No one knew what to say. I expected a lot from them and they looked at me as if I was a stranger. (1)

The post-surgical experience is usually accompanied by two affective experiences. One of these has been called depression and tends to be overt and acute and the other is a general sense of physical and mental weakness experienced by all those who are subjected to this surgery.

Depression is a common experience among patients. Ostomy depression is triggered by the belief that the surgery has mutilated and abused one's body. The patient believes that he or she will be perceived differently by others.

The surgical creation of the stoma is usually permanent. The possible removal of cancer or painful symptoms of colitis and other infections and conditions is not in itself enough to remove the fear attached to the other ramifications of this surgery. Removal of the bowel, closure of the anus and the creation of an artificial stoma, as well as perhaps the fear of death, requires major internal psychological adaptation responses on the part of the patient and his family. There are also many sensitive physical adjustments that the patient must make - adjustments to the appliance, to the fitting, to the emptying of the sac of feces or urine with its embarrassing smells and sounds and changes in appearance. A doctor summarizes some of the common emotional upsets experienced by ostomy victims in the following quotation:

Some of the feelings most often encountered immediately post-operatively are expressed as embarrassment, disfigurement, deformity, helplessness, a reduced sense of value, disgust and revulsion. These are the terms that people sometimes use when they describe their feelings about themselves after ostomy surgery (Schuster, 1973:9).

Reaction to Stoma

The participants in this study displayed interesting and varied reactions to surgery. After most types of surgery, there is a general relief that it is over. One participant who had a colostomy and the apparent successful arrest of malignant cancer remarked:

After the operations my first thoughts were one of relief that it was over. Then I became very depressed, but that didn't last too long. I was relieved to have a chance at a normal life; I'd been in such pain and I knew I could make it. (1)

The most difficult situations appear to be encountered by patients who had no idea that they were going to have any ostomy operation. Fourteen of the thirty-five patients maintained that they had no idea what an ostomy entailed and subsequently, during their post-surgical period, suffered from shock.

I knew I was going to have it, but the reality of it was different. Somehow, in spite of the fact that you know - you just don't believe it!

Even those persons who displayed positive actions postoperatively tended to do so as a facade and were often depressed. There was never a particular reason for becoming depression, but rather a variety of causes.

The first sight of a stoma is invariably upsetting. No matter how well the patient is prepared, the actual sight comes as a surprise and a shock. Twenty of the participants interviewed described their initial reactions as unpleasant and uncomfortable.

I couldn't believe it after seeing it. It was just impossible; I was sick! I wanted to jump out of the window when I saw it!

I avoided looking at it for days because it made me feel sick. The smell added to it - it was just impossible. It was the most revolting thing I'd ever seen. (1)

There were only a few patients who actually accepted the stoma soon after surgery.

I was curious to see the stoma, but the first time I looked at it, I vomited. I looked at it again and re-examined it as soon as possible. The pain was terrible, but I made up my mind that I had to do it. By the end of the third day, I could look after myself completely. And what do you do - you live with it. (1)

One individual displayed her stoma during the interview. The surgery had been performed a week earlier, leaving a liver-coloured, finger-shaped organ about two inches long and one and one-half inches in diameter. One can only imagine the initial shock encountered by this patient and many others on first seeing the stoma but it is understandable that the first sight of the "created" organ produces a very frightening situation.

The relearning of bowel control after a colostomy is reminiscent of original toilet training. The patient goes through a stage of heightened body awareness. A period of trial and error leading to habitation takes place. All of this occurs in a setting where 'accidents' can lead to shame and fear of social rejection (Druss et al., 1969:425).

Of the individuals who were interviewed, twelve indicated a denial of any impact through the use of such negative statements or omissions as: "I can't remember," "I wasn't shocked or depressed, I don't think." In one case, the patient was actually forbidden to see her stoma and concerted efforts were made by the hospital personnel to prevent her from viewing it. But this secrecy only served to

increase and heighten her apprehension.

After surgery, things were really strange. The pain was gone, but I couldn't see it. They would not permit me to see it immediately after the operation. It was one week before I had a look at it. When the doctors would come, they would put up a screen in front of me. Doctors would come in and look at it and make light of it, yet all of the time I did not know what was going on! When I finally saw it, it was really a shock. Why they would not let me see it earlier and why they hid it from me like that, I do not understand - they certainly were not preparing me to adjust to it gradually. All the time I kept wondering what it would really look like. All this makes you feel even more incapacitated. (1)

In the postoperative period, it is a usual occurrence for an ostomy victim to encounter severe depression because the stoma is often regarded as "ugly, disgusting, smelly and unnatural". (3) Although pictures and diagrams are often given to the patient to show him the pattern and shape of his stoma, the actual visualization of it often leads to a sense of shock. Even the fact that one may have known for a long time that one would have to have an ostomy operation does not seem to prepare one any better for the sight and acceptance of the stoma.

I knew what it would look like. I knew what I would have to have. But you just cannot believe it when you see it. It looks like the tissue inside one's mouth. I got that description from a nurse who told me in advance that it would have that appearance. But none the less, to me it was like seeing a ghost, a ghost in myself. The difficulty is that I knew I would have a stoma, but I could not comprehend it until I actually saw it. Somehow you think it really can't happen. I really became upset with my surgeon. He told me my stoma was beautiful! Have a look at it if you want - nothing is beautiful about it! (1)

It seems, then, that the first reactions to the stoma are those of bewilderment, rage and shock, later accompanied by depression and shame. These reactions stem from the appearance of the stoma and

the realization that one must now have to depend on artificial appliances. In addition to these difficulties, patients must strive, if possible, to regain control over their bowel and bladder functions either through the process of irrigation or through proper physical management.

Consultation with doctors revealed that practically all patients go through a state of depression, even though for some the knowledge that they are free of cancer should act as a supportive factor. In Druss's study of thirty-six colectomy patients, he found that many of them experienced "depressions approaching the psychotic, being agitated, irrational and often suicidal" (1969:425). The same reactions were true for ileostomy patients, as Schuster reports:

...we have to recognize depression because 25% of ileostomates that we have interviewed indicated to us that they had at one time or other seriously considered suicide and the Lahey Clinic figures found that 2% of people who have had ileostomies for ulcerative colitis commit suicide (1973:10).

Most patients are greatly disturbed about how others will react to their ostomies. These fears tend to become exaggerated and out of proportion because of the patient's unnaturally heightened sensitivity to others.

One patient burst into tears when she thought a nurse grimaced at her colostomy during a dressing change. Another required psychiatric consultation because of a marked agitated depression (Druss et. al., 1969:422)

One volunteer was particularly candid in her discussion about her opinions regarding ostomy surgery and the stoma that resulted:

I've lost my anus, but I am living. I guess that's enough. But you know, how will I look to my husband? I do not look the same, look at my body! But you have to define this as mutilization don't you? (1)

One middle-aged woman interviewed who said it took her three years to adjust to her ostomy, remarked:

When I first saw the bag, my reaction was, 'look what you did to me!' There was no pain, it was gone, but look what they have left me with. My initial reaction was one of terror and disbelief. (1)

Value judgments and denial are inefficient as adaptive mechanisms. Postoperative despair is common and understandable, ego esteem is lost and the body image has changed. Overt anger is less frequent in women than in men, according to Lenneberg and Cohn (1972:542-579). Their research seem to indicate that the wrath becomes transformed into tearfulness; refusal to eat, a refusal to learn and other resistant behaviour. The patient must also face maintaining or re-establishing personal relationships. In most cases where the patient adjusts easily after surgery, it is due to the help and acceptance of a spouse or other family members.

One happy woman stated she was most reassured following surgery that her husband did not seem to mind her stoma and that 'he didn't care which end I went to the bathroom from!' (Druss et al., 1968:56).

The effect of personal relationships on the ostomate is far-reaching.

The more intimate the relationship, the more likely it is to impinge on touchy areas of individual personal vulnerabilities. The touchier the subject, the more sensitive the person! The more sensitive the person, the less likely is he or she to verbalize feelings; thus conflicts are buried, tensions built up and secondary maladaptive (defensive) attitudes emerge to interfere further with the return to healthy function (Dlin and Perlman, 1971:114).

Major Complications Following Ostomy Surgery

Major complications may be a direct result of any type of surgery. It very often requires further surgery for correction and therefore naturally impedes a person's rehabilitation. Some of the major complications following ostomy surgery are stenosis, heriation, prolapse, retraction, fistualization, perforation, bleeding and dermatitis, all of which are described in the Appendix to this work. The development of these complications has the effect of increasing patient anxiety regarding their ostomy condition and of making them even more apprehensive concerning the 'nature of their future'.

This investigation of patients with ostomies found various degrees of depression and anxiety commonly associated with the existence of the ostomy itself. The findings and observations indicated the presence of lowered self esteem, depression and a marked alteration in patients' self images. Some of the psychological adjustments that were observed were not only due to emotions surrounding the acceptance of the artificial intestinal stoma, but in the case of some men and women, to the acceptance of organically based impotence and loss of vitality which may accompany surgery. For these patients, while the psychopathological reactions may decrease over the years, there is little likelihood that they will ever feel as they once did.

Most ostomates did not seem to experience a feeling of personal well being. They feared spillage, inadequacy or undesirability, odour and embarrassment in social settings. In essence, their anxieties evolve because they fear coping with their spoiled identities.

POST HOSPITAL PHASE

Changes in Body Self Image

An understanding of how and why the perceptions of body self image can become drastically altered enables one to better comprehend the various negative and/or abnormal responses some patients make to their new body condition.

A major concept that we need to understand is body image because we are talking about the type of surgery that results in a change in the patient's body and in the patient's body image. The body image is the way we see ourselves; and the way we see ourselves determines to a very large degree our interactions with people, the type of image we display and the way people react to us (Schuster, 1973:7).

Childer defined body image as: "The picture of our own body which we form in our mind, that is to say, the way in which the body appears to ourselves" (1967:1050). This includes the patient's emotional investment in the various parts of his body as well. What happens when our body is suddenly changed?

... a sudden change in body image invariably arouses anxiety in the patient. Distortion of the customary body image is experienced as a distortion of self. Mourning for the loss of a part, similar to that of separation from significant persons, is expected after an amputation. This is aggravated by fear of rejection if the patient should become disfigured in the procedure (Kolb, 1959:74)

Twenty-seven patients expressed the opinion that they felt that their bodily form had been destructively altered. As one man bitterly said:

I was very upset, angry and depressed. I felt that I was not a whole normal man. My feelings haven't really changed. I try to keep happy by joking about it so as not to get too depressed.

My initial reactions were - I sort of wished I was dead. I felt useless, no good to myself or to anyone else. I needed time to adjust and this took a good year.

If you really want to know what I feel like - I feel like a guinea pig after this operation! (1)

This is a reflection of the modification in body and body concepts that follow after surgery. The participants differed in their estimates of the extent to which they felt the form and function of their bodies had been changed. This investigation focuses on the identification and description of the modification process initiated by this radical surgery. It will attempt to describe how the patients try to adjust to their changed body state and function.

One male patient, Mr. Evern, reacted as follows:

I realized that something would be eliminated and something added which was abnormal. After surgery, I didn't feel myself normal like other human beings. It was difficult to go to the washroom, and not to move your bowels like other people. Suddenly I had to get used to a new opening in the front of my body and to the situation that it comes from the front now.(1)

Mrs. Terry's reaction to the construction of the stoma was more extreme:

Whoever invented this operation must be a genius because it saves lives. I know some anatomy and it revolutionized the whole system.

But I often say, 'Why didn't I have a breast operation, both breasts off? Why this operation?' I used to feel proud of my body because I was so dainty. I had white skin and now when I look at my body, its so nasty. It's an ugly red and forever bleeding and my body used to be firm and white. (1)

Any discussion of revised body concepts following ostomy surgery must consider the patient's concept of the operation itself. The data

indicate that many patients were confused about the specific details of what had been done to their internal body structure and its physiological functioning.

Orbach and Tallent (1965:126-128) found that when the patient has undergone surgery with anticipations of spoiled identity, he almost invariably regards the stoma during the immediate post-operative period as evidence of an injury which has been inflicted. On a fantasy level, this was perceived as either a physical or a sexual assault, and in other cases, as a violation of body intactness. Still others who initially regarded the surgery as a life-saving procedure, nevertheless perceived more injury and pain than they had anticipated, due to the lack of satisfactory pre-operative information. These perceptions of assault and violation represent a symbolic extension of the actual mutilation which was performed on both the anus and the abdomen. The perineal wound and ostomy opening are such unmistakable mutilations that it is not irrational for patients to believe that the external body barriers have been ruptured and intactness destroyed. As the case studies illustrate and as Orbach and Tallent discovered:

One of the most significant findings is that the closing of the perineal wound and the decrease of bleeding from the colostomy opening did not materially reduce the sense of having been subjected to violation or assault. It was almost impossible to escape from the fact of a bodily mutilation and equally difficult to integrate the insult. Over a period of five to ten years, there were not many patients who could develop a conviction that their body's intactness had not really been seriously disrupted or its functioning had not been seriously compromised. They appeared to live with the opposite conviction as part of their daily experience (1965:127).

The idea that the amount of energy ordinarily available to a patient has been permanently reduced can often be traced to the removal of an organ regarded by the patient as the keystone of his bodily structure. According to Orbach and Tallent:

This need not involve mutilation or extensive surgery, but it is much more allied to beliefs about the organ's function and its role in relation to basic physiological processes (1965:127).

An illustration of this is provided by observations reported by Bieber and Brellich. They show that some women consider the retention of an intact uterus as the foundation of their energy and vitality.

Although no change in body form is visible following an hysterectomy, a drastic change in body concepts still can occur. Their components consist of the beliefs of having aged in appearance and having been stripped of their reservoir or source of their energy and vitality (Bieber and Brellich, 1959:236).

Similarities can be traced to patients who undergo ostomies. The changes in body concepts do not emanate from factors created by responses to altered body form and function introduced by surgery. They are, rather, secondary to other changes in body concept or functioning which have already become firmly established. For example, the perception that one's body is and has always been fragile and weak not only produces a variety of protective measures to maintain this established body concept, but also results in the reduction of many valued life activities. Thus, if sexual performance and physical exercise are sharply reduced after surgery because of beliefs about fragility and weakness, the body is regarded as more compromised and functionally inadequate because of the surgery.

A secondary change in body concept often occurs after ostomy surgery and is paralleled by pervasive alterations in self image. The reduction of functions and the relinquishment of social role require a revision in how the patient assesses his relationships.

Two of the individuals in the congenital and childhood categories, Miss Handon and Mr. Moon, curtailed their activities as they were often subject to ridicule by their contemporaries. According to Mr. Moon:

The kids laughed at me, rumours about the fact that I did not have any anus circulated freely amongst my classmates. They used to scream insults at me. I stopped playing with them. I didn't partake in any student activities but rather went home. My social life up until the time I was fifteen centered around my family. Although I experienced considerable difficulty from young children, at least with them you knew where you stand. As you grow up, adults become more discreet. They always find some subtle excuse why they can't get involved, but nonetheless, you are made to feel that you are different and certainly this affects practically everybody. This for certain affects myself because once you spend fifteen or twenty minutes with me, you know that there is something definitely wrong. (1)

One of the participants interviewed claimed that her relationship with people outside her family has changed radically. She is embarrassed by the noise of the gas and feels very insecure in any group, including the Ostomy Association. She withdrew from social activities as she reacts anxiously in these settings. Excessive perspiration and bowel gas are two symptoms of her anxiety. After the interview, this patient was re-admitted to the hospital with possible metastases, and her liver had an enlarged tumour. This only served to aggravate her worry about her colostomy and she said it made it more difficult for her to mix with anyone outside her family. She even finds these relationships difficult and cries frequently.

Initially, the activities of most ostomates are curtailed by the fact that they must have ready access to washroom facilities. The ostomate often feels an oppressive sense of being chained to the proximity of the washroom, and this seriously affects mobility and, indirectly, autonomy. In the social sphere, this loss of autonomy is often described as being a "prisoner of the washroom" - a symbolic re-enactment of a much earlier form of submission. Thus, being a prisoner of the bathroom introduces subtle revisions into body concepts. One of the more important perogatives accompanying the increasing maturity of an individual is greater freedom in going and travelling as far as one wants to go.

Compulsive concern of maintaining cleanliness was found among two of the mature adults, one of the sudden accident victims, and three of the four elderly patients. In the case of the elderly patients, not only was their concern about keeping clean, but about their expectation that "cleanliness assistance" would be given by others. The participants often complained that they no longer directed their own bodies but were run by them. This was the case for a 76-year-old ostomate whose social life had diminished since the surgery. In an interview with his wife, she complained that:

My husband has become compulsive; he is constantly emptying his bag and washes his hands countless times during the day. Quite often he asks me if he has an odour about him. I have never noticed anything. His life is unhappy, he doesn't know what to do. He never had any problems like this before; he was a normal man. (1)

In three instances, this assistance was necessary because of the reduced physical capacities. Sixteen of the mature adults required

no assistance whatever and, in fact, took whatever precautions necessary so that they would be able to look after themselves in private.

Making certain that one has ready access to washroom facilities results not only in social confrontation with imprisonment and submission, but also in a bodily concept of loss of control over mobility. No doubt the loss of a body organ through surgery can also have other consequences. These are summarized by Sutherland and Orbach in the following:

Any bodily organ, such as a rectal sphincter, a breast, a stomach or a leg, can play a vital role in the emotional development of the individual. Conflicts with parents can centre around the use of the organ, or it can be secondarily involved in the solution of other conflicts ... An organ can, therefore, play a basic role in the solution of childhood problems, and in the ability to relate to others. Whenever an organ which plays a basic role in the specific character defense is lost, that defense is disrupted and the individual is left with the basic problem once again unsolved. It returns the individual to the setting in which the problem arose and in which the character defense was first elaborated (1952:128).

Thus, the limbs and organs of the body become extremely important, especially when loss or disfigurement becomes a possibility. The organ, or segment of the body, often becomes a medium for the expression of an endless number of motivated aims.

The expression of defiance through the rectum in the act of defecation, and the search for power through the penis in the act of sexual intercourse, are two common examples (Sutherland and Orbach, 1952) 128)

An example of the utilization of an organ secondarily in the solution of other conflicts is provided by women whose sense of value and acceptability to others is enhanced by the appearance of breasts and legs. Within the western world, sexual attractiveness as a criterion

of value and acceptability employs as signs bodily parts which are ordinarily overtaken by clothing. Unlike the genital area, however, their appearance is not concealed but is frequently accentuated through the device of specially designed clothing worn to enhance physical attractiveness. It is permissible and, in fact, culturally sanctioned in North American society, for women to use their breasts and their legs for the purpose of sexually arousing men; as a consequence, great significance is attached to their firmness and shapeliness. These physical attributes are ordinarily of concern even to women who do not employ sexuality as a basis for relating to others. With the loss of a breast or a leg, an undesirable modification of body form takes place for most women, as well as an interference with bodily functions; the techniques which they serve are also disrupted. Once removed, these body parts can no longer function as cues to elicit or heighten desired male responses.

Thus, the various subtle perceptions one has about the appearance and function of one's bodily parts influence how one adapts and adjusts to the sudden loss or disfigurements. A loss or mutilation of body parts requires a major psychological adjustment - some people achieve this quite readily, while some people react negatively and take a long time to adjust.

Concern over physical fragility is expressed by all elderly patients and other patients who find themselves prone to "accidents", among those who were able to irrigate in the adolescent and mature

adult categories, there appeared to be little if any concern about possible stoma-related injuries. As one fifty-year-old adult stated:

I still play basketball three times a week to stay in condition. The doctor told me to work into it gradually, but I have never had any problems at all. Because of the fact that I can irrigate, the majority of my contacts probably are not even aware that I am an ostomate. I have taken several nasty falls, particularly as a result of being pushed on the floor by accident, but up to this point, I am not concerned at all. (1)

It appears that, for the older patient, when depression and weakness persist, there is an impairment of total activity - social, physical and psychological. One patient who was interviewed remarked: "I don't go out like I used to. We used to go out walking along the mall, but it is just too difficult now." (1) What often takes place for older patients is prolonged confinement and marked incapacitation. Two of the elderly patients in this study became more depressed after surgery and during convalescence. As is to be expected, the older person's depression continued much longer. Among the elderly, there is often the prospect that from this point on, life is all "downhill".

After my surgery, I did not have the freedom. I was injured in an automobile accident. I didn't have any idea what an ileostomy was. I can't walk yet; we don't get out as often. I mean, I walk in the house, but we could not go out in public. It's too difficult and I may have an accident. People don't come to see me. Somehow they believe that I am different; I guess I am. I do have some problems with odour, but my wife tells me she never smells it. Perhaps I am too sensitive, but who wants to get caught like that? (1)

One participant reported acute headaches and nausea, but these were the only severe, prolonged symptoms encountered by any of the participants. One middle-aged patient remarked:

It took me a long time to recover - you just feel so easily tired and weak. And then in your weakened state you have to do all the things - it's tough! (1)

Another middle-aged patient commented:

It saved my life. I have to cooperate with them. My daughter is a nurse. I know the problems, but you just can't let yourself go. It's nice to have a family like I have - I've had no problems. (1)

Some of the participants remained depressed. One young woman commented:

Although I no longer wear my 'diaper', what am I going to do later on? Do you think someone is going to marry me? I hate to admit it, but I've only been kissed three or four times. I'm afraid to get too close to an individual. I know that socially I have not developed. Hopefully, someone will come along who's understanding. But even if they do, I have a great deal of difficulty discussing my problems. After all, even my parents don't know. (1)

During the most severe period of depression (i.e. postoperative stage) twelve of the subjects interviewed admitted that they had contemplated suicide. Unfortunately, one of these individuals carried out his threat.

Most patients had a fear of a recurrence of their difficulties especially in cases involving cancer. This fear tended to be very inhibiting.

I was a little bit depressed after my first operation. The colostomy was not as shocking as having cancer again, the second time. I don't think about it much - cancer is scary! Every pain I have is associated with cancer. I'm afraid of dying, and every time I get a pain, I think it's cancer. From the first operation I felt so good to be alive and after the second operation I was relieved I was still alive. But now I wonder; I used to be concerned about just living. (1)

FACTORS TO BE CONSIDERED IN PATIENT ADJUSTMENT

When a patient is faced with a choice between life and death, sickness and health, an operation that tends to insult body integrity may be readily accepted. However, continued acceptance following the completion of surgery is a difficult and complicated process. The working through and accepting of one's new body status and changed body image, is a struggle for the majority of ostomy patients. The variety of adjustments that ostomates display are a reflection of the numerous factors playing an important role in influencing the ease and manner of adaptation.

There are a number of interrelated factors that affect the patient's ability to adjust. These factors include the type and duration of the condition which originally led to the ostomy, subsequent hospitalization and treatment, physical problems associated with ostomy management, sexual implications or surgery, age and sex of ostomates and subsequent effects on one's social and economical opportunities.

Type and Duration of Disease

Patients stricken with ulcerative colitis have usually been subject to a long history of this chronic and debilitating illness. It may involve as many as twenty bothersome visits to the washroom each day. The resulting stoma surgery and the relief of symptoms is seen by these patients as an appreciated benefit of surgery.

After surgery, I was up in nine days and went back to school about a month later. I was eighteen, a sophomore in college and I realized that for those five years of my life - a very important five years - I had been fooling myself into thinking that I was a normal, happy kid. But all this time, I was really pre-occupied with being sick and having to memorize where every bathroom was in that school, having to run there all the time, being so weak that I couldn't do things, having hemorrhages, and spending half of my life waiting in doctors' offices. All of a sudden all this was gone and I realized that I had a whole new life opened up for me. I could do things I could never do before ... I could do all kinds of things! (Vine, 1968:14).

Some patients who have an ileostomy feel that the surgery was preferable to living with the severe symptoms and pain of ulcerative colitis. The surgery is a relief, not a burden. This same pattern of acceptance was found by Druss et al. in their study of thirty-six ostomy patients.

They found that:

Manifestations of emotional problems were less evident than would be expected, due to freedom from the debility and diarrhea that had existed for many years. Half of the groups, however described problems with their ileostomy such as fear of 'accidents', odour, 'staining' or sexual difficulties (1969:419).

On the other hand, a person suffering from carcinoma, for example, is usually stricken quite suddenly and has not endured pain or discomfort during a long period of time, so he does not perceive his ostomy as an improvement. Suddenly, extreme changes have to be contemplated, an operation performed, and without previous history of sickness it becomes difficult to rationalize the value of the surgery.

It is interesting that 40% of patients who underwent ileostomy for ulcerative colitis reported relief when being told of plans for surgery. But a disturbing statistic is that 75% of patients who were unable to adjust to ileostomy had lived with their disease for less than four months prior to surgery.

Surgery came to them as a bit of a surprise. They were not convinced that the cure was better than the disease. In a sense, unfortunately, they had not suffered enough from their disease to recognize that they required this particular kind of surgery (Schuster, 1973:7).

The following is an example of how difficult it is for one who has been relatively healthy for most of her life, to accept colostomy:

Sixteen months ago, I was apparently healthy and leading a full, active and happy life. Within forty-eight hours I learned that I not only had rectal cancer, but that a colostomy would have to be performed. Two days later and without further explanation, the operation was over.

I had heard the term 'colostomy' only twice in my life, both times in the most unfavourable context possible. I awakened from the anesthetic in a state of physical agony and with an emotional attitude that alternated between despair and disbelief.

The disbelief gave way to stark reality the first time that my colostomy acted up and the despair increased. I awakened in the middle of the night to find myself lying in a pool of liquid stool that extended from my waist to my neck. I had not been given an appliance of any kind. The experience was certainly a traumatic one.

... by that time I had decided that I would simply have to accept the fact that life as I had known it was over. Obviously anyone living in this condition could never be able to manage a home, wear stylish clothes ... Without question, life as I had known it had ended in forty-eight hours time. 'Acceptance' seemed the only reasonable thing for which to pray (Fowler, 1971:45).

The timing of surgery is often an important factor influencing one's acceptance of an ostomy. If the surgery is performed for chronic ulcerative colitis, the patient has usually suffered long and severely enough so that he is willing to undergo a major operation for relief. If, however, the patient becomes the victim of carcinoma or fulminant ulcerative colitis, which are potentially lethal and rapidly progressive diseases, he has very little time to experience his affliction. His surgery is thus looked upon in much less favourable terms.

Subsequent Hospitalization

Complications associated with ostomies are not only connected with the actual surgery, but also with the period of adjustment which may range from one to a number of years after the operation. The first year is generally perceived as the most difficult period. Many patients require further hospitalization related to their ostomy. Returning to the hospital frequently for resections and other surgical corrections tends to cause emotional setbacks in one's recovery. A middle-aged woman, who was interviewed, expressed this despair:

I feel alone. I've felt alone for a long time. I think it's fairly obvious what has happened to me. I'm down from my normal weight of 128 pounds to 90 pounds. They didn't get all the cancer and they are going to try again. (1)

In the cases where a colectomy is performed, it is often required that the patient have two or three additional operations for collective surgery, such as stoma revision, relief of obstruction and prolapse. Another middle-aged patient interviewed expressed her surprise at having to return to hospital:

I had to re-enter the hospital and this was not explained to me. I thought once I had the operation, all of my difficulties would be over. But now, I understand that this is normal. But why didn't they tell me in advance? I found out that it was normal afterwards because I talked my situation over with somebody in the ostomy group. (1)

Initial and subsequent hospitalization usually serve to maintain and increase the anxieties experienced by patients. The first hospital experience is one in which the patient encounters

surgery and post-surgical care accompanied by the physical and socio-psychological pain that is associated with becoming an ostomate and its subsequent effects on the identity of the individual. Further hospital care often increases the patient's fear because of the possibilities of further complications like the spread of cancer. It is only in the case where resection is possible and the patient is thus only a temporary ostomate that the second hospital visit is seen in positive terms.

Ostomy Management and Related Physical Problems

It is imperative for the ostomate to learn to cope with several physical difficulties that can arise without warning. These include spillage, accidents, malodorous and noisy emission of gas from the stoma, problems with diet and the difficulty and time it takes in learning the efficient management of one's stoma.

Of those who participated in this study, the four belonging to the aged category and eleven of the mature adults believed that their conditions were problems if not actual handicaps. Seven of the adolescents and the remaining mature adults categorized their conditions as only presenting minor difficulties now. Thirteen of the subjects encountered problems with their skin surrounding the stoma; eighteen mentioned fears concern the possibility of producing unpleasant odours in public places. All of the female subjects indicated that it was necessary to make special adjustments regarding clothing. None of the subjects described occasional accidents that occurred and their ensuing

embarrassment. One patient complained:

I wish I could irrigate. If I could irrigate, I could control my situation. I can't yet. I've spent so much time trying! Every time I go out, I live in terror that I may have a spill. (1)

Irrigation is an important measure that requires time and patience to learn, but it also gives the ostomy patient a greater degree of control over his body functions. Irrigation lessens, if not totally eliminates, the possibility of spillage. Some ostomates are unable to irrigate due to their particular physical condition. With regard to limiting social activity, Druss et al. found in their study that:

There was a definite deterioration in social relationships in 72% of the group. The most common cause cited was fear of producing odour. One patient described how he always stayed near a window for good air circulation and was careful to keep away from women. Others mentioned continuing restrictions in their social activities related to fears of leaving the safety and protection of the home. Many described feelings of weakness, fragility and inferiority. One patient explained how he had learned to master his anxieties when away from home by carrying his colostomy equipment in a small doctor's bag and leaving a duplicate kit in his car. Knowing he was prepared for an emergency situation mitigated his feelings of concern.

One-half of the patients felt that the colostomy had changed their life chiefly in terms of travel restrictions and in terms of the long time required for the irrigation and care of the colostomy itself (1968:423-424).

The Sutherland study (1952:857-872) noted the presence of depression during spillage. The depression at times reached the point of suicide contemplation. There were feelings of shame and degradation when control was in jeopardy. These researchers also noted that irrigation was an important means of re-establishing bowel control.

They suggested that:

The symbolic meaning of irrigation lies in the attempt to re-establish by an external procedure the destroyed inner mastery over bowel functions (1952:867).

E. A. Katon (1967:534-541), in her paper, "Learning Colostomy Control", addresses the problem of educating colostomy patients after surgery. She suggests that the ostomate must develop a totally new set of habits which is best begun while he is still in hospital. This involves learning to control his ostomy so that it will not control him, by draining his energies and dominating his personal, social and economic life. According to Katon, the best way to achieve this is through irrigation as this measure has the effect of freeing the patient from the anxiety of possible spillage. If this control is learned, the patient can become an adult in terms of his own self definition by once again being in control of his own body.

Surgeons regard irrigation as an important means whereby the patient can manage the loss of a rectum. Patients, however, regard this loss in a different light. In North American society, childhood control is so fundamental that the removal of the rectum usually results in severe emotional and social disruption. Therefore, when a patient is able to irrigate, he attempts to readily do so because the emotional significance of being able to irrigate has positive psychological manifestations. Those patients with colostomies who can irrigate express the keen desire to do so because they become 'almost human again'. As one individual commented:

I am lucky, at least luckier than those who had an ileostomy, because after a period of time ... approximately five months, I was able to (although this sounds funny) toilet train myself again! In other words I learned from the doctors and friends

of the Ostomy Association who prodded me to control my defecation. Once I did this, I realized that I had relative freedom.

Three individuals from the Ostomy Association spent a lot of time with me and I learned, although I had many accidents. The learning takes a long time and to irrigate usually takes me three hours a day. (1)

Only those who have colostomies (and generally only transverse or sigmoid colostomies) are able to irrigate. The irrigation process is difficult to learn. Techniques of irrigation differ in terms of how much water to use and whether other substances like a mild soap or small amounts of potassium permanganate should be added. The amount of water used varies from patient to patient from as little as two quarts to more than a few gallons. Four patients who were interviewed could directly connect the tap water to the catheter in order to "push out" or "flood out" the fecal matter. The time required for this function ranges from less than an hour to as many as three hours. Some people irrigate daily while others irrigate every two days; one patient irrigated only every three days and it took him less than an hour. Most patients attempt to achieve regularity through the use of irrigation. One of the subjects claimed that he did it only when he felt like it or when he had the time.

For those who must spend three hours irrigating, this is a time-consuming effort and it means setting aside twenty-one hours a week. Two of the patients in the Sutherland et al. study (1952:857-872) were classified by the researchers as "irrigation addicts" as they had to spend as long as twenty-four to fifty-six hours a week. The authors

suggested that these 'over-irrigators' may tend to think of spillage as evidence of incomplete irrigation and so they rigorously re-irrigate as soon as possible.

Most ostomates irrigate at the beginning of the day. Others irrigate at a certain appointed time and one insurance executive claimed:

I irrigate before business meetings and at least once before I come to work, once at noon and once at 3:30 p.m. - just to make sure! You can't be too safe. (1)

When most of the subjects talked about irrigation, they demonstrated some degree of anxiety or apprehensiveness. One woman anxiously explained:

It's a very difficult thing, but it's something you must do. You must avoid spillage. The smell is impossible! I want to be accepted by my friends. What choice do I have? (1)

Another individual described his opinion about irrigation:

Irrigating is a very difficult thing to do, especially if you are at work. I find that if I can go into the washroom when everybody is on coffee break, or out to lunch, it is much easier. I used to spill a lot and I used to have nausea as well as vomiting, sweating, perspiration and fatigue. I think these are past now. You get used to it. I don't notice it at all now but for the first six months it was pretty rough. You have to make sure what you are doing because if you spill the waste on your skin you get irritation and then you can really have problems. (1)

Two of the nine persons in the study who were able to irrigate still used potassium permanganate in spite of the fact that two of the surgeons consulted claimed that this was no longer useful. The two patients still using this had had their colostomies fifteen and eleven years ago respectively.

Some ostomates eat immediately after irrigation while others believe that one should not eat in order to rest the stomach. Most patients were told by their doctors to do what they felt most comfortable doing. Some liked to go out for a brisk walk while others preferred to sit for a while. One woman's opinion was that:

I think one should do whatever one feels best doing. We discussed this at a meeting one time and so many people were doing so many different things, that I just think that it is what makes you feel good - that is the best way. (1)

Successful irrigation leads ostomates to be able to resume work and maintain social relations without the same degree of anxiety faced by those who are unable to irrigate. For those who irrigate, the symbolic significance of the process is important.

Some patients noted the distaste and inconvenience of having to empty the bag at specific times and places, and the wish to avoid public washrooms. One subject complained:

I have to know where I am every day. What happens if I'm caught out somewhere? I can't go on trips up north any more. I went once with a group of friends to Muskoka and we had to stop on the highway four times! I have not had to go that many times since my operation and I think the difficulty was partly psychological. In any case, I feel much better when I am at home and have access to the washroom. (1)

Seven of the men and two of the women maintained that they were very careful about straining themselves, especially in sports like golf, swimming and running. Although the majority of the participants kept their previous athletic leisure time pursuits, they found they had to make minor changes.

I gave up diving in a pool, but we go to the river occasionally and I still enjoy it. Occasionally, I do have an accident but in the river - so what! I do try though to swim away from my friends. (1)

One of the male participants remarked that he had to give up his membership in an athletic club as his friends "gave him a bad time."

Many ostomates live in constant fear of spilling. Spillage occurs most frequently among individuals who are recent ostomates and it is usually this fear that influences some ostomates to avoid most social events.

Certainly I go to church and occasionally I go to a hockey game, although I don't do that (i.e. play hockey) any more. But if I go to church, I go an hour ahead of time and I am the last one out of the church. I don't want to bump against anybody just in case. I had an accident once and it was terrible! (1)

Another individual expressed her concern about spillage:

I only have spillage about once every six weeks. Something happens you know, you forget about it. Things are going well and then you just get that bump or perhaps you don't put things back together correctly. (1)

It appears that fear of spillage becomes so paramount for some ostomates that Sutherland et al. (1952:857-872) consider it a major factor in inducing some persons to commit suicide. It is this ever-present threat of spillage that leads an ostomate to restrict social, work and leisure activities. This often leads to patterns of hermit-like existence. Any abdominal disturbance forces the individual to retreat from his current activity to use the closest washroom, preferably in the privacy of the one in his own home. One man describes what an embarrassing experience having an accident in a public place can be:

Once I was forced into a public washroom because I was a long way from home. I had to empty the bag, and it smelled. I had to clean myself up. The people took one look at me and immediately left. One nine-year-old boy and his friends came in to look. You cannot imagine how I felt! Perhaps the kids are the cruelest - I guess because they say what they think without really thinking about how it affects others. (1)

For most ostomates, even though spillage appears to be a relatively infrequent experience, it continues to be an ever-present threat and serves to restrict or inhibit activity. The degree to which it does so depends on the individual, as evidenced by the following comment made by a participant in this study:

I still bowl, but I don't take a run up to the line any more. I stand straight and just throw the ball gently. Believe it or not, my score is about the same! (1)

In addition to this fear, there is the realization that one may soil one's clothing or bedsheets unintentionally. This violates the social code of cleanliness and may lead to loss of acceptance and esteem from one's spouse, family, friends or work associates. This constant anxiety is illustrated by the following quote from a patient who almost gave up hope of learning to control himself. "What can I do now? I am an untrained animal, and a sick one! The stench is incredible!" (1) One man explained:

It's not like someone who has broken an arm or lost a leg - people look at you as if you are different. If you have a broken arm or leg and are trying to do your best, they usually will even help you. But when you are stinking in public everybody avoids you. They not only avoid you then, but they avoid you completely afterwards. (1)

Most ostomates tend to be extremely conscientious about how other people view them and feel towards them. One person stated:

I've never had spillage, but the gas escapes and that does me just as much harm. Therefore, I have to avoid others. What can I do? If I don't avoid them, they avoid me.

I am a businessman and I have had to change the way I do things over the years. I used to visit people all the time but it is possible to conduct most of your business over the phone when you have to. (1)

Many ostomates have serious reservations about how they are perceived in public. A woman expressed her reasons for withdrawing:

Well, it's not a serious problem except when you eat the wrong things or drink the wrong water. If you get diarrhea for instance you can be spilling all the time. That is the time when you just go home and forget that other people exist. (1)

Some ostomates who can irrigate find that they do not have to wear an appliance at all times:

I go out in public and even when I go to the gym I just wear a piece of tape over my stoma. No one has ever remarked on it and I don't think they even know. (1)

The fear of having an accident becomes pronounced after it has actually happened. Spillage is associated with lowered self-esteem, feelings of inferiority and self-degradation. If these feelings are allowed to continue and if the important individuals around the ostomate do not relate to him in a positive way when this occurs, then the ramifications of spillage can be disturbingly negative.

It has been discovered that the majority of ostomy patients identify certain foods which they feel they should not eat, as these tend to produce diarrhea or an excess of gas. However, this research found that there was no agreement among the participants as to which foods to eat and which to avoid. Some of those interviewed made absolutely no dietary restrictions, whereas others tried to avoid certain types of vegetables and wines as well as soft drinks. The following is a description of one patient's views about dieting and a colostomy:

I have restricted my diet a lot. I find that I eat all that is necessary, but I used to enjoy eating. But eating

has become a science to me now. I guess it is related to my colostomy but I have been reading what you would call this health food literature. I realize that most individuals feel that it is a quack but now I don't eat for fun - I eat for business. I know exactly what vitamin content it is, what caloric content I am supposed to have. I have restricted my intake of meats substantially, cut down on cholesterol - that certainly will benefit my heart and I think I am better off.

I think people who go out for dinner at fancy restaurants and spend fortunes on food are absolutely ridiculous! It's surprising how much money I save eating now. I'm not trying to save money but I just know what is good for me. Not only the type of food, but the method of preparation and amount as well. (1)

This attitude represents one of thirty-five different opinions expressed by those who participated in this study. Even in the literature, there is little agreement on diet. Most physicians and surgeons maintain that going on a health food fad is certainly not necessary.

Twenty-two subjects admitted that within the first six months after surgery their ostomies caused them to alter their socializing patterns. Five individuals who were past the age of fifty believed that their lives were now more home-centred, and two of them could almost be classified as "recluses".

Nineteen participants were concerned about vacations and public gatherings. Fourteen tried to plan adequately and attempted to attend and participate, but eight avoided both completely. One individual explained:

I go to movies and dances, but I don't go to banquets. I guess I could but I had an accident once. There were only three people around me, but you can understand. I watch what I eat anyway so I avoid these affairs. (1)

Another patient was less fearful at social events because of the support he received from his wife:

Because my wife is so strong, I go to everything I was going to before. I am somewhat apprehensive but we both take good care of it. She watches me like a hawk so there is no problem. But I must say, I have the anxiety all the time. It's funny, I have the anxiety but I have never had an accident, but I know it could happen. I have never had an accident in that I have spilled - it's just the escaping gas that embarrasses me. (1)

The most common reasons given for a change in socializing patterns are the fear of escaping gas, actual spillage, feelings of unacceptability and the length of time required for irrigation. In addition, there is the fear expressed by another patient that his most significant problem was "not the smell or the gas, nor the threat of spillage, but the loud noise of the escaping gas." (1) Older individuals are more likely to be reclusive. The increasing openness in society allows younger persons to be able to discuss their problems more readily with friends and family whereas older persons believe that such things as ostomies must remain in the realm of the "private".

Sexual Implications of Surgery

Sexual adjustment to an ostomy usually requires a major adaptation as the sexual sphere tends to be the most sensitive. It is in the area of sexuality that the most negative type of adjustment occurs. The "misplaced anus" seems to go against every idea of sociability and intimacy in North American society. Many patients are under the

impression that their sexual lives will be finished. This concern over the curtailment of sexual activity is one of the most difficult psychological, emotional and physiological barriers faced by ostomates, especially those under the age of fifty.

The male's concern is with the ability to "perform" while the female's concern revolves around maintaining "desirability".

After surgery, a woman commented:

I have had no marital relations since my surgery. I am a repulsive object since surgery so my husband and I live as a man and wife in such matters as support, otherwise my marriage ended with surgery. (1)

Another woman stated:

My husband and I have separate rooms. We just don't ask or talk about it any more. We had a fairly active sex life before. I don't know whether he has sex outside our marriage now or not - I really don't care. We don't get along that well, but that's life. (1)

A twenty-nine-year-old mother of three commented:

I had my ostomy when I was sixteen and I have had three children since. If you're really in love then it doesn't make any difference. I never knew sex without my colostomy! It never made any difference to my husband. (1)

A fifty-year-old male pointed out:

I wondered in the beginning whether I would have any sexual problems and how my wife would take it. I soon found out that there were no problems whatsoever. I can't really say that the operation has interfered in any way with my life. I do more or less what I have always done. (1)

There are individuals whose sexuality is actually improved by an ostomy operation. One of the men who was interviewed claimed that his social and sex lives were much better since his surgery. Prior to the operation, he and his wife could not do much visiting

or socializing because of his incontinence. He could not control his bowels during intercourse and thus his sex life became limited. However, now that he has had ostomy surgery, he finds himself able to perform his "family duties" better than before. He maintains that the operation was the highlight of his life and the first night home from the hospital he made his wife pregnant!

A Toronto surgeon who was consulted maintained that he can lessen the risk of impotency in males by leaving a rectal stump in place. This is permitted when the rectum is not diseased. However, when this procedure is followed, it is necessary to maintain close surveillance on the patient to make certain that colitis does not spread or that there is no pre-malignant lesion. This surgeon explained:

This is a possibility which, as you appreciate, has to be practiced when you are dealing with young individuals, although personally, I do not favour it because I am of the opinion that the potential for malignancy is raised.

Somehow, you feel uncomfortable when you don't do a complete job. But when you are subject to an interesting dilemma - should you as a surgeon only be concerned with remedying the physiological problems, or should a surgeon also be concerned with the social ramifications of surgery? (2)

This problem becomes more difficult when one realizes that in some cases the solution of the latter may lead to renewed malignancy. V. Dericks summarizes the female's point of view:

For females, intercourse may be painful while the perineal wound is healing. But most can eventually return to a satisfying sex life. One exception, however, is the woman with resection of the vaginal wall and other organs who may continue to find intercourse painful, difficult, or impossible. Often such problems can be alleviated by vaginal reconstruction or dilation. Most female ostomates also can carry full term babies, provided that they receive careful medical supervision to avert urinary and intestinal complications (Dericks, 1974:54).

One woman participant revealed that she could not have sexual intercourse because of the pain and she would not enlarge on this any further. Understandably, the majority of the participants were reluctant to respond to questions relating to matters of sexuality.

It appears that the majority of ostomates are physically capable of sexual relations; however there are numerous psychological barriers to be overcome. Dericks advises that:

... nearly all need reassurance and psychological support. How the stoma appears to their spouses, the time and frequency of the discharges, the appearance of the appliance, possible injury to the stoma during intercourse - all are fears that create psychological blocks not only to sexual relations but to everyday relationships (1974:54).

In this area of readjustment, counselling can render a distinct service to the patient. Unfortunately, except for hospitals such as those in New York where Dericks did her research, the majority of hospitals leave patients on their own in this matter. Of the patients interviewed, twenty-six of thirty-five had received no counselling in the sexual area.

A patient's concern with sexuality is often thwarted by the fact that many medical and paramedical personnel are reluctant to discuss the subject. A patient who had her colostomy seventeen years ago reported:

My first thoughts were that I would never have a baby. I have had two since, by Caesarean birth.

I felt frustrated when they told me about it. I remember exactly what the doctor said. He said he didn't know how or what to tell me, that he could never be in my shoes. This made me feel much more frustrated. He wouldn't talk about it either.

If anyone came in they would try and steer the discussion away from what was going to take place. This made it much

more difficult. Because I did not have children at the time I was extremely afraid as to whether or not I could have a satisfactory relationship and have children. (1)

Most patients are reluctant to discuss the implications of sexuality in terms of their own lives.

Sexual adjustment after this type of surgery is rarely discussed openly. The average person remains uninformed, fearful and the victim of various myths, such as the loss of male potency (Dericks, 1974:54).

The loss of potency is viewed primarily as a concern of the young. Yet in Dlin's study of ostomy patients over the age of fifty, he found that most males in his group over the age of sixty expressed fears of impotency which were further reinforced by the guarded attitudes of their doctors.

The doctor gave me an explanation of the chances of becoming impotent. He said there would be a possible chance of losing my erection, but this was a chance I had to take. He said, 'You're getting to old to worry about sex. At this age, why should one be concerned about sexual performance? Isn't it good enough to just be alive?' (Dlin et al., 1971:114).

An older gentleman interviewed for this study reported:

I don't think that the operation has interfered with my life patterns, except for my sex life which since the operation has ceased completely. The doctors and booklets all say the operation has nothing to do with sex and everybody I've mentioned it to claims that a 67-year-old man shouldn't have a sex life anyway. Believe me, it's depressing! (1)

Geiger stresses the importance of adequate counselling:

It is necessary that the doctor or someone on the medical team initiate discussions about the patient's sex life. These should be started in good time, before the patient is discharged from the hospital after the operation. Sometimes some very uncomplicated information can be of great importance, such as the assurance that there is no risk of loosening the appliance or damaging the stoma by intercourse (Geiger, 1972:2).

On sexual matters, the data from the interviews reveal that the role of the spouse is important. According to Druss et al.:

The value of a man as a worker, or a woman as an attractive wife is often seen through the eyes of the partner. These issues are of a particular importance in the colitis population since these patients are often quite young when colostomy is performed, and at an age when not only are the sexual issues directly important, but also indirectly in terms of dating, courtship and childbearing (1968:58).

Sutherland et al. (1952) found in their investigation that one woman maintained an active sexual life but never allowed her husband to see her colostomy. It was not impossible in this investigation to accurately determine if the ostomy surgery was a major deterrent to the sexual patterns of the subjects. One participant in this study stated that he was engaged and that his fiance knew of his ostomy and they had engaged in sexual relations with no problems.

The patient's previously established sexual patterns and modes of relating to his sexual partner are also an important influence in how well he adjusts after his surgery.

One major concern in sexual rehabilitation is to create a good relationship in the home environment with the patient's family and sex partner. We must realize that people have different attitudes on sex, based on education, personality, religion and the like. Such attitudes may not have anything to do with the intestinal diseases of the ostomate. The prognosis is best when the patient has an understanding family and a regular sex life, well established before surgery. However, we must not forget that among the patients operated on, particularly for colitis, are people who have been sick since childhood and who have had no sexual relations prior to the operation (Geiger;1972:3)

According to one of the psychiatrists consulted, the eventual psychosexual adjustment that all ostomates have to make is dependant

upon several factors. The eventual return of the patient to a normal positioning in his family is determined by the following factors: 1) the basic psychosexual attitude of the patient, 2) the physiological changes which make the patient more concerned with survival than with sexual matters, 3) the postoperative period when the patient is learning the functions and care of the stoma and 4) the readjustment period when the ostomate progresses relative to his own abilities and attitudes. According to the psychiatrist, these four factors all interrelate to determine the eventual psychosexual adaptation that the patient will make (refer to Appendix, Chapter 4, A).

According to Dlin's survey, surgery did not alter habits of masturbation, petting or premarital sex. There was, however, a significant decline in extramarital activity. (Dlin et al., 1971).

A large number of the men and women expressed concern over their body image. Many felt ashamed, less attractive and more withdrawn. An illustration of this can also be found in one of the interviews conducted for this research. A twenty-five-year-old male made the following comment on his body image:

I suppose once you have the operation, there is a self image that you have that it mars. You don't feel like a young, unscarred man any more. Physically, you have some battle scars of living. (1)

Dlin and Perlman summarized the results of their survey by stressing the importance of the educative role of the physician in assisting the patient's successful adjustment to ostomy surgery. In concluding the discussion on the sexual problems and adjustments of the ostomate, it should be remembered that:

Every patient's self image is altered by this surgery. His capacity to rebuild or re-establish a workable self image is intimately related to a healthy social response, and even more closely related to his capacity to respond sexually. The latter, on an equal level, implies his ability to re-establish healthy objective relationships (Dlin and Perlman, 1971:380).

Despite the taboos and myths surrounding the sexual functioning of the ostomate, twenty-one subjects in the present study claimed that they had an active and interesting sex life after surgery.

In summary, the following advice can be given regarding the sexuality and sexual adjustment of the ostomate:

Attractiveness to the opposite sex was considered and resolved in that the person is more important than the existence of an imperceptible disability. If the ostomate has accepted his stoma and new bathroom habits, as he would either glasses or false teeth, the real personality will be attractive. Love and desirability in a worthwhile relationship can easily be developed. If the surgery and the new adaptive implements are unacceptable to the partner, the partner's maturity and true love are questionable, not the ostomate's physical abilities (Geiger, 1972:3).

Age and Sex

It was not possible to come to a definite conclusion from the interviews as to whether or not males or females adjust better to their ostomies. There was no evidence in any of the literature reviewed to demonstrate that one's sex influences one's capacity to adapt. In the study by Druss et al. (1968:422) assessing the psychological responses to colectomy in thirty-six patients, the authors were able only to make the following conclusion: "There was no significant difference in the responses of men and women."

It seems, however, that the younger patients are better able to cope physically with their altered status. The age at which one has the ostomy operation influences the "speed" of recuperation and efficiency in managing the resulting physical problems (i.e. skin care, irrigation, etc.). Older individuals have less physical strength and body resources to recuperate and this may be further complicated by the onset of senility and once they return home they often require the help of a spouse, friend or nurse with the management of their ostomy. Older patients also tend to develop post-surgical complications more often than young patients. The following case from the interviews will illustrate the difficulty the older patient has.

Mr. K. is a 76-year-old man who is married and has no children. He is now functioning with a colostomy. He had a cancerous tumour on his bowel that required surgery. He has another tumour and is treated weekly with chemotherapy. His rectum was not closed and blood and mucus drain from it creating obvious problems for him.

Mr. K's wife appears to have accepted her husband's colostomy but regards him as a sick man, which is undoubtedly true. Often she helps him care for his appliance. Mr. K's appetite has decreased considerably and he is not very active. The couple used to go on long walks every day but these have had to be discontinued. Mr. K received no pre- or postoperative counselling regarding the nature of the operation or the subsequent care required. Until a Victoria Order of Nurses worker visited him he was confined to bed and used only dressings to cover his stoma. His rectal drainage aggravated the problem. Since the arrival of the nurse, communication lines have been opened between

the out-patient department where Mr. K. is treated with chemotherapy. Mr. K uses disposable bags which he gets free from the Cancer Society and feels quite guilty about this.

Other than this purely physical distinction between young and old ostomates, one cannot accurately conclude how age influences the psychological adaptation of these two groups. The consequences of sexual impotency appear to affect the younger ostomate more profoundly. However, it is still not possible to do anything more than speculate on how age affects one's psychological adaptation. There are too many other factors intricately related to consider age a major determining factor.

Effect on Employment Opportunities

The ostomate's economic earning power is liable to change substantially when he or she is not able to continue with his or her former occupation as a result of impaired ability. The ability to earn a living appears to be an important factor in one's acceptance.

Of the thirty-five subjects interviewed, four of the sixteen men were rejected by their employers after their operations and only one of these four is now contributing to the family support. An individual who lost his position after surgery commented:

I had ulcerative colitis for my last four years on the job. It was terrible, but they were very good to me. When you work for a large company, the benefits are very good. If it was a smaller firm, I would have been in big trouble!

As a consequence of my disease I was retired as soon as I was eligible, actually two years before I was sixty-five. I'd worked for them for twenty-five years and - retired. Now I

would like to go back but they will not take me. However, they call me into the telegraph room on days such as Christmas and New Year's and whenever they are short of staff, or have extra rush business. (1)

Except for one individual who was a jackhammer operator, all those interviewed stated that they felt they could have returned to their original jobs. Obviously, some occupations (i.e. those requiring strenuous physical work) present the worker with a great risk of injury to his internal body structure. Two men were in the moving business and one had delivered crates of vegetables. These individuals changed occupations by their own choice as they feared possible stoma injury. Druss et al. determined that:

Fears of inadequacy on the job that disturbed some male patients may have materialized in fear of organ inadequacy and in excessive concerns about 'straining' themselves and injuring the stoma. The issue of how to advise the patient, if - and how much - to tell their fellow workers and employers, is a most important matter. Some patients prefer to keep the matter completely private; others derive support from the acceptance given them at their place of work (1968:58).

A young man reported his problem at work:

The guys at work kidded me about it at first. They kid me about it when I change my overalls. At first I found it very difficult to take - it really bothered me. Then I would go home in my work clothes and they really laughed at me. Now it doesn't bother me. (1)

A thirty-one-year-old steelworker commented on his work situation:

For the most part, they (fellow workers) were just conscious of what they said in front of me and for a while that was the way it was. But after a while, they weren't any more - they tended to try and do things for me and stop me from doing really heavy work for a while. Some of the guys were kind of ignorant and would make wise cracks about my bag. My family was good and understanding, but at work I didn't like the way the guys would try and pamper me

and do things for me. So I usually tried to prove what I could do. I tried to prove that I was normal by doing more work than was necessary, or heavy work that needed to be done. I narrowly avoided some fights when at work or when playing sports. The guys would kid around or be ignorant about my condition.

I have tried to control my temper a bit more, but I don't like it when the guys openly ask me about my stoma when I take a shower at the plant. I don't mind if they ask me in private, but when one asks in front of everybody, it is not out of concern, but out of mere curiosity. (1)

Having an ostomy not only creates problems in trying to keep one's job, but also creates what seem like unsurmountable obstacles in searching for new employment. The following case of a young woman reveals how damaging to one's ego this can be.

... so I started pounding the pavement looking for employment. It was at that point that I first came up against the cruel, hard world. As far as I was concerned, I felt I was perfectly healthy and normal and in much better shape than many of my peers. But with this terrible medical history, I found that most companies were a little reluctant, and that is an understatement, to have anything to do with an ostomate. I had a lot of doors slammed in my face and I was pretty unhappy about it. (1)

With regard to the effect of ostomy surgery on a person's work or employment capacity, of the thirty-five people in the sample, eleven returned to their same positions and two assumed other positions within the same organization (e.g. a mechanic working for a large automobile outlet became a salesman). The majority of the women encountered little difficulty in doing their housework and the three professional women interviewed all resumed their former positions. Eight subjects had retired but expressed the opinion that they could have returned to work if the opportunity presented itself. Only two individuals experienced a loss in earning power. One commented:

We're lucky; we're not doing any physical work. If you had to do physical work, you'd be less able to do it, as all individuals I have talked to, including myself, are definitely much weaker and we must watch out. (1)

Thus it appears that the nature of one's work primarily determines whether one can return to it after becoming an ostomate.

SUMMARY AND CONCLUSIONS

To summarize our analysis of the first four stages in the career of the identity formation of an ostomate, our data indicate the following significant patterns:

1. The Minor Symptom Phase

This awareness may be sudden or congenital, but the normal pattern is the gradual awareness as long-standing symptoms become aggravated. Young people have less of a recollection of and experience with 'normality' than do older people. Except for the congenital or youthful ostomate, this phase is characterized by denial and reluctance to confirm the status.

2. The Major Symptom Phase

In this stage, confirmation of the illness is forced by the symptoms and physical relief becomes a necessity. All, except the youthful and congenital ostomates, experience this stage similarly and vary only by approach-avoidance motivations in seeking help.

3. Diagnosis Leading to Surgery

In this stage, ostomates experience heightening anxiety about the extent of their illness and about their subsequent adjustment after physical repair. The adjustment concern is equally or more important as a cause of anxiety. The major dimensions of adjustment vary by age group: adolescents and early adults are concerned about sexuality, marriage and reproduction; mature adults are concerned about completeness of information as to the extent of their illness, while anxiety about adjustment is more generalized and not centred around sexuality. Concerns about survival increase with age.

4. Hospital Stage

In the pre-operative period, surgery is imminent and survival is the central dimension of anxiety. Adjustment problems continue as pre-occupations but are less clearly articulated. As in the major symptom phase, although survival is at this point the paramount concern for all age groups, the young tend to exhibit stronger concern for sexual adjustment than do the old. Most ostomates consider pre-operative care to have been inadequate preparation for problems of adjustment. However, this was not a significant factor in the relative capacity to adjust as will be subsequently illustrated. This stage is highly anomic for the patient and produces considerable anomia and related depression.

Concerns in the immediate post-operative stage centre around physical problems associated with the nature of the surgery. In this stage, identity renegotiation begins to emerge. Except for the young, retreatism and suicide are common reactions to the handicap. Gradual acceptance of the physical aspects of the handicap is followed by increasing concern with the reaction of significant others and the new identity.

Adjustment centres on how the new physical trauma relates to past concepts of identity and subsequent involvement with significant others. This process is analyzed in Chapter V.

FOOTNOTES

- (1) Statement by ostomate, personal interview.
- (2) Statement by surgeon, personal interview.
- (3) Excerpted from statements by several ostomates during the course of their personal interviews.
- (4) These conditions are described in the Appendix of this work.

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CHAPTER V

NEW ROLE FORMATIONS:

ROLES AND REACTIONS OF SIGNIFICANT OTHERS INVOLVED WITH
THE OSTOMATE IN THE REHABILITATION PROCESS

The patterns of adjustment illustrated by ostomates are invariably enhanced or deterred as a consequence of the patterns of interaction which the ostomate establishes between himself and the significant others with whom he comes in contact.

It is the general practitioner and the surgeon who provide the future ostomate with his first definitions of the consequences of the affliction with which he is affected. Thus, the general practitioner not only provides initial information but, because of this role, is in a position to provide knowledge, security, trust and support for the patient. As the data indicates, patients inevitably encounter less difficulty with regard to adjustment when their initial difficulties and future "consequences" are conveyed to them by an individual who not only clearly describes the ramifications of being an ostomate but who is able to do so in a forthright, honest, sincere and understanding manner. It appears that the general practitioner's role is often crucial in motivating ostomates to accept and subsequently to adjust to their new status.

Surgeons, nurses, therapists and other medical and paramedical personnel also play crucial roles affecting the future adjustment of ostomates. It appears that the clinical reservedness

exhibited by surgeons often deters acceptance and subsequent adjustment of ostomate patients. Initial contacts with nurses in their role of looking after the physical difficulties associated with having just become an ostomate appear to represent a dramatic illustration of self identity for the patients. Nursing personnel who are supportive and regard their work in maintaining patient cleanliness as an important and routine function assist the ostomate in adjusting to his new status. However, as will be illustrated, some nurses regard working with ostomates as among the lowest esteemed positions in the nursing profession. Those nurses who are repelled socially and physically by their duties inevitably provide the patient with an exceptionally negative self-image.

Ostomy therapists, where available, provide new ostomates with a positive perspective of self and ease their period of adjustment in illustrating to them the mannerisms and techniques available for dealing with the physical problems which they are required to manage. Likewise, Ostomy Associations, when possible, provide members who serve as role models, providing in many instances the same functions as stoma therapists.

It is the influence of the family that tends to play the most crucial role in influencing the possibilities of attaining adjustment for the ostomate. As has been illustrated by numerous studies (e.g. Roth, 1963; Davis, 1963), it is the family's function to provide a sense of normality and esteem to its members. Those families which are characterized by positive primary relations (being close) provide osto-

mates with the motivation, affection and support which is crucial in motivating them to seek maximum rehabilitative potential. However, families characterized by "nonsupportive structures" (weakened primary relations) tend to have their pre-operative difficulties increased by the post-operative tensions brought into the family by the new ostomate and hence their familial difficulties are often increased and the ostomates within the confines of these families tend to encounter more difficulties as a consequence of not being in an atmosphere conducive to the high levels of support of which they are often in need. As the data illustrate, subsequent adjustment of ostomates is enhanced by the closeness of family relationships, for the young, the old, the single, as well as the married individual. Young teenagers and those ostomates in the post-sixty category often are subject to severe anxiety as a consequence of the social and physical significance of their acquired status. For them, family support, openness and esteem is vital to their subsequent adjustment. The support of one's parents, spouse or siblings inevitably aids the new ostomate in making an easier transition to his altered status. Significant peer groups are often as important as family for ostomates in their subsequent patterns of adjustment.

THE ROLE OF THE GENERAL PRACTITIONER

The role of the general practitioner is complicated by the fact that he is viewed differently by the patient and by the surgeon. To the patient, the family physician is usually the medical professional who first discovers the ostomatic condition. Patients interviewed agreed that they possessed a high regard for their family doctors and any hostility they acquired towards the medical profession was directed not at the general practitioner but rather at the surgeon who performed the operation. The patients felt that their family physicians provided them with the sense of security, trust and support.

My family physician diagnosed my colitic condition many years ago but it was decided that I could forego surgery. Gradually, as the pains increased in their intensity, we decided that I should seek the advice of a surgeon. My family physician sent me to a surgeon whom he said was the best in the area but he told me that he would have very little if anything to do with me during and after surgery. The surgeon regarded family physicians or general practitioners as 'flunkies who do not belong in the operating room'.

I realized after it was established that I was going to have surgery that I desired the presence of our family doctor, but the surgeon said that if he was going to perform the surgery then he was going to do it his way with the people whom he desired to work with. This guy was completely emotionless, but I had the distinct impression that he knew exactly what he was doing even though he treated me as a mechanic working on a car.

In retrospect, it would have been helpful to have the presence of my family doctor. If I had of consulted him at least when it was decided that I would have the surgery, I would have been prepared in terms of knowing what to expect. Would you believe it - a week and a half after surgery he was visiting me for the fourth time when the surgeon came in and told him to 'get out'! (1)

A general practitioner made the following comment:

I made the diagnosis but when you are diagnosing severe affliction such as ostomy status, one always directs his patients to a specialist. I work well with most surgeons and, in fact, they invite me to participate in the surgery. However, in some instances, the surgeons make it quite clear that they would rather not have my participation in any way during and after the surgery. (2)

Five of the general practitioners interviewed expressed reservations about their participation in surgery. They thought it was important for them to be present during surgery for the patient's sake. But unfortunately, as far as they were concerned, the surgeons did not request, require or desire their presence during surgery. As one family doctor stated: "There is probably as much anxiety and difficulty in relations between general practitioners and surgeons as there is between most physicians and nursing staffs." (2) In clinics such as the one in Cleveland, ostomy teams have been developed with the role of the general practitioner considered to be vital. He is always included in the presurgical, surgical and post-surgical programs. However, it was found that in the hospitals utilized for this research project that the participation of the family physician was not standard practice. The subjects emphasized that they would have been more comfortable if their consulting physician had been in attendance. The reluctance of surgeons to utilize the participation of family doctors in the surgical and post-surgical processes seems to heighten the anxiety of patients. The barriers to communication that are often noted among surgeons, nurses and other paramedical personnel, are also in evidence between the surgeons and general practitioners.

The victim of these patterns of strained relations is often the patient, although the victimization tends to be of a psychological nature.

My surgeon maintained that he had his own surgical staff. I explained this to my doctor and he understood. But fortunately he came to see me every day after surgery for the four and a half weeks I was in the hospital. During the first four days when I was in a lot of pain, he was exceptionally helpful and told me about the difficulties I was going to face.

The surgeon, on the other hand, came in a total of five times during the total period of my confinement and I don't think once during that entire period he spent more than thirty seconds with me. Randolph (the family physician) was very helpful to me, had a pleasant sense of humour and got along with everybody. Even the nurses really respected him, but everybody around that place had absolutely no use for the surgeon. He's supposedly the type that drives a new Rolls Royce every year, but I cannot argue with the fact that my operation was successful. (1)

It appears that proper medical care during the operative and post-operative period can be enhanced with the participation of the family physician. (3)

The family doctor often retreats from his important role of maintaining the continuity of doctor-patient relationships as the patient is shifted more to the 'scientific' area of a specialist's care. Unfortunately for the patient, the family doctor may feel that his role - educative, personal, caring, guiding, etc. - is of minor importance in the arena of major medical care. Should the family physician withdraw, the patient must seek his emotional and psychological help from other sources. Mostly, he does it himself, aided by loved ones such as his family and friends and by informed 'strangers' such as nurses and other ostomates (Dlin and Perlman, 1971:114).

THE ROLE OF THE SURGEON

The role of the surgeon is crucial. This specialist is usually the second professional person to see the patient. His function is to confirm the diagnosis by administering a series of tests and then to proceed with surgery if warranted. He assesses the patient's physiological state and examines him to find the best site for a stoma that will function readily and will facilitate the application of an appliance. If an ostomy specialist is on staff, the surgeon frequently consults him regarding the best site for the stoma to provide maximum manageability. In theory, the surgeon continues supervision of the patient after the operation in coordination with the referring physician. In actuality, the surgeon usually visits the patient three or four times and often for only a few minutes. This is a recurring area of dissatisfaction among patients.

In retrospect, what is not emphasized as strongly as it should have been was that the man who made the ileostomy or the colostomy is always one of the important people if he will allow himself to be (Prudden, 1971:326).

One patient who was interviewed stated: "I never really saw the surgeon. I saw him when he came in to check the wound, but he didn't even have time to talk to me." (1) Another woman was quite disheartened as she exclaimed: "It's like everything else today - you are just a number worth a minute and a half on bi-daily rounds!" (1)

The essential difficulty encountered by physicians is the problem of time. Surgeons are of the opinion that it is impractical to devote the time necessary or required by the patient to instruct

him in the details of ostomy management. These matters are usually left to a stoma therapist or other paramedical personnel and appliance consultants. Thus, the patient feels that his immediate needs and the immediate concerns of the surgeon are not congruent. In some cases, the patients regard nonsurgical persons as outsiders: "I want a specialist, not just some 'Joe Boy' who is repeating instructions from the surgeon. How do I know they got it right." (1) Thus, the patient builds up an emotional dependency upon the surgeon both before and after the surgery.

After the nurses ran out of surgical rings, I had no use for them. A social worker came to see me, but I wanted the surgeon. I would trust nobody else. My family physician was not involved as I had the surgery following an accident in another province.

The surgeon seemed to know what he was doing and during the first week his visits lasted three or four minutes each, but after these visits I never saw him again until the day before I was released.

When surgery takes place in a foreign environment, you are really at a loss and in this particular case, I wanted my surgeon because it seemed that nobody else knew what was going on.

I didn't meet my surgeon until after the operation, but the nurse was very helpful in telling me exactly what would happen to me. She and I had more problems with my wife whom the surgeon would have nothing to do with. (1)

The surgeon seldom "donates" the necessary support during the immediate post-operative period. Some hospitals endeavour to overcome this by using an ostomy team to help the patient readjust.

As far back as 1776, Pillora (M.D.) emphasized the importance of establishing rapport with patients before surgery in order to help the patient understand his predicament. 'My patient and I conferred

together and thought of all these things before the operation. I then operated" (quoted in Sterling and McIlrath, 1970:81). He also emphasized the importance of establishing a warm and trusting relationship with the patient and of providing helpful instructions regarding the care of the stoma. This initial description was recorded two hundred and two years ago.

A survey by DiZerega et al. (1967) of patients with colostomy and ileostomy revealed that: "Thirty-five percent of the patients did not receive instructions about the care of the stoma and that twelve percent were unaware that the operation would 'put their bowels on the outside'" (quoted in Sterling and McIlrath, 1970:81). In the research at hand, twelve patients were not instructed how to care for their stomas while seventeen were uninformed as to how the operation would physically alter their bodies. One surgeon matter-of-factly stated:

I have them up for an examination, but there are some people who just cannot contend. They have to have it or else! Let nurses and their families put up with their whimpering and whining. I have to perform a function. I do it well, I have never had problems, but I don't have the time. (4)

This appears to be a calloused approach to surgery. The surgeon's function is viewed as that of a technician only interested in the physiological changes that he is in a position to effect. This research reveals that most surgeons tend to confine themselves to the immediate task of the operation and its aftermath. They usually withdrew from any personal involvement in their patients' social and emotional reactions to the surgery. The patient is forced to rely on his

family doctor who may or may not be knowledgeable of the possible difficulties and complications, or rely on paramedical personnel, family, friends and other associates who seldom possess adequate knowledge. The new ostomate is often afflicted by anxiety. He tends to agree with Letton when he says:

Too often surgeons may say to their patients, 'I have performed a good operation, now you must learn to live with your colostomy'. This physician has not completed his duty. He must guide the patient to a successful solution of his post-operative problems (1971:21).

Although a few patients are knowledgeable about ostomies, most have gross misunderstandings based on hearsay from misguided persons. This lack of information is reflected in the area of sexuality. Dlin et al. (1971) found that 326 of their respondents had little or no discussion with their doctors about sex before or after surgery. Advice to men was usually curt: 'This may affect your ability to have an erection' and the area was largely ignored in the case of women. Dlin cites the example of one woman who was concerned about her sexual adjustment, to which her doctor replied: 'That depends upon how important sex is to you' (1971:110).

In his article on psychosexual problems following ileostomy and colostomy, Prudden concludes that there is no area of surgery which calls for greater patience and compassion on the part of the surgeon. To all ostomy patients, the surgeon represents an immensely important authority figure whose interest and support are critical in the re-establishment of hope. Prudden concludes by stating:

'Therefore, if one is not prepared to give himself to this degree, he ought to refrain from the performance of the colostomy" (1971:327).

The data in this study illustrate the fact that the majority of surgeons tend to be only marginally involved in the recovery process.

One should recognize that it is impractical for the surgeon to devote the time necessary to teach the patient the skills necessary for ostomy care as there are often others who are perhaps better qualified in this area. Only a very few patients seem to realize this.

The surgeon mentioned something about diet and said I would have to experiment, but I was left on my own after that. I don't think surgeons are bad, or doctors, or nurses, they just don't know, they just don't care, or perhaps what I guess is probably the real truth is they just have too much to do, and if they worry about their colostomy patients, their heart patients, and their tonsil patients to the same degree as we all expect, they wouldn't have time to do anything. (1)

However, it is important for the surgeon not to forget the patient's emotional dependence on him during the crucial pre- and post-operative periods. Even the tone of voice and the choice of words he employs become important in subtly influencing the patient. Most surgeons and general practitioners are not aware of how important thoughtful semantics and a positive approach are. A stoma therapist presented this personal view:

One of the greatest difficulties I have encountered is how the doctor originally approaches the patient. It is my conviction that many surgeons and doctors regard this as extremely dangerous and difficult surgery in terms of the effects on patients. They approach their patients in the wrong manner, that is, unintentionally they transfer their emotional anxiety to the patients, where a patient, although obviously affected by such anxiety, should be able to rely on medical personnel for the alleviation of such pressures.

In other words, I believe the doctors and physicians should be much more positive in conveying to the patient what has to be done. Believe it or not, I think their usual approach is: 'I'm sorry, there is nothing else we can do.' And I think the

negative approach is definitely the wrong approach. (5)

A patient with an ileostomy illustrated this detrimental negative approach:

My surgeon said: 'We've done everything we can for your ulcerative colitis. You are going to keep suffering and suffering. You do have the other difficulties, most important of which is your heart, and it is harder on your heart to suffer from your ulcerative colitis. Therefore, we have no choice, you have to submit to an ostomy operation.' (1)

The case of Mr. K. is evidence of the suffering that can happen due to failure in the "educative" role of the doctor. Being an elderly man of seventy-six, learning new methods was extremely difficult for Mr. K. and he felt ignored. Initially, his doctor told him that the colostomy was only temporary, but now, as he put it, "they have just left me." (1) He was not referred to an enterostomal therapist nor to an Ostomy Association. This patient was sent home without an appliance or knowledge of where to obtain one and how to use it. The visiting Victorian Order nurse taught him and his wife the new mode of body elimination. Lenneberg and Rowbotham (1970) cite the example of an ostomy patient who went home from the hospital without any training as to how to care for herself. As a result, she remained in bed for five years. This lady was not sick, but without an appliance she was totally handicapped. She was not rehabilitated from her ulcerative colitis, although she had been physically cured of the disease (1970:77).

One of the participants in this study was a seventy-one-year-old woman who had had her operation ten years previous to the interview. She had had no counselling to prepare her for her operation. Now an active member of the Ostomy Association, she readily counsels others.

When the surgery was first performed, I was just so glad and happy that they removed all the cancer. The only thing I learned in the hospital was how to do an irrigation.(1)

The role of the surgeon was discussed by Druss et al.:

The central role of the surgeon cannot be minimized. It is to him that the patient will turn for all aspects of his care after a colectomy, not just for surgical adjustment. The intense relationship between the patient and internist prior to surgery may now be shifted to the surgeon. Neurotic elements, as well as operative results, may determine if the patient regards his surgeon as the curer and healer, the violator and mutilator or the omniscient guide and counsellor. The surgeon should be aware of the many emotional difficulties the patient may have, in spite of good overall functioning. Patients are often reticent about discussing matters concerning bowel function and other intimate problems and unless specifically asked, may not verbalize the anxieties they are experiencing. We doubt that problems will be 'suggested' to patients who don't already have them (1968:57).

Another surgeon related the following:

The professors in medical school always talked about the quality of the relationships we were supposed to maintain with our patients. However, because of the way medicine is organized, because of my case load and because of my responsibilities to my family and the four persons I employ in my office, it is impossible for me to develop the type of relationship that various functionaries believe should exist between patient and surgeon. Psychiatrists are often noted for the quality that exists between them and their patients, and as you know the folklore exists concerning male psychiatrists and their female patients. To my knowledge, no folklore exists concerning the intimate relations between surgeons and their patients.

From a cynical point of view, perhaps we are technicians or mechanics, but at any one time, I have thirty to sixty patients who you may classify as active in that they are awaiting surgery, in or out of the hospital and/or recuperating. It is physically impossible for me to spend any social time with them. Successful surgeons find themselves in a situation where they only have time to treat the physiological symptoms. If you want me to categorize the activities that I am involved in, you will certainly see that it is difficult to reasonably develop social relationships with my patients. I am concerned but the concern is with the physical wellbeing of my patients as related to their surgery. (4)

Researchers like Druss suggest that a highly specialized and close relationship should be established between surgeon and patients. Yet, according to the data at hand, only seven of the thirty-five individuals interviewed felt that they were adequately counselled and treated by their surgeon. Ostomy teams have been formed in some of the larger metropolitan hospitals in the United States. A team includes the surgeon, his assistants and usually the family doctor. Surgeons sometimes suggest that it is the family physician who should have the overall responsibility for the mental or emotional well being of their patients because most surgeons see themselves as "specialists" who perform only a physiological function. However, when a team organization is structured, various members have specific functions with a desirable overlap of paramedical staff and disciplines. In this investigation, it was found that after surgery, ostomy care was delegated to paramedical personnel who often appeared to be inadequately trained. (6)

Some problems encountered in the management of an ostomy include maintaining cleanliness which sometimes involves irrigation,

diETING, in many cases, and the knowledge of proper care of the stoma and appliances. During the immediate post-operative stage, substantial reliance is therefore attached by the patient on the medical and paramedical staff. Casual remarks, subtle reactions and behaviours of staff members become very important to the patient. For example, referring to an appliance as a "bag" is thought by many new ostomates to be offensive. Ostomy patients often become very sensitive. Incidents involving a lack of tact, a lack of proper care (i.e. fitting and use of appliances) and difficulties in maintaining the cleanliness of the patient are often reported. During the immediate post-operative period, many patients feel alienated by the fact that they are not able to spend as much time with their surgeons as they desire. It is at this time when paramedical relationships can be most supportive. For the most part, these relationships involve the nurses and, in larger hospitals, stoma therapists, psychologists, psychiatrists and social workers.

THE ROLE OF NURSES

There are many assignments in nursing that are unpleasant. You must realize that often patients hate nurses. They soon realize that many doctors regard us and treat us as slaves.

However, I used to be a surgical nurse and you would be surprised at the number of cases which I and other nurses in surgery have seen where doctors have been negligent even to the point perhaps of unnecessarily killing patients. But doctors are gods to patients while we are precisely the opposite. Therefore, whenever anything goes wrong, the patients treat us worse than the doctors.

We soon learn that the worst place to work (next to the psychiatric wards, where we can be in danger and most of us don't want to work there) are the wards in which you have to deal with ostomates. When one knows the nature of the surgery, it is a foregone conclusion that the patients will always be hyper, and why shouldn't they? Getting used to being an ostomate is a painful and terrible experience. To see patients in this condition and to be responsible for maintaining hygiene is exceptionally difficult. I've never encountered difficulty in cleaning up blood, pus or urine, but when you are cleaning up feces you have the worst possible problems. To be blunt, the smells are always different and always terrible! One has to pity the patients who through no fault of their own become soaked in their own wastes. How would you feel?

Now that I am training nurses, I instruct them in looking after these kinds of patients. I have seen the girls pass out in this ward and the only male nurse we've had in the last five years vomited when he first saw the situation above and beyond the call of duty, but I feel that looking after these patients is the most difficult assignment a nurse ever has to face. (7)

Nurses who are trained in the care of ostomy patients are often considered to be the source of support and therefore they can be a positive aid in the patient's recovery. Resentment and bitterness were harboured against some nurses who appeared to be relatively incapable and lax in their method and manner of treatment. This caused agony among some of the patients interviewed. One nurse in the urology ward of a Toronto hospital related her position.

As you know, the hospitals in Ontario have had their budgets cut substantially. Occasionally we run out of supplies because we are no longer permitted to order surplus. Thus organizational directives have caused many problems in the ward. Last weekend, we spent a lot of our time washing out disposable bags, and the patients and doctors often become disgusted with us but we cannot operate any differently because we do not have the equipment.

I might add that most of us enjoy nursing, but I do not know anyone who enjoys it on that ward. If I was in that situation I would also bite the heads off nurses. They would never vent their frustrations on their surgeons and most of the patients who see their family doctors treat them as personal friends who can sometimes be trusted to let them know what's going on. In this situation there is a climate of much frustration and the only people the patients can take it out on are the nurses. (7)

For most nurses, the opportunity to treat ostomy patients is seldom viewed with enthusiasm. One nurse expressed her negative view:

On this ward you are not just helping the patients to get well. You must force them to learn to take care of themselves. On other wards, this means training patients to change their dressings, alter their diets and in other ways to take care of themselves. However, in this ward we have to teach them how to look after their excretions. I bet you could not do it just like that!

We find that the best patients are young males who are very much embarrassed by the fact that we have to train them in this area of intimacy. I have looked after about thirty of them I would say and all but two were looking after themselves without any assistance within a few days.

The biggest problems are the older patients and the children, some of whom will never be able to manage their conditions.

They gave an eighty-five-year-old man a colostomy three weeks ago and he has been moved into a private room. He is being fed through a tube and he is always sick. One cannot help but think that he would have been better off if he had been allowed to die. I heard someone say that they may re-attempt a resection. What is worse, a painful death on the operating table or being allowed to die in peace? I'd be satisfied with sixty-five years let alone eighty-five!

You want to know why I am on this ward? The answer is very simply. In Hamilton, nurses are a dime a dozen and if I give up this job I would probably be forced to go on relief. Salaries are great, but wards are being closed down and no new people are being hired. This is probably a temporary situation but this is the reason why I am here. I would go to any other ward given the chance, with the exception of the psychiatric ward. Don't get me wrong, it is probably far more peaceful than life around here, but I only weigh 95 pounds and therefore I may not be able to take care of myself up there. (7)

A second nurse expressed another negative opinion:

The first time I was in that ward there was supposed to be an orderly to clean up that mess. I wound up cleaning it up. As far as I am concerned I am a nurse and there are orderlies for that - that is why I would never go near that ward. If they ever ordered me down to that ward, I would quit! Some jobs are hard to get, but others are not worth doing.

It is tough there not only because no one wants to do the work, but because most of the staff feels the same way. In most wards during most shifts there is an esprit de corps which makes working on the wards worthwhile. When you are working on that ward it is tragic. I feel badly for the patients but I just won't let myself become a hospital garbage worker. As a matter of fact, I would sooner collect garbage than do a job like that. Although I was trained many years ago, I was not trained to look after them, and even if I knew all the techniques of installation and emptying of the bag, I physically could not bring myself to do it. I don't know how they can live with themselves. I think I would rather die first. (7)

The hostility that patients tend to direct towards nurses is evidenced by the following statement made by a patient:

They actually ran out of surgical rings! What was I to do? I am sure I saw other ostomates there, I was not the only one. You just can't believe how inefficient they are in the hospitals today! (1)

Patients did not express hostility towards all nurses or all doctors. There were usually a number of personnel with whom the patients could closely ally themselves and whom they considered to be extremely

helpful, interested, efficient and supportive. Another patient remarked:

When the first nurse changed my dressing, she was so open about it. She knew all the procedures; she knew exactly what she was doing. She made me feel reassured and she asked, 'Well, after all you changed babies didn't you? Really, what's the difference?' She made me feel supported. (1)

Some nurses are more capable of handling an ostomy patient probably because in their nursing careers they had the opportunities and training to treat them. One nurse was an ostomate herself and another nurse's brother had become an ostomate and this nurse became an ostomy specialist after having cared for him. One individual made the following statement about the nursing care he received:

After the surgery I was very depressed. The doctors had mentioned that I would have to wear a bag on my side; I didn't know it would be there for the rest of my life! After surgery, I wanted to stay in bed; I had the drapes drawn all the time and put a 'No Visitors' sign on my door. My doctor was concerned and had a nurse come in from outside the hospital to see me. This nurse was also an ostomate and wanted to help me. She touched me and it was like God touching me. She said all she wanted me to do was to be able to smile. (1)

Often there were just one or two of the nursing staff who, due to their apparent lack of interest, negative reactions and/or inefficient treatment and means of dealing with spillage, created hostility in their patients.

The reactions of my family were that they felt sorry for me. I had anger when I was in the hospital - a lot of anger and that was because of the incompetent nurses who did not know how to take care of me.

The only person who was a real help to me after my operation was the VON nurse when I got home, who came around twice a day to irrigate my stoma and help me with a bath. (1)

Of the twenty-seven patients who recalled surgery, twenty-four felt that they had been unprepared for the consequences of surgery and they all expressed shock during their initial exposure to their stoma. Eighteen of the participants felt that their family physician, surgeons and nurses were unable to instruct them in the day-to-day care of their stoma.

The nurses that the participants encountered appeared to be divided as to the manner that should be used in the treatment of ostomy patients. One group of nurses believed that in the best interests of the patient, he should be treated relatively harshly in order that "he would be able to take care of himself as soon as possible." Other nurses expressed the belief that "because of the extent and effect of this surgery, the patient should best be taken care of with affection, sympathy and understanding."(7).

I was really upset when I was in hospital. Right after the operation they (nurses) forced me to see my stoma. They showed me how to keep it clean and they pushed me to do it. I was really angry ... But they were extremely strict, and you know what - it was a good thing! Because when I left the hospital I could look after myself. I have met several individuals at the Ostomy Association who, when they went home from the hospital, were complete invalids. They had had around-the-clock care and they hadn't had to do anything. When the necessity of doing things emerged, they were at a loss. (1)

Proper nursing care becomes important to the patient's first impression of what life is going to be like with an ostomy.

There are certain realities in the nursing profession. We always have the image, I hope, of being kind, good and perhaps not very bright. On the ostomy ward, however, we are seen as jailers. In making sure that patients can look after themselves, it is usually necessary to be very strict,

otherwise they will depend on others forever. I don't mind most nurses, but in that ward to be good you must be an ogre. Most of the patients don't realize this when you are treating them, but I have had many patients come back to the hospital and one actually said to me: 'Thank you for being a bitch. It's the only way that I could have learned to look after myself'. (7)

There are considerable disagreements among ostomy patients as to whether or not nursing care should be administered in an "aura of strictness" but most felt in retrospect that this pattern of care was most beneficial to patients.

From the perspective of nursing staffs, working with ostomy patients appears to be one of the least desirable assignments. In a survey of twenty-four nurses from each of two hospitals in the Cambridge, Waterloo and Hamilton areas, the following results were obtained. Nurses were asked to list in order of preference the nursing assignments they would prefer. The six wards were emergency ward, cardiac ward, internal surgery (ostomy ward), children's ward, maternity ward and communicable diseases ward.

At the Hamilton hospital the ostomy surgery ward only had three first choices and these choices were made by nurses who were permanently stationed on this ward. Of the twenty-one remaining nurses, only two rated nursing in this ward in their top four choices. Sixteen of the nurses rated assignment to the internal surgery ward (working with ostomy patients) as their last choice. One of the nurses working on this ward commented:

I have been working here seven years and I have seen a lot of progress with respect to the manner in which the surgery is conducted. I have had advanced courses and although I do not qualify as a stoma therapist, I am capable

of looking after most of the difficulties encountered by post-surgical patients. Indeed, I feel skilled at this particular work and it is not as difficult as most people would think. (7)

Two other nurses who were working with ostomy patients maintained that the only reason they were working on this designated ward was due to the fact that nursing positions are extremely limited owing to government cutbacks and therefore finding other positions would be difficult if not impossible. One commented:

This is a ward where nobody works by choice. I consider myself skilled in what I am doing, but I don't like doing it. It's a case of my wanting to maintain employment, and this is particularly important in these days of double-digit inflation. (7)

At the hospital in Kitchener, Waterloo, the results were similar. Two of the nurses expressed second and third preferences in terms of desiring to work with ostomy patients. Eleven rated work on ostomy wards somewhat negatively but preferred the possibility of working with ostomates rather than being assigned to the emergency ward or the ward dealing with communicable diseases. The remainder of the sample rated working with ostomy patients to be the least desirable assignment and expressed the view that they would work on this ward only if there were no other alternatives.

It appears that the majority of nurses in southern Ontario hospitals strongly disapprove of working with ostomy patients owing to the difficulties involved in these assignments. Fourteen of the nurses in both samples had never worked with ostomy patients and nine of these subjects maintained that they possessed strong reservations

as to whether or not they could handle the assignment. Six of these nurses maintained that they would resign before accepting assignment to surgical wards. However, as pointed out by one head nurse in a Hamilton hospital:

I suspect most of the nurses in your samples expressed reservations about working in our ward. Let's be honest, no one cares to work with these individuals, at least initially. However, what one finds is that the individuals can become skilled and very productive working in wards which were not 'picked by choice'. Although you will probably encounter extreme reservations on the part of the individuals responding to your questionnaire in participating in our ward work, what I have found over the last five years is that about 5% of those who initially become involved in our type of work usually maintain it. On our ward, we build up a strong esprit de corps amongst the nurses and other paramedical personnel. Except for the difficulties that we frequently encounter in dealing with surgeons and to a lesser extent with practising family physicians. Perhaps it is the nature of our work that allows us to build up this spirit. We attend three or four seminars every few months and our technical skills have improved. We do get many difficult cases, but most of the nurses now know how to handle these situations and have become quite professional at it. Unfortunately, in your sample survey, you did not include psychiatric wards because perhaps our perspective, or our position of rating or whatever you want to call it would have been somewhat higher. At least in this ward you are never 'threatened'!

(8)

The apparent reluctance of the majority of nurses to work with ostomies is indicative of the fact that working with ostomy patients is often held in low esteem by members of the nursing profession. The difficulties anticipated and encountered by those working with ostomy patients serves to deter nurses from working with these patients and in part may explain some of the inadequate care encountered by ostomy patients during their immediate post-surgical recovery period.

THE ROLE OF THE ENTEROSTOMAL THERAPIST

The enterostomal therapist is a trained individual who participates in the pre- and post-operative preparation and counselling of ostomy patients by talking with them and letting them express their fears and thoughts about the physical realities and difficulties they will face. Many larger hospitals are now employing stoma therapists who are usually trained nurses or trained lay people. The function of the therapist may be demonstrated by the following interview with a stoma therapist:

The first think I do is try to encourage the patient. I talk to him about actual cases of individuals with a similar background and predicament as he now finds himself in. And then I teach the patient how to master control of his particular situation. If possible, I try and consult with other individuals and particularly the surgeon, and the patient's M.D. in order to ascertain important background about the patient. Sometimes, if you have a good knowledge about the patient you are able to make his adaptation easier. I try if possible to establish some liaison with the patient's family. I think that this should always be done because it is where the patient encounters most of his difficulties. And if a patient has not had contact with a member from the Ostomy Association, I arrange for such a meeting, as such contact in addition to my own counselling, establishes reassurance and information which is useful to the ostomate in mastering his physical and emotional difficulties. My function actually is just to help the individual to overcome the physical difficulties in terms of usage of appliances and other substances which they must use. (5)

Prior to surgery, the therapist usually marks the site of the stoma and conveys to the patient the situation he must expect to face in the treatment and management of the stoma. Following surgery, the therapist participates in the direct management of the patient's stoma by selecting the proper appliance to be used and demonstrating methods of care and utilization of appropriate equipment.

I answer all the questions I can from a patient. A patient needs someone to express his feelings to. Often it is difficult for them to interact with their surgeon, family or other individuals with whom they may associate. They feel lost. I try and illustrate to them the fact that they can maintain a normal life. As I am a colostomate myself, I can illustrate this with more than an outsider's perspective. I do my best in counselling them to resume their normal lives.

In addition to these functions which are part of her direct role with the patient, the stoma therapist also promotes the interaction and participation of other paramedical personnel who may be able to contribute to the rehabilitation and adjustment of the patients. Some stoma therapists go beyond their formal in-hospital roles in order to organize the resources available within the community. This involves establishing relationships between the ostomate, the Ostomy Association and perhaps the Cancer Association. According to Lenneberg, the objective of the stoma therapist is:

On behalf of the patient, throughout his course from the earliest pre-operative preparation, the objective in enterostomal therapy is not to do for the patient, but to do with him so that he may soon be led to self reliance and independence from hospitals (1972:25).

The enterostomal therapist is a relatively new form of paramedical specialty. Very few hospitals have a full time stoma therapist employed on staff. (9) The therapist becomes sensitive to the difficulties experienced by the patients in terms of their age, stoma types, cultural backgrounds, families and other related factors. A stoma therapist commented on her role:

I try to spend as much time with the patient as possible before he leaves the hospital, as I believe that every patient

should know how to take care of his stoma and should know how to control its function before he leaves. Knowing how to control their stoma and being accepted by family members is extremely important because after all, the problem that you are looking at is the self esteem of the individual. (5)

A stoma therapist interviewed for this study went beyond her duties in the hospital and attempted to coordinate the work of the hospital personnel and community resources. In the process, she set up the Ostomy Association in the community and supervised its functioning. She volunteered her opinion of the Ostomy Association:

Most self-help organizations such as TB organizations generally operate by themselves. But at least in this particular instance, since I have set up the organization, I have found that it functions as a consequence of my direction and if I decided not to be involved, there is a good chance that the organization may fold. (5)

This professional therapist, in addition to her services to the hospital and to the community, keeps abreast of all advances technically related to the rehabilitation and treatment of ostomates. Another stoma therapist revealed that in addition to aiding the patient and participating with ostomy organizations, she has attempted to train the wives, brothers, sisters and other important next of kin in order to help them contend with the situation. The difficulty was that her formal role as a stoma therapist in a large metropolitan hospital did not permit her to devote as much time to this role as she wished.

I believe that perhaps it is in the counselling of families that the best opportunities for rehabilitation lie.

Unfortunately, I have too much work to do within the hospital and my formal commitments prevent me from spending as much time with the relatives of ostomates as I think is necessary. I tried to have our ostomate association invite the relatives of new ostomates to our meetings in order to explain the difficulties. For seven different meetings, we invited the kin of ostomates which would have involved perhaps as many as twenty people, but in only one instance did the girlfriend of a new ostomate avail herself of the opportunity and, after the meeting, we talked for four hours until three in the morning about the problems one encounters. As far as this particular situation was concerned, I enjoyed the social exchange but the therapy wasn't necessary, if in fact it really was therapy. The unfortunate situation is that the families who require this type of group therapy seldom obtain it. As you know, it is usually the ones who need treatment most who are amongst the last to acquire it. (5)

Lenneberg comments:

Enterostomal therapy is the outgrowth of work first identified by ostomates and ostomy groups. It is the systematic development of professional response to the needs, expressed and observed by ostomates and those who are for them. It is only since enterostomal therapy has become a recognized field of endeavour that systematic and standardized rehabilitation of the ostomy patient has come into being (1972:25)

The need for stoma therapists is apparent both to the public and to the medical profession.

Certain historical facts suggest that the problem facing patients with intestinal stomas have not been well handled by our profession. For example, medical school curricula have almost universally skirted the issue of the intestinal stoma. Similarly, nursing curricula have tended to assume that knowledge concerning enterostomal care will occur by osmosis as nursing students and young graduates encounter such patients. Results of this approach within medicine and nursing have been unsatisfactory (Benfield et al., 1973:62). (10)

The difficulties encountered by ostomy patients and the shortage of trained staff demonstrate a distressing lack of insight into the nature and magnitude of the problems encountered by ostomates.

Benfield et al. (1973) considered the training deficit of therapists (i.e. 1,844) that their study projected as "perhaps too conservative" in that they could not have considered the growing demand for enterostomal therapy, nor the growing numbers of operations that are requiring intestinal stomas. It also ignores the fact that the geographic distribution of surgeons equipped to perform such surgery is becoming more widespread. They suggest that:

We believe our projection for the future is almost unrealistically conservative, and that there would likely be a significant residual training deficit in 1980 even if our current goals were achieved (2,138 therapists) (1973:62).

This results in inefficiencies as evidenced by the difficulties experienced by ostomy patients who are inadequately treated due to the shortage of stoma therapists, and the lack of technical knowledge possessed by nursing and other paramedical staff. Enterostomal therapists often come from nursing backgrounds but there are others who enter the field without medical experience. Some have Master's degrees in paramedical disorders. Others may be staff nurses with Bachelor of Arts degrees or nursing diplomas. In a few exceptional cases, there are registered pharmacists who trained as therapists. Their importance in assisting the new ostomate to adjust positively cannot be underestimated.

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THE ROLE OF OSTOMY ASSOCIATIONS

Ostomy Associates are now providing a vital service in enabling recent ostomates to adapt to their altered status. Many authorities consider counselling to be a crucial influence in determining how rapidly and how successfully the ostomate's physical, psychological and social adaptation occur.

Not long ago, and in some quarters still, removal of a bowel or bladder was regarded as a physical event. It was seen as the absence of an organ. But ostomates have always had a different view of the experience: they see it rather as the presence of a new physical reality which has many ramifications.

In the early struggles with the technical problems of the physical reality, ostomy associations quickly saw the role of the psyche as it enhanced or defeated a patient's progress and return to normal living. The morale-building work of the associations was an acknowledgement that physical and psychological well being were intertwined. These were perhaps the beginnings of the modern rehabilitation process (Lenneberg, 1973:24).

The United Ostomy Association, the umbrella organization for individual groups, has grown at a rapid pace evolving into an international organization which has yearly meetings. The Association publishes informative literature and a quarterly bulletin. These associations in North America have similar structures and functions. They provide counselling, education and information to ostomates, their physicians and families. One club was attempting to help train staff in the local hospital. Some groups act as a lobby to government agencies, private employers and insurance companies so that ostomates will not be viewed as handicapped with regard to insurance or employment. Most insurance companies will not grant life insurance to ostomates.

The Ostomy Association conduct educational meetings, usually on a monthly or bimonthly basis in community centres, hospitals or private homes. These meetings are attended not only by ostomates but all interested persons. This type of support gives all those affected the directions needed to contend with ostomatic conditions. The interviewed patients who belonged to an ostomy organization felt that these clubs were helpful, not only to them, but to their families as well.

The most important function of the association is the establishment of visiting committees whose members visit both prospective ostomy patients prior to surgery and post-operative subjects. A patient who is very anxious what an appliance will look like is reassured by the sight of others who are neatly dressed and who display no visible signs of their stomas. Many feel that these types of liaisons are more beneficial than any reassurance given by medical or paramedical personnel. An ostomy association member who had given counselling during the last fourteen years explained the process:

I start out by explaining what is going to happen immediately after the operation. I tell them that there are considerable amounts of drugs administered prior to the operation ...

I carry with me in my briefcase, a diagram to explain what is going to happen, that is, the type of operation, be it colostomy or ileostomy, and how the bowel, the colon or intestinal workings are changed during the surgery.

I reassure them of the situation and spend a long time discussing the fact of how I first reacted to my stoma. I tell my patients that like them, I experienced a fear about spilling my waste and the fact that you feel like a child prior to toilet days. I also carry a number of appliances and show them how they work. One patient asked to see my stoma and I was quite open about it. (11)

A nurse commented:

Perhaps the most valuable form of reassurance of all is to introduce the prospective patient to a successful case with a well-established and well-managed permanent colostomy. Such a person is better fitted to guide the prospective patient through the hazards of colostomy management than any doctor or nurse (Sergeant, 1968:36).

The majority of pre-ostomy patients experience varying degrees of anxiety which is often heightened by the fact that medical personnel often convey to them information which can best be described as imprecise. Functioning ostomates are able to provide pre-ostomates with information and a role model that serves to alleviate much of their pre-operative anxiety. One male Ostomate Association member commented:

You can't understand the pain I went through, but I couldn't get help from the doctor and I didn't get help. How can they understand the problems you have? Probably the best help came from my friends at the Ostomy Association who set me up to the point where I was able to experiment with various substances and appliances in order to be independent. Finally, I was able to get under control. (1)

When the visiting committee of an Ostomy Association is requested to provide a visiting ostomy contact, a patient profile is always submitted so that the Ostomy Association representative can be carefully selected. Visiting ostomates will be of similar age, sex, marital and socio-economic status, and will have been afflicted by the same type of condition as the patient so that he can identify and relate to the prospective ostomate on a meaningful basis. The Association maintains that age is now less important than the matching of the type of person and the type of affliction. According to Winkelstein and Lyons:

One forty-year-old man who underwent a rectal resection and colostomy afterwards courted and married a very attractive girl and such successes communicated through the societies and encouraged others. Similarly, the first pregnancy of a New York society member was watched with close attention. The result (apart from a comfortable pregnancy and normal birth) was a swift rise in the pregnancy statistics for ostomates! (1971:5).

The strategy behind the ostomate visiting program is that the most constructive listener is usually one who has had a similar physical experience and is subject to similar life conditions. The Association believes that it is beneficial for the patient to encounter a fellow ostomate who has overcome his fears and has learned to manage his ostomy.

I found the help from the visiting ostomate to be very helpful. I discussed practically all subjects with him, except sex (and I don't intend to discuss that matter with anybody). (1)

Prospective ostomy patients are therefore able to view other ostomates as normal. These visits function to give prospective patients a psychological support in that the visitor is seen to have coped adequately. Thus, many anxieties can be alleviated. One patient commented on his experience with the Ostomy Association:

What I found out from Peter (an Ostomy Association member) was that I could only feel safe when I felt I was in control and that I would not have accidents. He showed me how to irrigate. This took a lot of time, but when you irrigate, accidents become impossible. Peter taught me what I should know about keeping clean, what appliances to use, what creams to use, how I could eliminate my odour through the use of charcoal, and how helpful diet was.

Actually, I think some of his advice was wrong. I eat vegetables, soup, I eat almost everything with the exception of some soft drinks; the gas in soft drinks is murder! Not all of this information I got from Peter. (1)

Ostomy Association members therefore perform the vital function of providing information. They consciously and unconsciously perform the function of psychologically preparing the pre-operative patient. Their counselling enables the patient to know exactly what is going to happen. Some Ostomy Association members endeavour to speak with the surgeon prior to surgery in order to know how much information the patient has already received. This conscientious effort by an ostomate prevents vague, incomplete or conflicting answers being given to queries from the pre-operative patients.

The approach of the United Ostomy Association appears beneficial. Only four of the thirty-five subjects were visited by ostomates in advance of their surgery. Many persons became ostomates without the knowledge that these organizations exist. In communities like Hamilton and Toronto, in the year 1976, individuals have undergone surgery without being informed that these associations are available. In New York and Chicago, there are independent ileostomy and colostomy societies. Areas like Hamilton and Toronto continue to encounter difficulties in establishing liaisons with physicians and in some instances with hospitals. As is often the case, the medical personnel involved tend to regard these associations skeptically. Ostomy Associations in southern Ontario are still regarded as an unfamiliar innovation. This mistrust of the new creates many problems for these associations in their efforts to create relationships with medical personnel and patients. One surgeon reported:

I am not sure that I am in favour of Ostomy Associations. They may become very similar to the CNIB (Canadian National Institute for the Blind). That is, we don't want to see ostomate members become dependent on one another and retreating from society into an association atmosphere and avoiding open society. (4)

In the course of this research, no individual was discovered who confined the total or even the largest part of his social life to the Ostomy Association. In this connection, perhaps these ostomy groups can be compared to AA (Alcoholics Anonymous) in that members give other members substantial support in readjusting to society.

I couldn't talk to anybody but Mr. A. who came over three or four times. We have become friends and we now bowl together. It's funny, he's the first Catholic I've ever been friendly with and he's the only person in the world to whom I can really talk. What is also quite funny, this association is taking care of me now in the same way the AA took care of me five years ago. (1)

In this study, only one local Ostomy Association had the cooperation of a surgeon whereby he allowed the members to visit his patients pre-operatively whether or not they had been invited to do so. The visiting ostomates never experienced any rejection.

Where contacts were made between members of an Ostomy Association and patients, not one negative opinion was expressed by those interviewed. This sharing of experiences by fellow ostomates appears to be helpful and reassuring. All of those interviewed who had come into contact with Ostomy clubs maintained that their endeavours caused a most positive force in their adjustment. The visitors whom they saw were the most active members of the association and had made satisfactory adjustments. In addition to being able to provide

practical guidance and first-hand experience, they acted as successful models with which the new ostomy patient could identify. One lady remarked:

I never met a doctor or a nurse who was as helpful as these people. They know the problems because they face them. The difficulty with trying to get help from people who don't know what it is like is that they can't possibly understand. After all, it is only we who live with the smell. (1)

One visiting ostomate noticed that the ostomy patient had her appliance put on incorrectly and rearranged the apparatus. Another found a patient who was deeply depressed after having his surgery. He showed the patient his own stoma and advised:

I've been living with this ostomy for twenty years and the only thing I can't do is dive. If you want to feel sorry for yourself and ruin your life as well as your loved ones', you can continue to cry like a baby, but there's no reason to do so.(11).

These two individuals subsequently became friends and the patient concerned is making what can be termed a positive adjustment.

The development of the Ostomy Association in North America is an indication that there is a higher degree of social interaction amongst them. As much of the literature on delinquent bodies illustrates, the disabled like many other groups frequently develop their own sub-cultures. The Ostomy Association provides a forum in which members can discuss their affliction and learn how to come to terms with their own difficulties. As Myers has suggested:

The deaf, to give an extreme example, have developed national, fraternal and professional associations, clubs, churches, insurance societies, athletic associations, newspapers and journals operated by and for the deaf (1965:41).

Ostomates have formed their own clubs and in some localities their own athletic associations and there is pressure to attempt to develop an insurance society. (12) However, only ten percent of ostomates, according to various surveys, belong to Ostomy Associations.

It is interesting to consider the reasons why ostomates, like other disabled persons, have chosen to join "mutual benefit" organizations. The functions of these organizations fulfill for the members and the factors that influence others to maintain their social distance from those similarly affected should also be considered. One man gave his reasons for joining the association:

I joined the Ostomy Association right away. I wish I had had a chance to see the members before hand because you have the opportunity to talk to other people who are experienced in the same type of problems you have. You get a host of good ideas and help in dealing with difficulties. Also, association with other people like yourself makes you feel that you are not alone, and that you have the kind of problems that other people have and this gives you a bit of moral support. (1)

Four women who were members of Ostomy clubs spent up to eight hours a week counselling others on irrigation and methods of aid. This is what Druss et al. refer to as an "obsessional defense" but on the other hand, it may also be the result of finding something useful to do. According to Druss et al.:

The extension of an obsessional defense, helping others to control oneself - is a common one (and may be an added benefit for the more established members of colostomy clubs). (1969:425).

There is a predominance of female members in the three associations visited. It was also noted that women tended to be amongst the more active members. No male members of the clubs spent more than

two or three hours a month counselling other ostomates. An explanation of this could result from the traditional difference in male and female roles. Some persons reaped the benefit of the association but did not participate further, while others continued in a counselling or organizational capacity. In one instance, an individual went on an active crusade to aid all persons subject to ostomy surgery.

In this limited study, it becomes difficult to assess the effectiveness of the Ostomy organization for its members and for non-joiners alike. Due to the fact that non-joiners generally refrained from participation in this study, it was impossible to ascertain the consequences of ostomy status for those who did not belong to the organization. Those who refused to join or who were not aware of the organization were difficult to contact. Among the reactions of these individuals were statements such as: "Leave me alone, I'm O.K." "I've got my own problems and you can't understand." "Why bother me, I'm normal." "I don't need them and I don't need you." Thus, it fell beyond the scope of this research to ascertain whether or not rehabilitation was more or less successful among members of the "sub-culture" than among non-ostomy club joiners.

Studies by Davis (1963) and others have illustrated that some individuals afflicted by debilitating conditions refuse to associate with others who are likewise disabled and often find contentment by maintaining their formal social relationships thus experiencing little if any social impairment. These organizations may also have a deleterious effect as some handicapped individuals can escape from the

the reality of society by settling within the confines of their own "deviant" subculture. This is not to say that organizations for the disabled are deviant, but that they can become deviant when the individuals who utilize them refuse to maintain and establish normal social contacts at least as normal as it is permitted as a consequence of their physiological affliction. It is not only a consequence of how the patient chooses to use this subculture but "deviance" is also influenced by the extent to which the subculture is able to exercise social control over its members. Therefore, if one looks at organizations like Alcoholics Anonymous or organizations for the blind and the deaf, one finds that frequently these groups expect and pressure individuals to fully participate within the organization.

In addition to the roles of nurses, surgeons, physicians, stoma therapists and Ostomy Associations, the roles of psychologists, psychiatrists and social workers may be instrumental in aiding the ostomate to readjust. The institutions within which this research was conducted did not consistently utilize these personnel. (13)

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THE ROLE OF THE FAMILY

Home is the place where, when you come, they have to take you in. The family has universally been recognized as the agency for the protection of the aged and the infirm, and care of the sick. The basic function is true of all cultures though the manner and the extent of care has varied at different periods and within different cultures (Kluckhohn, 1949:55).

Ostomy surgery usually induces varying degrees of anxiety within the environment of the family. The reactions of the family to the patient, be they supportive or negative, are exceptionally important in terms of the patient's subsequent adjustment. There are many difficulties that occur after release from hospital which affect the patient's family as well as himself.

As is well known, family crises can have two dynamically opposing results. On the one hand, families are often united through difficulties which were thought to have been impossible to resolve. In these instances, a crisis serves as a bonding agent to unify the family. On the other hand, a crisis may also produce the opposite consequence; the family becomes the victim of "disorganization". A complete breakdown in family ties may occur resulting in rejection, separation, perhaps even divorce.

It was apparent in this study that where difficult situations existed within a family prior to ostomy surgery, relationships further deteriorated, strain increased and new areas of dissention developed. In the words of A. M. Sutherland:

It is clear that whenever there was poor rapport in the family before the colostomy, the relationship deteriorated, previous tensions were increased and new areas of conflict

were created. This is true for both men and women. Where, on the other hand, the rapport between husband and wife or other relatives was good before the colostomy, it continues so. In summary, good relationships are almost always maintained and poor ones regularly deteriorate (1952:863).

One of the case studies illustrated this:

We never got along before. It gave my wife the excuse she always wanted - not to maintain our sexual relationship. It was never a warm one to begin with. We stay together because for us there is no other way.(1)

A wife of an ostomate related her problems:

When my husband went into the hospital I don't think he knew what was happening and I did not have the vaguest idea that he would be changed so much. We have had many fights in the last two years as he is not the same person he was. The surgery has changed him and how we have both changed. Except for work, he is a recluse. I go out without him as that is the only way. (14)

The role of the family was quite diverse in terms of its impact on the patient and his experiences. During the hospitalization period there was considerable disagreement among the participants as to the importance of their families. The majority of those interviewed maintained that visits from families and friends served to encourage them and made the lonely life of hospital existence more tolerable. Some of the participants claimed that during visits from family and friends they thought they were being regarded as "freaks". One person stated:

The people came, even my husband, because they thought it was their duty. But I think that he always thought that my capacity as a wife would be lessened. Perhaps it has but I have had to go to considerable lengths to prove that this isn't so. (1)

A sixty-eight-year-old spouse of an ostomate sadly reflected:

We made it through the Depression and World War II, but this is impossible! He smells and he can't do anything about it. I have not filed for divorce and I do not intend to, but I live across the street with our children. You just can't be with him. The smell is just too hard to take. I realize that most people think that I am an ungrateful woman. I feel worse for him than I can say, but I cannot live with that. (14)

Another patient maintained:

My wife knew when I married her the difficulties that ran in the family. Our children had grown up so that our family was complete before I had my operation.

My sex life is the same, perhaps slowing down because of age, but because of the relationship that we always had, the surgery did not make any difference to us.

My brother had the same thing and my mother died because of some surgical complications some twenty years ago. It must be a real shock though for people who have no idea of what the surgery is and how it is to be managed. (1)

This patient's wife further commented:

My husband has always been exceptionally clean; I am more aware of his ulcer scar. My husband does not have to wear a bag because he irrigates twice a day and we have no trouble. I did feel bad when he had the surgery, because I realized the terrible pain which patients encounter the first week or two after surgery. Frank bit his lip so hard one day after surgery that it had to be taped. (14)

The majority of patients learn to look after themselves while they are in hospital, but for older patients, management becomes difficult once they return home. Many spouses and other family members are unable to help with the management and control of the ostomy and in three instances the subjects were forced to rely on outside paramedical persons such as Victorian nurses. Six of the subjects (four of them widowers) were not living with the same individuals as they had been before the operation. Four of the patients continued to live

alone; two because they had done so for a long time prior to the operation, and two apparently due to their becoming unacceptable to relatives and friends. As one fifty-five-year-old man stated:

I have been a bachelor all my life and up until the time I had the operation I either lived at the 'Y' (Young Men's Christian Association) or with one or two individuals, depending on the time. After I had my operation and two fellows who I was sharing the apartment with told me that they were moving out, I moved back to the YMCA and there were a lot of problems. When you empty the bag there is a smell and I was unacceptable in the washroom. People were making all sorts of comments. Therefore, I had no choice but to live on my own. (1)

Single ostomates appear to be apprehensive in seeking residence with strangers. This can be appreciated in view of the fact that ostomate management involves procedures that tend to occupy the washroom for long periods of time. The emission of gas and spillage also presents difficulties which inhibit ostomates from seeking shared accommodations.

Esteem is accorded those who are able to maintain normality. In this instance, normality is ascribed to those who are able to perform their functions that they fulfilled prior to surgery. Patients tended to lose their spouses' esteem when they encountered severe difficulties in ostomy management. Patients frequently expressed the desire to conceal their conditions as they felt that the existence of the stoma pointed to their own feelings of lack of value and self-worth. Therefore, even in the most congenial family surroundings many patients reported loss of esteem. One participant commented:

Let's face it, I'm just not the same person I was. When you walk around with a bag, you are different and you are not completely human. (1)

One strategy common to ostomates is concealment and secretiveness with respect to family members, friends and associates. One single girl, four wives and seven husbands in this sample concealed their stomas from their spouse and/or family as they feared revulsion if not total rejection.

Why do I need their help anyway? Things are difficult enough. They help me, they prepare my dinners, they look after my clothes, no problems. We sleep in separate beds but we have always done this. (1)

In addition to the fear of rejection, many patients desire to demonstrate their independence and self-sufficiency. Those that desire to regain normal or near-normal status felt that accepting the aid of others could be interpreted as the first sign of adopting a handicap status which they wished to avoid. However, a few patients tend to be very open regarding their conditions. One male patient whose daughter was a nurse readily divulged his condition claiming that:

In our family, everything has always been open. We have always been honest about everything. My daughters and sons knew the facts of life very early in life from us and we have always been open in discussing everything except money matters because we never wanted our children to be concerned about these matters. (1)

The majority of ostomy patients appear to seek emotional support from their families. However, all of the patients interviewed maintained that seldom did their spouse attempt to discuss the consequences of the surgery and they felt that this was due to fear on the part of the spouse that they might further upset the patient. Five

of the patients desired this type of conversation so that no misunderstandings would occur. They soon realized that attempting to discuss their difficulties presented problems which were too oppressing for other family members to bear. After surgery, eleven out of thirteen men discussed the difficulties in taking care of the stoma with their wives, but in only one of six cases, did a wife seek the help of her husband. In this particular instance, the two individuals involved were part of a "farming family".

Males tended to rely on their wives as "nurses" during the post-operative period while women preferred other women to provide this kind of aid. As Druss et al. point out:

The husband's perception of his wife and whether she was a person who accepted the sight and smell of his wound and stoma, in the immediate post-operative stage, was most important. (1968:54).

Another set of problems arises when patients attempt to manage their conditions. Two of the male patients maintained that their wives endeavoured to aid them but that they were repelled by the odour and sight of the stoma. In seven other cases, the men reported that their wives were exceptionally helpful. Among the women, on the other hand, only one received physical help in managing her condition. She commented:

I was at home alone; it was the first time I had ever been alone. It was four days after I had come home. I had an accident and it was spilling. My husband came in in his work clothes and took one look and told me not to get upset and he helped me clean up. That was really terrific! I knew he accepted me fully, there was no problems. He laughed at my concern. (1)

Four of the older patients required the help of outsiders. Two widowers relied on visiting nurses. None of the males relied on their sons or daughters for any support. Two women sought and received the aid of their daughters and/or sisters in the care of their stomas. This same pattern of care was found by Dyke and Sutherland in their study of colostomy patients. According to these authors:

For the men, the primary source of nursing care was their wives. The women on the other hand, had recourse to daughters, sisters, and other female relatives, as well as husbands. Such help was essential because the illness of husbands or their employment limited the assistance they could give. However, the marital partner was regarded by both wives and husbands as the most desired source of care, especially where care involved the sight of the colostomy.

Thus, though fears of humiliation existed even in relation to a spouse, and though some spouses could not tolerate the sight, odour or contact with the colostomy, those who stood in this relationship were expected to be the most tolerant in giving care.

Both men and women expressed strong feelings of wanting to be independent of their children in regard to physical care and financial aid (1956:128-129).

In this research it was noted that four of the wives despised their husbands, at times quite openly. They tended to feel that their husbands now had diminished value due to their impaired social activities, reduced income and possible source of embarrassment. They expressed the opinion that they thought their husbands' bodies were more fragile, less masculine and that the stoma was ugly. A forty-nine-year-old woman stated:

Our life seems to be over in many respects. We do not travel and as a matter of fact, I do not have contact with him any more. He seems weak; he has problems and he does

smell. I know I am his wife and am supposed to contend with these conditions but you can't understand how difficult it is unless you are really involved. (14)

Husbands tended to be more supportive towards their wives and less disturbed by the sight of the stoma. Strangely, this was quite the opposite reaction to what most women expected - that their new physical appearance would make them less attractive and desirable to their husbands.

It is apparent from this research and from the literature that ostomy status may cause considerable marital pressure. It appears that the spouse plays a crucial role in a patient's recovery. A negative example of spouse support was illustrated by a patient who told this researcher that his wife referred to him as "the stinker" and that his five-year-old child had picked up the label. In an interview with this man's wife, she admitted: "I used to lean on my husband all the time, but now he can't help me at all. He's just a weakling and he smells!" The man himself stated: "She could not accept the odour of the gas, nor the sight of the stoma." It was not clear whether this patient suffered from impotence. However, the crude rejection by the spouse may have been the final event that made a return to normality a social and sexual impossibility for the patient. Four months after the interview the patient committed suicide - an unfortunate but not uncommon consequence of this surgery. This dramatic case study illustrates that it is not only the ostomy patient who should receive pre- as well as post-operative counselling, but also the patient's family members as well.

The concept of rejection may be real or it may be fantasy. Unfortunately, there is a very real rejection at times by a spouse or a family member, an amazing sort of rejection. A

third of the people who were interviewed indicated that their spouses had seen their stomas either not at all or only initially when it had been formed. Even more astonishing is the fact that one-fifth of the ostomates reported that their wives showed a strong adverse reaction to the stoma manifested by expressions of disgust by fainting. This simply reflects poor management of the total family unit. Everybody has got to live with a person who has the stoma! The family as well as everyone else. (Schuster, 1973:9).

Due to the lack of family counselling, many ostomy patients fail to receive needed familial supports. A twenty-four-year-old nurse describes the difficulties that occurred after her ileostomy. She encountered considerable anxiety in accepting and managing her condition and her husband provided no support whatsoever. She stated:

I received some counselling from a nurse, but I was her first ileostomy patient, so that wasn't very helpful. Counselling at that time was offered to my husband but he refused.

My husband just won't talk about it. He pretended it just didn't happen. He wouldn't talk to me or to anybody about it as if it wasn't there. He didn't want counselling or anything. I have never been able to talk with him about it. One day I was having problems and I was sick; he just got angry and went out of the house.

I did feel some hostility towards friends who obviously did not know how to behave with me. They were embarrassed. They didn't come to visit me as often as I expected them. When they came they looked at me and they talked to me in a very funny way, almost as if I were some kind of monstrosity or freak of nature.

Towards my husband, I don't know whether I feel any hostility; I don't think so. I think that it is mostly hurt and confusion - not being able to understand why he reacted like that. Sort of rejecting me, even though he denies this. But he can't see how the operation has affected me and denying that it practically never happened, well I don't know. Maybe I am hostile towards him; I don't know. (1)

This view illustrates that support often expected by patients, sometimes does not occur and the usual result is that the patient becomes anxiety-ridden. The anxieties encountered by many patients indicate the value of a rehabilitation program that is often provided in hospitals

where ostomy teams exist. The anxieties placed on the patient and his family often interfere with his rehabilitation process and may, in fact, spawn family disorganization. One patient felt distressed because counselling was unavailable for his wife:

After the operation, I was given a booklet that told about colostomies, and I was taught to take care of my appliance. That was all. My wife became very nervous and upset after the operation. She didn't know what to do; but she felt there was a need that had to be fulfilled.

I feel strongly that family members should be counselled and it would help them understand and deal with the problem. It would put them in the right frame of mind and their favourable attitude would be appreciated. Everybody would benefit from them. When you leave them totally in the dark, it creates problems when you get home. I was extremely frustrated with my wife and others because I needed help that they could not give. (1)

Familial support serves to alleviate much of the anxiety and difficulties encountered by ostomates. It appears that the ability to contend with the consequences of ostomy surgery within the family are a function of the patterns of relationships that have existed prior to surgery. As Dyke and Sutherland maintain:

The operation and its residual clearly introduce new factors that must be integrated into the continuum of existing relationships. The family's response to the patient's needs do not occur in a vacuum. It is profoundly modified by the long-standing relationships between its members and the patient. The operation does not set up new relationships superceding all others (1956:135).

One participant remarked:

We had a lot of difficulties when I first came home from the hospital. These difficulties came from the fact that neither myself nor my wife realized the implications of what we were facing. There was no satisfactory counselling. The only counselling I had was from the stoma therapist, and my wife was not present. I think she was accepting my situation. Now that I know how to look after myself, and I do not have any odour, we have not had any difficulties and our sexual lives are the same as before surgery. Perhaps even better because I am not impaired by the pain. (1)

This is an example of a "close" family. In this case, even though problems existed in the immediate post-surgical period, the strong emotional family ties which existed were a long-term asset to both the patient and his wife. Thus, when marriages and family relationships can be classified as "close", the difficulties associated with ostomy surgery tend to be alleviated. However, when families have been subjected to histories of anxiety and disorganization, these conditions not only inhibit the recovery of the patient but further serve to disintegrate the family structure.

THE ROLE OF SIGNIFICANT PEER GROUPS

In addition to the family, one's social affiliates, work mates and other significant peer groups at times play crucial roles in influencing the ostomate to assume either a positive or negative self definition.

For the young ostomate, his contacts with those of his own age group are often crucial.

I was born with spina bifida as I told you before, there were rumours circulating around the school that my anatomy was male. Because I used to leave class twice a day up until the age of eleven, my fellow classmates, except for the boy next door, were very cruel. They used to taunt me and the kids used to scream, 'You look like a boy inside.' In the long run, this treatment by others was probably very important in determining the type of person that I became. As you know I am rather shy and rather unassertive. I fear kids and realize that this fear is a consequence of the cruel treatment that I received when I was young. I now realize that children are harmless and perhaps one of the great things about kids is that they are fully honest. Not only are they truly honest, they are apt to pick up any rumour, treat it as fact and be very cruel in 'checking it out'.

Today, when I go and see my nieces and nephews at a dinner party I still feel uncomfortable. I realize that this is irrational, but I just cannot shake that prejudice, I guess it is. Today, I am not certain whether I distrust, hate or just don't understand children. Whatever the psychological explanation, which incidentally, I could not care less about, I prefer to be in the company of adults and always make efforts to avoid environments where there are children. (1)

Another individual who had an ostomy during early adolescence commented:

The kids all came up to the hospital as I used to be 'one of them'. I had difficulty telling them what I had because from my recollection, I did not really know. In any case, they found out that my feces were being channeled into

a bag. One day when I got out of my bed, as three or four classmates were visiting me, I slipped and fell and the bag came off. It was a real mess. After that, they just treated me different. A number of them told me how sorry they were for me. I did not feel any negative feelings towards them but rather I did not understand what I had become and it was not until I reached my early twenties that I guess I stopped hating myself. It seems that my relationships with my friends, that is, those who were my own age, were probably no different than the relationships that I subsequently had with my parents, that is, my relationship with them was different after the operation. (1)

Another victim of spina bifida commented:

My parents always took very good care of me. I had an aunt who was a nurse. By the time I went to school, I was normal. I could take myself to the washroom and there were no problems with regard to looking after myself that I could not handle. I believe the kids knew something was wrong as I was always somewhat weaker and more fragile than most young children. However, I was accepted as one of the group. There was no problem. My problems did not really emerge until I was a teenager. When it comes to dating, ostomates have an exceptionally difficult time. I would rather not discuss any problems from here with relation to 'sexuality'.(1)

It appears for young ostomates that their identity is often threatened by the negative treatment they receive in their peer groups. The subsequent effect of this treatment appears to explain why young ostomates appear to be subject to much anxiety when in the company of children. Therefore, young ostomates tend to limit their associations with their age compatriots and even in later life many of them are inclined to avoid contact with children.

For the ostomates in the other categories, the significance of peer group affiliations cannot be underestimated. As previously illustrated, positive affiliations with significant peer groups serve to enhance an ostomate's self image and enhance opportunities to achieve maximum rehabilitative potential. Interaction between medical, para-

medical, peer groups and the patient is often crucial in influencing the ostomate to adopt positive or negative adaptation strategies.

CONCLUSION

Thus, patterns of adjustment illustrated by ostomates vary from patient to patient, depending on the patterns of relationships that they establish with medical and paramedical personnel and the measures of support and esteem provided by their families and other significant peer groups. Thus, for ostomates as with other victims of disability, their subsequent potential and motivation to adjust is a function of their estimation of what being an ostomate entails. Hence, the patient and the significant others with whom he comes in contact often have different views as to the significance of ostomate status. From Thomas's (1918) perspective, each of the interactants often possesses differing views as to the significance of the spoiled identity which is often produced by ostomatic status.

FOOTNOTES

- (1) Statement by ostomate, personal interview.
- (2) Statement by general practitioner, personal interview.
- (3) Refer to page 349 in the Appendix for a description of the general practitioner's role in the section entitled "Recommendations".
- (4) Statement by surgeon, personal interview.
- (5) Statement by enterostoma therapist, personal interview.
- (6) A study of 92 colostomy and ileostomy patients in Wichita, Kansas revealed interesting insights into the proficiency of the hospital staff. Like the study at hand, that particular investigation indicated that the nursing profession and other paramedical personnel need to become better informed in the care of ostomates, and that the surgeons are too often derelict in this respect (Bierman et al., 1966:647-650)
- (7) Statement by nurse, personal interview.
- (8) Statement by nurse, personal interview. The reason the psychiatric ward was not included as a choice was that one of the hospitals surveyed did not have a psychiatric ward.
- (9) A special training program developed for enterostomal therapy is offered in only five schools in the United States. The program is six weeks in length for a total of 240 hours. The curricula are similar for they all must conform to the minimum standards set by the Curriculum Committee of the International Association of Enterostomal Therapy (McConnell, 1972 :15) These five schools

were established between 1965 and 1972 and were based on an experimental training program initiated by Dr. R. Turnbull and Norma Gill at the Cleveland Clinic. The existing centres are now able to train eighty new therapists annually and, to date, a total of 198 new therapists have been certified (Benfield, 1973:63). About 175 hospitals in the United States now have an enterostomal therapist on staff. No comparable figures were available for Canada. It is known that there are no schools or hospitals in Canada that offer training for enterostomal therapy.

- (10) According to Benfield et al. (1973), in the United States there is currently a need, based on a survey of hospitals with 600 or more beds, of 2,138 stoma. therapists and as of now in the U.S. there is a deficit of 1,834 stoma therapists. This was derived from the difference between the current supply of such therapists (i.e. 198) plus the anticipated yield of trained therapists from existing schools (i.e. 80% for seven years equals 560 therapists) and from the training goal of 2,602 therapists by 1980. Often, as some of the cases in this study reveal, the nursing staff is expected to look after ostomy patients without having the training required to perform the necessary services required by these patients.
- (11) Statement by Ostomy Association "visitor", an ostomate; personal interview.

- (12) Currently in Canada and the United States, ostomates are ineligible for private life insurance, health insurance, and/or income protection insurance.
- (13) The roles of these individuals (i.e. psychologists, psychiatrists, and social workers) will be described in the Appendix under the section, 'Recommendations'.
- (14) Statement by wife of an ostomate, personal interview.

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CHAPTER VI

NEW ROLE FORMATIONS:

PATTERNS OF ADAPTATION

Within the various sociological studies referred to earlier in this investigation, such as Scott's The Making of Blind Men (1969) and Roth's analysis of the victims of tuberculosis (1969), one finds that not all victims of disability are able to maximize their rehabilitative potential. Thus, sociological and psychological factors may enhance or deter the ability of a patient to regain measures of normality. The patterns of adjustment illustrated by ostomates evolved from factors associated with self image, the patterns of treatment elicited from others, the physical limitations imposed by the disability, as well as factors relating to the manner in which one has been accepted or rejected by significant others. As will be illustrated, some ostomates often utilize means of concealment as it is their belief that if they are not detected as being different, they enhance their chances of being treated as normal. Concealment generally conjures up strategies of misrepresentation which are often defined as deviant by various segments of society, but such strategies are rationalized by ostomates as a means to achieve normality. Other ostomates as a consequence of their age, marital status and/or sex utilize strategies that are geared to gaining acceptance within their societal structures from a positive perspective, and from a negative perspective another segment of the ostomate population chooses to isolate themselves from societal contact. Some

of these ostomates resort to other strategies which involve the utilization of special diets, appliances and at times psychiatric support in their attempts to accept their new identities. Psychiatric support often becomes important, especially when the patients are afflicted with consequences of their ostomate status that make their condition apparent. These identifiable ostomates are forced to contend with situations that are often perceived as exceptionally negative, especially in North American society where one of the main emphases is on cleanliness. Those who become victims of spoiled identity often resort to what Lindesmith and Strauss label:

...defense mechanisms, security operations and the like, the central idea being that the person meets supposed threats to self regard with characteristic modes of defense. Defense modes include, among others, selective inattention, anxiety reduction, evasion of responsibility, rationalization, pretence and the disowning of undesirable qualities in one's self (1968:327).

In Presentation of the Self in Everyday Life (1959) and in Asylums (1961), Goffman illustrated the patterns by which individuals with "interpreted" stigma deal with their spoiled identity. They utilize a series of defense mechanisms which may include self deception, avoidance, denial, reaction formation, rationalization of the new condition and/or isolation. These mechanisms are frequently pathological in nature in the sense that they may create other problems for patients. According to Lindesmith and Strauss:

There are, however, many other techniques of adjustment that are perhaps more successful and that are used by people who do not seek professional help. To indicate the existence of more normal techniques, we have called them 'coping' rather than defense mechanisms (1968:328).

Sociologists and social psychologists like Scott and Davis have illustrated the manner in which those with spoiled identity endeavour to maintain or regain their self esteem. Likewise, ostomates may choose pathological or socially desirable methods in coping with their spoiled identity, such as 1) seeking information about ostomatic status from medical, paramedical personnel and members of Ostomy Associations; 2) cooperating with those who endeavour to illustrate to the patient how to manage one's ostomy; 3) endeavouring to maintain normal routines of living; 4) communicating with others who are afflicted with the same disability. The pathological patterns of behaviour include: 1) withdrawing from various patterns of activity; 2) becoming a recluse and 3) in the continuum of maladaptive patterns of behaviour, resorting to suicide.

In coping with their spoiled identity, ostomates may or may not be able to regain "normalcy". However, their patterns of adaptation are attempts to establish relationships with society that will be workable in their subsequent patterns of adjustment.

Whether or not patients desire to achieve maximum rehabilitation is a consequence of the factors described herein. The patterns of adaptation evolved by patients inevitably illustrate whether or not a disabling condition becomes a physical handicap.

Each individual develops his own unique pattern of adjustment. A survey of these adaptations reveals that adjustment spans a wide spectrum between the two extremes of positive acceptance and negative denial or escape. The following individual's attitude is indicative of a positive adjustment:

Looking back on it, for the first few weeks after the operation I was depressed; I was low in morale. But once you get used to living with it, and once you perfect irrigation with some routine you come to accept it almost as natural. After all, I am still alive! (1)

Yet, there are still many others who refuse to accept their altered body status. A young nurse who was an ostomate recalled her initial feelings:

The permanence of it scared me and upset me a lot. I felt depressed, uncertain of how I would adjust, somewhat lost. I cried a lot and this lasted for over a week, then I came to some kind of relative acceptance of it. Mind you, I am still sorry I had to have it. The only positive thing now is that I have no pain, but nothing else. (1)

Ostomatic surgery is regarded by many people as an unnecessary alteration in their physical being and is therefore perceived as negative, disagreeable and devaluative to the patient's self esteem. The degree of this negativity is a consequence of the patient's perceptions of his altered body functions, his capacity to deal with them, his perception of others and the sensitivity of those significant others.

Although this surgery presents the patient with a disability that necessitates his behaving in new ways in order to best care for himself and his stoma, it is not necessary that the disability become a handicap.

I had to have it done. The first fifteen or twenty times I changed the appliance myself, I was sick and I vomited. The sight and smell of the stoma and the discharge were just too much! But as the nurse implied, it was almost like changing a baby - you become desensitized. Now that I can irrigate, and I only have to do it three times a week, I do not find it a discomfort or a handicap at all, although according to definition, it is my disability. (1)

Winkelstein and Lyons suggest:

Indeed, to many patients, it is at least as severe a calamity as a mastectomy or an amputation of a limb, for there is a sense of appalling loss regarding not only external appearance, but internal organic and functional integrity (1971:1).

To a young woman, this loss can be symbolic and devastating to her self image and future expectations. One woman who was interviewed asked: "What am I supposed to do? I am a very young person. I am not married, but I hope to be some day - what will this do to me?" (1)

The participants in this survey were asked to describe how they viewed their adjustment. Four replied that their health was excellent, nine reported that they felt good and seventeen claimed that they were in some degree of difficulty. Fourteen of the patients complained of experiencing frequent difficulties with accidents and spillage. Eleven of them claimed that accidents never occurred, while the remaining patients maintained that it happened only occasionally. Sixteen of the thirty-five participants considered accidents to be a distinct problem which negatively affected them in terms of their activities. Twenty-one of the individuals used a deodorant to control odour. Twenty-three of the patients did not discuss the fact that they had ostomy surgery with anyone outside of close family members for reasons of embarrassment or fear of being viewed as different. One individual who was a member of an ostomy association maintained that, aside from her husband, no one else outside the association knew of her operation. She reported:

Nobody knows that I had the operation; I can't discuss it. It doesn't make a difference; we just avoid trips with other people. I never participated in athletics anyway and

so no situation would come up whereby individuals would be made aware of the difficulties that I face.

Although I could have had my operation in Kitchener, I went to Toronto - there, nobody would find out. (1)

Sixteen of the individuals radically altered their diets. Others had made minor changes such as avoiding soft drinks. Seventeen of those interviewed resumed their daily routines. Six persons changed jobs. Another altered his routine slightly - when his friends went out for coffee break, he went out to irrigate.

In their study of patients over the age of fifty, Dlin and Perlman noticed that in most instances, it takes at least one full year to adapt to ostomy surgery. They have suggested that:

This one year period may well be related to the duration of mourning and grief needed to work through any significant loss, such as loss of a loved one. When people face the loss of an internal organ, relocation of a body orifice and the possible loss of a natural body orifice, together with facing the possibility of death, they too suffer a significant grief reaction which must be worked through; thus, depression, anxiety, withdrawal, hypochondriasis and apprehensions are to be expected during this working-through period. During this time, people will pay attention to the body parts and their mechanics. The slow and tedious part of working through their personal feelings and their relationships with others depends on their psychological maturity and sophistication (1971:115-116).

Dlin and Perlman view the return of an interest in sex and sexual functioning as a very positive indication of a willingness on the part of the patient to return to a normal productive life.

The high ratio of interest in sex in that population over the age of fifty who have come through major surgery with body mutilations, speaks well of the fact that these people still have a significant investment in life (1971:118).

The inability to adapt after one year seems to suggest a failure in this working-through process and it might therefore be a

positive indication for psychiatric intervention. Dlin and Perlman suggest that if a patient has not resolved his difficulties after one year, he is likely to remain a psychological cripple for life. This analysis is indicative of the fact that there are a multitude of difficulties associated with this surgery and hence it appears that rather than waiting one year to make an ex post facto diagnosis, the goal should be the development of a series of rehabilitative programs into which all patients can be placed prior to surgery. These programs may be adjusted to the patient's needs and interests and the probability of his accepting and adjusting to the surgery. A professional assessment of the patient's psychological characteristics can aid rehabilitation personnel in guiding and instructing the patient using a personalized approach.

People will die sooner or have complications more often because of their giving-up attitude. It is a simple matter for the family doctor to tell the patient that he is not responding and that even though this surgery has been successful, his attitude has not. Attitudes can be repaired by sound psychotherapy. A positive and firm attitude will get these people to a psychiatrist (Dlin and Perlman, 1971:113).

Psychiatric treatment is necessary in many cases. All individuals encounter difficulties in living with their conditions, but some encounter more difficulty than others. An example of satisfactory adjustment is illustrated in the following quote from a twenty-five-year-old male:

I don't think that any young person wants to feel that they have had surgery like that - it's pretty drastic! You have to be re-routed completely. I felt pretty bad that it had to be done. My embarrassing moments occur when I don't chew my food properly. Certain times I know I can't go out to the gym. I don't change in the locker room any more - the people are just too cruel. But aside from that, I am not affected. (1)

Some ostomates encounter severe depression and overwhelming anxiety. These patients benefit from psychiatric intervention. A severe reaction after surgery was displayed by a thirty-one-year-old male.

I tried to avoid the operation as long as possible, diet, anything - nothing worked.

Immediately after the surgery the pain was hell and I was in agony, physically and mentally, for a long time. I was in intensive care for sixteen days, and two days after I came out I went through what doctors call a 'crisis'. I tore the room apart and they had to take the other three people out of the room. I threw things and hit people until they had to put me in restraints. I don't remember any of it - being sick physically, which I was, but sick at the idea of having to live with this! (1)

Another poorly adjusted individual stated:

I go to work, but I don't go out for lunch with my fellow workers. Let's face it - I'm not what they are any more. I'm not normal. You cannot imagine what it is like to find that you are changed physically and I guess it has changed me psychologically too. I am a different person than I was before.

Not only do I think psychiatric help should be available, I think it should be compulsory! (1)

According to a psychiatrist, "doctors generally hesitate to recommend psychiatric procedures prior to undergoing ostomy surgery because this advice raises patient anxiety." (2) He felt that post-surgical psychiatric treatment is often called for in cases where spoiled identity creates anxieties. There is a theory that has been popular in the psychiatric medical literature regarding symptom alternation:

... that is, when the target organ of a psychosomatic symptom is removed, it is assumed that the basic underlying conflict, still unresolved, will manifest itself in another psychosomatic symptom or a psychosis. While this theory has recently been challenged, nevertheless, it has led to the reluctance on the part of some psychiatrists to go along with the surgeons' recommendations that the patients have their colons removed (Druss et al., 1968:54).

According to Druss et al., however, they found in their study of the psychological response to colostomy that:

The fears of many psychiatrists concerning symptom alternation prove to be unfounded; there was no significant release of previously bound psychic forces in the form of a psychosis or the establishment of a new psychosomatic target organ. On the contrary, relief of a debilitating symptom appeared most often to have led to an ego expansion with new interests and new confidence (1968:57).

A crucial problem for many ostomates entails resolving the depression that accompanies surgery. In their studies, researchers have noticed that patients use two main defense mechanisms which they call "obsessional" and "phobic". That is, patients may develop ritual-like habits of irrigation and cleanliness that are carried to an extreme as already illustrated. According to Sutherland et al. (1952), these rituals help to give a sense of mastery to the patient who has lost anal sphincter control.

Eleven of the ostomates were very apprehensive concerning the possibility and the humiliation involved in having an accident. As a consequence, they would entertain suicidal ideas. Sixteen of these patients were phobic concerning the odour and noise of their gas. They also possessed fears which were pathological with regard to potential injury to their stoma. They would allow these fears to interfere with their ability to pursue employment and leisure time activities. Sutherland maintains that projective tests can indicate serious hypochondriacal preoccupations and ritual routines as a method of regaining a sense of self control. One of the doctors interviewed claimed that: "Some patients become food faddists in their efforts to regulate input when bowel control has been lost." (3)

Other individuals have obsessive concerns with cleanliness and as a result they may change their appliances as many as fifteen or twenty times a day. Some of those interviewed described how they irrigated until they obtained crystal clear water before embarking on daily activities. Being this phobic or hypersensitive to the possibility of odour or other related difficulties causes some ostomates to almost completely withdraw from society.

Some ostomates view their surgery as the source of drastic alteration of their self image. They find the surgery so abhorrent that they try to hide the fact, going to great lengths to achieve concealment. One of the surgeons interviewed told of a patient who was obsessed with hiding his condition from the world:

I had a sixty-year-old patient who decided to tell his wife that he needed drastic stomach surgery and that subsequently he would be forced to sleep in a separate bed because of possible injury. His wife assumed that he had some sort of operation relating to ulcers and was never aware of his ostomy.

So far as I know the patient has never told anybody and the only ones who know are the personnel in the hospital who treated him for his ulcerative colitis. (4)

Twenty-three of the thirty-five patients interviewed had some sort of minor or major emotional difficulties either before or after surgery. Twenty-three of these patients maintained they had no need of psychiatric help, yet nineteen of those interviewed felt that psychiatric aid would be a distinct benefit for all patients. The need for psychiatric treatment was recognized yet the desire to seek this treatment was acknowledged as a further indication of spoiled identity. As one person explained:

Psychiatry is probably good for people but you just don't go to a psychiatrist! Think of what your friends would think! I could never go to one. They may help me but if they had a program where everybody had to go and see the psychiatrist if they were having this surgery then I think it would have helped. Yes, it may even help me right now - I still cannot get used to the smell! (1)

Concerning the emotional problems associated with being an ostomate, another patient commented:

Well, what can you expect? Of course people having this surgery would have difficulty from an emotional point of view. One gets emotionally upset because this is a result of having an ostomy, and in order to get well you have to fight! (1)

May, Lyons and Small (1953) maintain that the emergence of obsessional mechanisms has a regressive meaning and it should be seen in "libidinal" terms. They suggest that the sexual problems created by neurologic damage may very well eventually lead to a greater libidinal investment in the bowel and to preoccupation with it. The stoma for some people becomes a new and more readily accessible anus. The stoma's red and moist membrane and the length of it, particularly in the case of ileostomies where the stoma must be constructed so that it is raised off the surface of the abdomen, tends to remind some patients of a sex organ. A long stoma is viewed by some, mostly women, as a penis, while a short one might remind the patient of a vagina. These perceptions inevitably promote sexual fantasies, confusion about sexual identity and, if carried to the extreme, the feeling of loss of one's sexual identity. Occasionally sexual analogies and fantasies are expressed openly but usually occur as fleeting thoughts never brought to the conscious level and as such, a range of psychological problems can result.

Those women who feel ugly or different, who say they would never show their stoma to a man - one would wish that they had been cared for by male nurses in the early post-operative days. Another thing is the symbolism inherent in the ileostomate, especially if the stoma is a long one. It may indeed resemble a penis to its female possessor, thus decreasing her self esteem and feeling of identity. She must be discouraged from giving the stoma any male nickname or referring to it as 'he' (Geiger, 1972:3).

Occasionally, the opposite reaction occurs.

Colostomy life is not ideal and few patients can view it with the equanimity of the gentleman mentioned by Devine, who preferred the abnormal anus 'because it did not develop piles'. Fewer still, but always present, are patients who welcome the abnormal opening as a means of sexual gratification. Mathan reported the case of a psychiatrist's wife who admitted that masturbation in the colostomy really caused orgasms, and she referred to her colostomy as her 'little girl friend'. Most patients tend to speak of their colostomies in less endearing terms (Cromar, 1968:445).

For a few patients, the stoma is considered an organ, surrounded by unimaginable consequences and sexual overtones.

Studies have shown that men react to this surgery at times as a castration! Some unconsciously perceive that the initial bleeding from the stoma is menstruation and hence evidence of feminization. Women were concerned they had been violated and eviscerated. Both sexes felt their bodies had been made weaker, more fragile and unattractive, and that they were now inferior. The patient cannot blame the mutilation on anyone but himself, because he is too dependent on the surgeon at this time to allow any feelings of anger to emerge. This impounding of resentment further contributes to depression (Orbach and Tallent, 1965:130).

Druss et al. note that a degree of obsessional defenses is necessary in a healthy adaptation to colostomy and they advise therefore that these defenses should not be discouraged (1969:419-427). In the majority of cases, these patterns of defense do not really inhibit, although they do admittedly change an individual's association with the so-called 'normal' world.

The preoccupation with sexual fantasies, cleanliness and irrigation rituals was also noted by Druss et al. These researchers attempted to relate these obsessions to denial and social withdrawal and they regarded both these reactions as interrelated attempts to adjust.

Psychodynamically, the phobia was not the typical agorophobic syndrome in which a forbidden sexual impulse is projected onto a place or setting where it can then be avoided and a dependent relationship on a parent figure maintained. Rather, it is the restriction of a premature old age. The loss of control of the stoma is projected onto the outside world which is seen as dangerous and forbidding. It can then be avoided. There is a withdrawal of interests from activities and others onto the self, and particularly onto the body and its functions (Druss et al., 1969:426).

During the initial period of convalescence and often during the first year, many patients withdraw from social activities. Inhibiting one's interaction within society is a phobic defence. It leads to a pattern of avoidance based on the fears of embarrassing "accidents". Twenty-eight of the individuals in this investigation indicated that their social life had changed and that they were not quite as active. Twenty-one ostomates maintained that distinct improvements were made in their health and that the "slowdown" was perhaps not necessary but "it pays to be careful". A man reported:

They really didn't teach me anything in terms of what I was supposed to do. But that was about six or seven years ago.

The first four years I was a social recluse. I must admit I was ashamed of what I had and I was an extremely modest person. This prevented me from asking for help. I would go into the bathroom and create a real mess and I was afraid to even ask my wife for assistance.

Finally I did see a psychiatrist - four years after the operation. He told me, like others who undergo this surgery, that I had taken a 'regressive' reaction with restriction of interest and

excessive emotional investment in, believe it or not, my stoma! He told me that he'd run across an individual who spent so many hours cleaning himself that in fact it was a substitute for masturbation. It's crazy what psychiatrists will come up with! How can one masturbate a stoma? (1)

Dependency is a typical reaction to the loss of the anus or colon; shame at being unable to avoid spilling or soiling, the fear of being repugnant to others, the anger at the surgeon for mutilating the body are other reactions. Being too helpless to express this results in depression. As a result, the less successfully adjusted patients can become phobic in terms of restricting their activities to the local environment. In other words, they avoid stigma by avoiding people.

What am I supposed to do? My family always wants me to get out and do things. I'd like to but let's face it, I can't afford to get into difficulty. The smell is too much! (1)

Anxiety is provoked by the loss of bowel control. In North America this anxiety is reinforced by the necessity of living in a social environment which places a high value on cleanliness, absence of body odour and concealment of bowel function. Newspapers, radio and television advertisements often dramatize the social isolation that is a consequence of body odour and lack of cleanliness. Many ostomy patients who are "clean" but who are revolted by possible emission of gas or spillage become convinced that others do not understand or tolerate these breaches of social conduct. When ostomates are able to continue social participation they are often harassed by a pervasive anxiety about the possibility of accidents.

I'm always aware of the possibility of spilling. I've done it three times; what am I to do? I'll tell you - I've gone out and done something. I have put in a special foam cutting

which I shape myself from sponge rubber that I pick up at the local store. This helps lessen my fears of spillage to a certain extent, but the fear is always there. (1)

I can't get around any more because I may have an accident. My husband and others pass it off and say I just refuse to be sociable. I don't want to bother anybody, I just want to be left alone. This is my right. (1)

It appears that withdrawal is also a means of achieving secondary gains.

One patient remarked:

I never enjoyed typesetting and so after surgery I exercised my right to opt for a five year early retirement which hardly affects the amount of my pension. (1)

The majority of patients are able to resume normal activities after a recovery period which ranges from a few weeks to a few months. Nineteen of the subjects expressed the opinion that although they resumed their normal way of life, they did so with heightened degrees of anxiety. One woman explained the change in her housekeeping routine:

I really don't do the housework any more, especially waxing, carpet sweeping, etc. It just was not worth taking the chance. Once when I was carpet sweeping the first day home, the back of the handle hit the stoma and since then I will not take that chance again. (1)

Older ostomates exhibit reduced activity in social, economic and leisure pursuits. Patients choose a continued state of invalidism even when they had no physical impairment. Due to psychic anxiety, activity is often lessened which may result in a lowering of self esteem. This is reflected in hardships associated with the loss or threat of loss of occupation creating economic deprivation.

The anxiety of being an ostomate appears to influence some towards feelings of self-hatred. The tendency to withdraw or to deny any limitations gives rise to the belief that many patients create within themselves feelings of self-loathing. Eight participants referred to themselves as "freaks" or "monsters" and spent most of their time socially isolated from all other contacts. Their self esteem had been lowered to the point where they no longer had self confidence.

It was found that those between the ages of nineteen and fifty-five did not curtail most of their physical activities because of the operation, although they did report that they refrained from violent sport activities (i.e. football, rugging, wrestling, diving). In ten of the cases, working men and women had consciously curtailed their social activities immediately after surgery in order to be satisfactory "bread winners". Within three years after surgery, twenty-four subjects had resumed their normal social activities but they confessed that they tired somewhat easier than before. Eight of the individuals were convinced that this fatigue was a consequence of the effect of the operation and looking after their stoma, while two others maintained that their fatigue was related to advancing age.

One may be tempted to postulate that the reaction of ostomates would be influenced by socioeconomic status. Socioeconomic factors appear to be of only minor influence on one's reaction to ostomatic status. This influence did not emerge in any of the data collected. Those interviewed were primarily of middle class status but some of the individuals were of upper and lower class backgrounds. From their reactions, there is no

data to indicate that fear of social rejection would be significantly different amongst the socioeconomic classes.

Another pattern of adjustment which was found to be common in the early stages of adjustment but which subsequently diminished over time was aggression towards the surgeon and hospital personnel. One man, age twenty-six, angrily reported:

They did not tell me I was going to have the operation. They couldn't because I was injured in a traffic accident, but I woke up with this! They had no right to do it. I think it could have been done otherwise; one should always consult a number of different doctors. I am seeking legal advice. (1)

A fifty-year-old male ostomate resented the poor treatment he received while in hospital. He was given no appliance or instructions after the operation. He bitterly related the following:

I was sort of disoriented; I guess mostly because of the pain. I was quite sick in fact for quite a while, especially over the messiness of my condition. Of course I did not have any appliance but just sort of a wad of gauze to cover the wound. However, stuff was oozing out all the time. Everything would just get soaked - my clothes, the sheets - just an awful mess!

I don't think that happens now though. I had my operation eleven years ago and from what I hear at the Ostomy Association, things are much better now. I certainly hope so! (1)

Two other means of adjusting are universal to human nature - denial and escape. In most cases, the ostomate's disability is "hidden". The hidden nature of the "disability" permits some victims to deny its existence. This is one pattern of adjustment where denial usually does not create adverse situations for the patients or their contacts. Camouflaging the condition allows ostomates to participate normally without encountering the stigma which significant others may attach to them. The denial mechanism of defense enables some ostomates to be fully rehabilitated.

CONCLUSIONS

The role of significant others in contributing to the rehabilitation of ostomates cannot be underestimated. Ostomates, like other victims of illnesses which may produce spoiled identity utilize adaptive and maladaptive strategies in adjusting to the consequences of their incapacities.

For victims of spoiled identity, their subsequent adaptation to their conditions are a result of the physical limitations imposed by their acquired condition, their abilities to overcome the physical difficulties associated with their conditions and their abilities to resolve the hardships which arise as a result of being victims of a condition to which they and/or others attach stigma. Although eighty percent of ostomates appear to be able to accept their conditions, many of those who may be defined as well-adjusted admit experiencing varying degrees of anxiety.

The thirty-five participants were asked to list the most undesirable characteristics associated with their conditions. The following responses were elicited:

1. Being found out - expressed by five individuals who always endeavoured to conceal their condition.
2. Experiencing an accident - this fear was expressed by eighteen of the subjects, nine of who had never had an accident.
3. Eleven of the subjects feared being affected by the odour and noise of escaping gas.

4. Twenty-two were concerned with cleanliness and the possibility of being thought of as inferior, dirty and unacceptable - they expressed the concern that not only cleanliness, but the maintenance of the appearance of cleanliness had to be maintained in order to avoid the discrediting label of being unclean - a label which is often associated with those defined as being ostomates.
5. Eleven, having been victims of cancer, were concerned with the possibility of malignancy spread and further surgery to arrest this condition.
6. Eight individuals expressed heightened concern associated with the difficulties associated with establishing and/or maintaining romantic and sexual relations.
7. Eleven of the middle aged and four of the elderly patients feared having to relinquish their normal activities - becoming handicapped and subsequently disabled.
8. Twenty-two feared being subject to further injury.
9. Twenty-seven of the participants were concerned with the limitations imposed by not being able to take vacations and having to alter their life style with respect to activities involving economic, social and physical pursuits.
10. Four expressed concerns involving not being eligible for life insurance. One individual maintained that he could not arrange a bank loan and hence had difficulty in securing a mortgage due to the fact that he was not eligible for life insurance.
11. Seven of the participants expressed a reluctance to be in an environment with children because of the possibility of injury

and insults as a result of having had prior negative experiences with children and young adolescents.

The possibility of having accidents and of the opportunity to opt out of obligations as a consequence of the supposed difficulties associated with the acquisition of ostomatic status inevitably induce some ostomates to maladapt. Thus, the strategy utilized by ostomates varies from person to person depending on the personal estimation of the effect and consequences which ostomatic status imposes upon them. Most ostomates are aware of and influenced by only some of the above concerns, but they subsequently organize their lives in order to best protect themselves.

FOOTNOTES

- (1) Statement by ostomate, personal interview.
- (2) Statement by psychiatrist, personal interview.
- (3) Statement by doctor, personal interview.
- (4) Statement by surgeon, personal interview.

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CHAPTER VII

CONCLUSIONS

INTRODUCTION

This study was undertaken to analyze the processes by which the victims of spoiled identity (ostomates) form new identities. We have conceptualized ostomate status as stigmatized deviance. The physical impairment imposed by ostomy surgery involves some degree of spoiled identity with regard to the perceived and, usually, the physical performance of sexual and evacuational functions. In most if not all cases, this impairment penetrates into the total interactional sphere of the victim. The existence of the physical stigma is a subjective and verbal aspect of one's self conception of identity and one's identity as perceived by many others. As illustrated in previous chapters, in modern western societies and especially within the North American environment, personal cleanliness and sexual prowess are central themes of mass culture and constantly emphasized in the mass media. These themes become significant parts of one's total identity.

Characteristics - be they physical, sexual, social or psychological - that are deemed to compromise one's cleanliness and to negatively influence sexual identity, generally lower the esteem of

the affected victim. Many of these characteristics in ostomates are the results of life-saving surgical procedures and dramatically affect the performance of sexual and eliminational functions. Because of their cultural importance, these physical changes have strong consequences for identity. The patient is perceived to be a victim and is thus an involuntary deviant. He is to some degree perceived in his own terms and in the eyes of others as violating important codes with regard to physical, sexual, psychological and social identity. Because their self image or their identity as seen by others is perceived to have been altered significantly and often radically, these involuntary deviants inevitably discover that they are required to radically alter many of their social relationships.

The ostomates that we studied are (or at first were) embedded, as involuntary deviants, in a social milieu where the consequences of the deviance or perceived deviance became the central organizing factor in their patterns of social relationships. The majority of our sample of new ostomates, because the stigma was and continues to be considered so significant, took on and presented a new identity, not only to themselves, but to their interacting counterparts. The identities that these ostomates acquired, like many other involuntary deviants, are perceived to be somewhat less than normal by themselves and significant others. Thus the ostomate, because of the almost constantly perceived importance of the stoma and his consequent spoiled identity, is required to take a series of measures that estab-

lish, maintain or change many aspects of his relationships with his interacting counterparts. The new roles which ostomates establish are negotiated and are directed towards their psychological acceptance by all the parties with whom they come in contact.

Sample Characteristics

Generalizability of the findings to all ostomates, and more broadly to all involuntary or stigmatized deviants, is limited by the constraints imposed by the specific nature of the stigma, the fact that most of the sample had group affiliations, and the small sample size (n=35). These limitations were offset by the breadth and intensity of the investigation into the ostomate career of each individual in the sample and the data base proved adequate for substantive analysis.

Self-Help Group Affiliations

The majority of the participants in this research belonged to ostomy associations. Groups such as ostomy associations (blind, deaf associations, etc.) are formed to facilitate the renegotiation of new identities with the goal of minimizing the effect of one's impairment on social relations. These "mutual benefit associations", in addition to providing their members with the strategies for coping with their impairments, often provide economic, social and, in contemporary times, political activities and support functions in order to maximize the welfare of their members. Some ostomates, of course, may elect not to be members of such associations. Seven

in our sample elected not to belong. Reasons for not joining vary. Some may elect not to join in the belief that the lack of association with other ostomates as a member of a corporate body organized around the nature of the stigma will lessen the salience of ostomate identity. Others may not belong because they wish to isolate themselves, not only from other ostomates, but from many segments of society as well. Still other ostomates are not members of ostomy associations because they may reside in areas where involvement with such associations, at least in terms of geographical access, is difficult.

From our data, we can generalize very little about the career of identity renegotiation for non-members of ostomy associations. We found, though, that for the seven individuals who were non-members in our sample, the salience of being an ostomate was not minimized by non-involvement with ostomy associations and, in fact, for some non-members, the fact of being an ostomate appears to be the prime negative factor in their existence. For these individuals, refusing or being unable to obtain the services of an ostomy association seems to have negatively influenced, if not destroyed, their rehabilitative potential. (1)

The Stigma

As already discussed, the nature of the stigma affects the sexual and waste elimination components of identity. Departures

from the normative standards of performance and cleanliness are negatively evaluated. The extent that these impairments are visible affects the degree of perceived deviance. The nature of the impairment is different from other permanent impairments such as blindness, but the consequences for identity renegotiation are similar. Because of this similarity in effect on social identity, findings about the renegotiation careers will add to our knowledge about the careers of permanently stigmatized deviants.

RELEVANCE OF THE STUDY TO THE PROCESSES OF IDENTITY RENEGOTIATION

For our sample, the renegotiation of identity, although highly variable in individual particulars, involved a career of five significant stages. The sociological, psychological and physiological consequences of the acquired condition forced upon the actor a new identity, which in varying degrees is influenced by the extent of the injury to which he has to adjust, his age, his sex, his patterns of previously established relationships with others and the willingness of himself and others to accept the involuntary and usually permanent results of the new status.

Briefly summarized, the theoretical approach utilized in this analysis is that of symbolic interactionism and its utility for studying deviant roles. In the past, symbolic interactionists have tended to focus on patterns of normality in their efforts to study ongoing relationships (Cooley, 1922; Mead, 1932; Thomas, 1918). However, the studies of current symbolic interactionists in the tradition of Davis (1967), Roth (1969) and Scott (1969) have focused on deviant aspects in social relationships where the involuntary deviant is forced to restructure many of his previously-established sets of "relations". In most instances, ostomates cannot retain normality and are defined as deviant.

With regard to restructuring relations it is well known that all victims of disability - be it social or physical - respond to

stigma-producing situations differently. Contemporary symbolic interactionists such as Goffman (1963), Roth and Scott, have illustrated that affected actors utilize a variety of responses to adapt or maladapt to the contingencies of new conditions in which they are embedded. However, consistency across individuals becomes apparent when the sequencing of renegotiation is made the unit of analysis. Whether one examines the roles of an ex-mental patient, a polio victim, an amputee or an ostomate, victims of disability exhibit a consistent sequence or career of responses during renegotiation of identity. These responses range from denial, anger, resentment, bargaining, inevitability, depression and usually renegotiation of a new identity. For the stigmatized actor, renegotiation involves three stages: a fictional acceptance of one's new status and acceptance of the disability; the normalization of role taking which includes acceptance of self and awareness and understanding of one's limitations; and finally, institutionalization which is a stage where one not only accepts oneself for what he or she is, but where the actor is accepted by others. In contrast, for actors afflicted with an illness where recovery is possible, illness involves a non-stigmatized deviance where there is an eventual return to the status quo. This pattern is revealed, for example, in the study of tuberculosis patients by Roth (1963). In Timetables, Roth illustrated the fact that once a patient has achieved cure, he encounters no social barriers as a consequence of his illness. However, when an indi-

vidual becomes disabled as a result of becoming blind or assuming the status of an ostomate, he discovers that his disability is a stigmatized deviance. He is placed in a situation which involves the substitution of a new role, owing to the fact that it is difficult and almost impossible to return to a state of normality. Therefore, the study of ostomates is a study of the career of ostomate's responses to a disability and the renegotiation of a new role. More generally, the study of ostomates is an attempt to study the corporate life of the stigmatized deviant.

THEORETICAL IMPLICATIONS OF THE STUDY

Career of Renegotiation and Factors in Adjustment of Ostomates

For ostomates, the career of renegotiating a new identity begins at the point when an individual realizes that the physical transformation is about to be accomplished or is already accomplished. Before this point, patients seldom realize the meaning of ostomatic status and the difficulties associated with the state. Most patients are apprehensive, hostile and even angry when they are exposed to the difficulties often encountered on becoming an ostomate. The steps outlined in Chapter I describe the careers and patterns of adaptation experienced by those who have become ostomates. Ostomy surgery relieves a disabling and often life-threatening condition but it also introduces new problems involving social and personal acceptance. It is often seen as threatening personal esteem and disturbing or altering one's body image. In the process of becoming ostomates, they have had to encounter blemishes on their identity associated with the stigma that is often accorded to ostomates by the patients themselves and by others who may or may not be aware of the difficulties associated with the acquisition of this state. Ostomates are often perceived as negative, unworthy and perhaps even incapable of maintaining or formulating relationships with others in a variety of domains. Some ostomates are able to maintain normality by keeping the stigmatized portion of their identity minimized in most of their relationships with others. This pattern of adjustment is the mode found in our sample and tends to be charac-

teristic of stigmatized deviants who belong to self-help organizations. Others, although being able to maintain normality from a physiological perspective, achieve only secondary gains as a consequence of their acquired status. Still others, being physically and/or psychologically inept, are unable to contend with the physical consequences and stigma associated with being an ostomate and hence adopt new identities that involve one of several patterns of disengagement from society.

The ability of the ostomate to build his new identity is more or less modified by the severity of the disruption or change required in his life style as a result of his ostomatic status. Thus, older patients who have physical impairment and psychological difficulties stemming from old age often encounter severe difficulty in attempting to manage their identities from a social, psychological and physiological perspective. When disruptions occur in one's family, occupation and profession as a consequence of becoming an ostomate, the likelihood of being able to function normally and maximize adjustment becomes limited. The greater the degree of disruption of an ostomate's existence from a social, psychological and physiological perspective, the lesser will be the likelihood of the affected individual achieving normality. On the other hand, when the degree of disruption is perceived as relatively inconsequential, the existence of an ostomatic status may only minimally affect an individual's existence and perhaps have little, if any, effect on the identity which he presents to society.

The characteristics that allow congenital ostomates, youthful ostomates, young adults, middle aged adult and the aged ostomates to adjust to their ostomatic status (spoiled identity) have been outlined in the previous chapters. The more positive careers of renegotiation in adjusting to spoiled identities are found in ostomates with those characteristics previously outlined. Likewise, also identified were the characteristics of those ostomates who were unable to come to terms with their acquired status and to cope with spoiled identity. Future studies may reveal that these negative characteristics which involve weakness in peer group support, lack of proper counselling and so forth, may be crucial in the difficulties associated with other groups of involuntary deviants in their attempts to adjust to their acquired status (spoiled identities). Hence, patterns of adjustment and maladjustment isolated in the careers of the blind, the deaf, mastectomates, as well as ostomates, in their careers of coming to terms with their disabilities may eventually be generalizable to all victims of spoiled identity.

Our data show that the ostomate, as an illustration of an individual who is subject to a new and involuntary identity, acquires the new identity more easily if he has the advantages of the following situations: 1) he is able to successfully manage or conceal the physical condition when he interacts with significant others; 2) he is born into or acquires at an early age an ostomatic condition

so that he is not aware of abnormality; 3) he is embedded in a familial situation characterized by the existence of strong, positive primary relationships; 4) he has his status already established to others by virtue of his acquired social status (achieved status within the community); 5) he is married, past the childbearing stage and physically able to cope with the activities required to physically manage the consequences of his ostomatic status; 6) he is not required to relinquish any of his previously established roles in pursuit of his economic and social goals; 7) he receives adequate counselling from medical and paramedical personnel, with such counselling involving both himself and his significant others, both prior to and following surgery. The extent that the above seven sociological and psychological preconditions are present determines the degree to which he can establish his self-identity and identity to others in a way that will be unimpaired by the consequences of a surgery and/or any other event which may serve to impede or affect his presence in society.

Importance of Age and Renegotiation

Those born into or who acquire an ostomatic condition early in life negotiate an identity as a stigmatized deviant with no socialized non-stigmatized identity as background. Return to normality or its approximation is precluded as a goal. These individuals readily form and accept stigmatized identities. From the earliest part of their lives, they experience a multitude of interactions,

especially in their interrelations with their peer groups who are often unable or unwilling to grant the ostomate acceptance. Even if these peer groups are willing to grant acceptance, the young ostomate's self identity often precludes the establishment of normalized patterns of relationships.

Contrasted to this pattern is that of the ostomate who acquires the condition as an adult. The presence of the past normal identity is a significant background parameter in identity renegotiation and, at least in the early stages, is not precluded as a goal. For these people, the less the salience of physical elimination and sexual behaviour, the more adaptable the primary group, and the more established self and social esteem, the more likely is near-normal identity to be renegotiated.

Importance of Family and Peer Group in Renegotiation

One of the major factors influencing a victim of spoiled identity (ostomates) to strive for and attain maximum rehabilitative potential is positive support emanating particularly from family and important peer group members. Involuntary deviants, such as ostomates, usually encounter less stress in their efforts to adjust to their "spoiled identities" if they are embedded in a supportive family atmosphere. On the other hand, those ostomates who find themselves embedded in a familial atmosphere characterized by stress, usually find that the relationships encountered within family structure are further deteriorated as a result of the pressures

emanating from acquiring the status of being an ostomate. Thus, ostomy status may result in the disintegration and perhaps even destruction of the existing family structure. (2) Those who are only marginally attached to familial relationships and peer groups often find themselves isolated and hence they appear to be among those less likely to be able to successfully make the transition from sickness to an approximation of normality.

In summation, the ostomate who is embedded in an atmosphere characterized by positive familial peer group relationships find that his condition often acts as a catalyst in amassing the supportive factors necessary to achieve maximal rehabilitative potential. On the other hand, those ostomates who do not have the advantages of these patterns of support are often less able to contend with the consequences of their spoiled identities.

Importance of Medical and Paramedical Personnel in Renegotiation

In addition to family and peer group supports, the medical and paramedical personnel with whom the ostomate interacts in the pre and postoperative stages of his adjustment are often instrumental in determining the ostomate's future self image and abilities and capacities to adjust to his spoiled identity. The comprehension and management of ostomy status is often enhanced by medical and paramedical personnel allowing many ostomates to successfully contend with the consequences of their spoiled identities. However, some segments of the medical and paramedical community, for various reasons, opt to disguise the conse-

quences and ramifications of ostomy status. It appears that failure to grant the ostomate full disclosure of his status usually acts as a deterrent in his ability to readjust to his deviant role. However, it must be stated that some individuals, in spite of positive familial and peer group supports and extensive pre and postoperative treatment and counselling by medical and paramedical personnel, are unable to accept the ramifications of their spoiled identities.

As previously illustrated, a 20% rate of serious difficulties associated with the subsequent adjustment of ostomates and an 8% suicide rate amongst this population indicate that large segments of the ostomy population subsequently encounter severe stress in their attempts to normalize relationships with themselves and others. Involuntary deviants, be they victims of physical, psychological or social stigmata, seldom enjoy the consequences of their "compromised selves" except perhaps for those who utilize their acquired status to achieve secondary gains. Ostomates, like other involuntary deviants, may opt for legitimate or deviant means in seeking acceptance from various segments of society. For ostomates and other victims of spoiled identity, their capacities for achieving acceptance are in many instances limited by the stigmata which the victims accept or the stigma which is attributed by others to involuntary deviance. Family, significant peer group and medical personnel occupy crucial roles in influencing involuntary deviants to accept their spoiled identities.

The Labelling Process

We have shown that studies dealing with devalued social positions and groups and those dealing with non-conforming groups or persons have been taken to constitute the area of study known as deviance - rule-breaking behaviour. Deviance is viewed not as a property of an act itself, but rather as behaviour which violates someone's conception of a rule and is identified as doing so. In this study, we have attempted to show that the distinction between voluntary and involuntary deviance is a useful and theoretically important distinction in the study of spoiled identity. The involuntary deviant, unlike the voluntary deviant, has not usually been responsible for his status, since it occurs through disease or accident. Sagarin in speaking of the physically disabled, noted:

In this context, the personal and social conditions conducive to becoming a deviant are legally irrelevant. In the capacity of sociologist, therefore, one is no longer concerned with how people got that way, but how and why they are defined in a devalued manner and with what consequences for all parties (1975:36).

The interest then is to understand how an individual comes to adopt a regular pattern of behaviour that is rule-breaking and the interactional effects. One link is through the labelling process. A label defines the expectations by suggesting that the individual's behaviours are taken as documents or indicators of some underlying essential quality of self or being.

Faced with the charge that one is some kind of different person (or not fully normal) the labelled person has two options, to attempt to fight the imputation of the label or to accept it. Acceptance of the label implies living up to the expectations of the labellers, e.g. being mentally ill, being handicapped, being retarded. The early symbolic interactionists pointed to the social development of identity - the expectations of certain behaviour for given social categories and situations - and the process of forming conceptions of self identity from the regularity with which one finds oneself addressed by others and with whom one has sustained association. The later symbolic interactionists have tended to show what happens to social and personal identity when the regularity with which one is addressed, as a result of being unable to meet usual expectations in interactions, is discrediting or labelled as deviant. The more contemporary symbolic interactionists pay closer attention to deviant identity formation and their studies can be grouped into an area referred to as "spoiled identity". Spoiled identity evolves when an actor has had or believes that he has had the attributes which normally define his presence in day to day interaction compromised so that he is perceived by himself and/or others as possessing attributes which are often negatively defined or labelled as discreditable.

These considerations lead to a number of conclusions about the referent of spoiled identity, how it develops and the problematic nature of interactions with those possessing spoiled identity.

The concept refers to those persons who are seen as filling a marginal or devalued position in society and who are seen to possess (though do not necessarily have to possess) some characteristic or attribute of behaviour which can be labelled as different from, or prevents one from meeting, the usual expectations of a given situation. Those subject to spoiled identity often find that their life chances are reduced in terms of economic opportunities, social pursuits and general patterns of acceptance. The problematic nature of their acceptance by others often leads to the need for renegotiating a new identity. The actor may believe that a new identity is warranted because of the discreditable attributes often attached to his acquired condition. His goal in renegotiating identity is to maintain and establish relationships which may otherwise be negatively affected by ostomy status.

Strained interaction between those who are designated as normal and those who bear the marks of physical, psychological and social abnormalities (stigma) or are at least deemed to possess these characteristics inevitably create conditions of strained interaction between the affected actor and his interacting counterparts. The works of Davis, Roth and Glaser illustrated that victims of the aforementioned conditions encounter social situations which often require that they renegotiate their images as the interacting audiences and the victim of spoiled identity seldom have clear perceptions concerning what ought to take place in the structure of relationships between them.

The Concept of Victim

The central sociological dimension around which the adjustment and new identity formation of a disabled individual articulates is the fact that societal images of the disabled, be they correct, ambivalent or false, are often shared by "victims". Unlike the social deviant such as a criminal, the disabled deviant usually shares the values of the dominant society with regard to the stigma involved with the status. The individual values and seeks legitimacy. Legitimacy is attained most easily through minimizing the visibility and the relevance of the disability in the presentation of one's self. When this is achieved, the next step to legitimacy is negotiating an acceptable new identity even though it is partially defined as deviant. The disabled such as ostomate do not have the potentiality of the return to the status quo ante as do, for example, rehabilitated criminals. The basis for the label is always integral in the individual's self concept of identity and it is often perceived by significant others. The disabled adapt to the stigma of physical disability in several ways. Some people make a definition of self and seek to work within the framework of that definition; they project themselves as physically different but not socially deviant. This is what Davis (1967) was referring to when he utilized the concept of deviance disavowal in which the person did not deny or try to conceal the handicap but sought to normalize relationships and to deny the awkward, embarrassing or negative aspects of social interactions. Others embrace the role of being disabled.

Legitimacy and Renegotiation

From a theoretical perspective, the literature on deviant behaviour and its utility for understanding the formation of identity, has limitations when applied to the case of the involuntary deviant. The involuntary deviant is like the Mertonian type who shares the group norms but is blocked in access to the means to conformity and either constantly attempts to conform, becomes the ritualist or the retreatist, but in any instance is usually not the rebel who, by choice, rejects the legitimate means to achieve goals (1938:672). Thus, the ostomate is subject to the consequent problems of anomia, depression, isolation and alienation. The majority of ostomates in this study (80%) opt for the acceptance of institutionalized goals and means as the route to establish their rehabilitation.

Ostomates, like other segments of involuntary deviants, share societal concepts defining deviance and conformity. When possible, most members of ostomatic populations, like other segments of involuntary deviant populations, attempt to achieve maximum rehabilitation. The majority of ostomates strive to achieve legitimacy by not allowing their difficulties to interfere in a dramatic way with their established life patterns.

When one examines the careers of the instantaneously blind, the severely burned, mastectomates and ostomates, as well as other segments of the involuntary deviant population, one generally finds

that each individual usually passes through a series of stages which are theoretically and from a research point of view crucial in the subsequent identity formation process of the involuntary deviant. The involuntary deviants exemplified in this research demonstrate that during the process undertaken in their renegotiation of identity, they undergo a series of events where their awareness and patterns of acceptance of self and others are developed. In the immediate post-operative stage for the medical involuntary deviants, their self identity appears to be more facilitative for acceptance because the group that determines their legitimacy to a large extent in the immediate post-operative stage is medical.

By noting the stages which ostomates encounter, we discover the processes through which they are assigned a social identity as involuntary deviants by others and subsequently enter upon ongoing careers as deviants. The labelling theorist Lemert states:

The empirical evidence now available makes it doubtful that the emergence of a new morality and procedure for defining deviance can be laid to the creation of any one group, class, or elite. Rather, they are products of the interaction of groups (1973:457-468).

Once an individual has been a victim of involuntary identity, problems generally arise in the managing of this new deviant identity. The involuntary deviant must decide how much to integrate his social identity with his personal identity in various social spheres. With medical and paramedical personnel as well as with fellow ostomates, the ostomate is well advised to be open about his difficulties, but with non-ostomates (non-deviants) the value of openness is problematic.

How the ostomate, as an involuntary deviant, manages his damaged identity affects how he fares in his deviant career. For involuntary deviants, the effects of their careers, their successes and their failures depend on their social, psychological and physiological capacities to manage and adapt to their conditions.

Ostomates, like other involuntary deviants, are required to assume multiple roles with resulting strain on their personal identity. For the involuntary deviants, knowledge of the legitimate as well as illegitimate means of encountering the ramifications of this stress is important in their subsequent adaptations (Cloward, 1959:164-76).

Awareness and Identity Renegotiation

The findings of this study support the early symbolic interactionist perspective established by Thomas and Znaniecki (1918). From a broader sociological perspective, when one examines identity formation theory, large segments of society may be forced as a consequence of their perceptions of self or by the attitudes and values of others, to renegotiate their identities. Thus, if one examines involuntary deviants such as polio victims, the blind and ostomates, their renegotiation of identity stems from the fact that they present a new identity to society which is defined as deviant. The extent of this deviance, that is, the extent to which it disrupts or is perceived as disrupting the actor's previous identity, determines the degree of negotiation in which the actor must engage in his ongoing relationships. The involuntary deviant is stigmatized by large segments of

society and often by himself. The barriers to his subsequent interaction with other segments of society may be self-imposed or imposed by others. The ostomate, like others who as a result of their acquired disability are members of the involuntary deviant category, is often manipulated as a consequence of his own identity and the expectations of others, into renegotiation of his identity in the society of which he is a part.

Ostomate patients, especially those who are initially aware of the condition, tend to pass through five distinguishable stages of identity formation. During their transition from normality to ostomy status, they encounter a range of interaction from significant others. Ostomates tend to attach varying amounts of importance to the social meaning of these relationships. They often discover that their social encounters during the post surgical period have problematic outcomes. This is to be anticipated as ostomates and their interacting counterparts often possess differing expectations as to the significance of their conditions and the manner in which they as ostomates desire to be treated. What is occurring is a process of establishing and perhaps renegotiating one's identity. Renegotiating one's identity is often difficult because both patient and interacting audiences often possess differing sets of expectations. The advent of ostomy status tends to have immediate consequences for both the actor and his significant others. The immediate consequences for all parties may not be as severe as first anticipated and hence the majority of osto-

mates are able to re-achieve a near-normal existence. However, as our data show, twenty percent of ostomates encountered difficulties ranging from mild afflictions to severe impediments which may lead to isolation, hermitization and, in eight percent of the cases, suicide.

Ostomy victims often discover that their self images which they desire to portray are not stable and they and their interacting counterparts find themselves in anxiety-prone situations. The stigma often attached to ostomy conditions may serve to create and maintain patterns of strained interaction between ostomates and their interacting audiences. The new ostomate, like the ex-mental patient, often discovers that he may not be able to exercise control over the image he wishes to portray to the same degree as was possible before the advent of spoiled identity.

Strained interaction, at least through the initial stages of being an ostomate, was encountered by those who had previously experienced normality. New ostomates, in their initial relationships with medical personnel and subsequent relationships with medical personnel and former acquaintances often encounter the four patterns of awareness as illustrated by Glaser and Strauss (1971). Of the twenty-three patients in our study who experienced these patterns, eight maintained that a pattern of closed awareness that existed between them and their doctors was probably helpful. These patients did not know whether or not they could have successfully dealt with the consequences they were about to experience. The remaining fourteen patients demanded that an open

awareness pattern exist between them and medical personnel as they felt it was their right to know the consequences of the conditions they were about to encounter. From their perspectives, open awareness facilitated positive relationships with medical personnel, trust and subsequent rehabilitation.

In subsequent patterns of social interaction between patient and non-medical personnel, the four patterns of awareness were also encountered. Nineteen ostomates experienced little if any difficulty in exposing their conditions to members of their interactional groups. However, twenty-three of the ostomates, including those who had physically, socially and psychologically adjusted to their conditions, found that the significance of their spoiled identities often precluded normal acceptance. They found that a concealment strategy often can be a positive social manipulation that facilitates subsequent unhampered interaction.

Interactional difficulties do not occur for those ostomates who are able to conceal their conditions. Many ostomates like the blind and/or others who are disabled or disfigured have no choice in admitting the existence of their conditions. The utilization of disguise may be viewed as positive strategy as it allows some ostomates to live a "stigma-free" existence. However, this adaptive pattern is not open to some ostomates and indeed to many others who are physically handicapped or in some other way stigmatized and may force drastic changes in one's identity.

When actors find that they are unable to elicit patterns of treatment that they desire to receive and especially if they desire to be treated as normal, they encounter the consequences of stigma. Being victims of spoiled identity, many ostomates - like many ex-inmates of prisons and mental hospitals - are required to renegotiate their identity. The ability to manipulate one's pattern of acceptance depends upon a host of factors including the characteristics of one's primary groups, one's previously established identity, and on the extent of one's affiliations. In the establishment of one's identity, there is often a tendency to internalize the views of others. In Thomas's terminology, we encounter various definitions of the situation. When we find ourselves encumbered by spoiled identity, we are often required to explore the behavioural possibilities open to us by marking out the limitations which new conditions may impose (physical limitations and stigma) on our behaviour. What the ostomate frequently encounters is similar to what other stigmatized individuals and groups often encounter. There tends to be a rivalry between spontaneous situations encountered by members of organized societies and the definitions which society provides for its organized members.

Davis (1967) in his research on polio victims, illustrated the effects of extreme changes of life owing to the severity and consequences of disease. Ostomates, especially those who are detectable, often encounter relatively severe consequences. The new ostomate is required to come to grips with the awareness of a new and

imposed identity which often is in conflict with one's previously established identity. Some ostomates tend to demonstrate a tendency to become overly aware of the social and physiological limitations imposed by their altered physical status. This awareness tends to differ from the awareness patterns which Davis found amongst polio patients. These child polio patients took a relatively long period of time to become aware of the social and physical limitations and implications of their spoiled identity. However, the patients in Davis's study were children who were first and foremost affected by their relationships. Self-definition and perception often influenced by those outside of one's primary groups.

As Davis illustrated in his paper, "Deviance Disavowal" (1967), normals seldom grant social equality to those who are defined as being different. Relationships between normals and ostomates often proceed under conditions of anxiety due to embarrassment, concern, pity, shock, revulsion and compassion. These conditions often serve to destroy the normal basis of interaction. This leads to the utilization of defense mechanisms amongst those who are subject to a disabling condition. Many individuals subject to handicapped status resort to some type of defense mechanism such as evasion of responsibility, rationalization and disowning of undesirable qualities in one's self. Those subject to spoiled identity often become aware that the core of their being is influenced and perhaps totally regulated by expectations that subtly govern interaction between normals and those defined as disabled, inadequate or in some other way discredited.

When an individual or group is deemed to be out of phase, the ordinarily interrelated interaction is out of balance. Expressive events are being contributed through the encounter which cannot readily be woven into the expressive fabric of the occasion. Therefore, both the interactant and his interacting audience are placed in situations characterized by anxiety, fear and ambivalence with resulting inconsistent patterns of interaction and acceptance.

In an undefined situation where norms regulating behaviour are not explicit, it is necessary to study the emerging process of definition which is brought into play. Thus, conditions deemed to have stigmatized patients often have serious ramifications for their identities. The feeling of being threatened, found out, defined as being different and unacceptable often produces a sense of identity anomia amongst deviants like ostomates who are usually not responsible for their damaged self images. (3)

Acceptance and Adjustment to a Deviant Identity

The individuals subject to spoiled identity may become victimized by self-hate which is often enhanced by those who have relationships with them. They fail to accord them the respect and regard that the "uncontaminated" aspects of their social identities have led them to anticipate receiving. They echo this denial by finding that some of their attributes warrant their subsequent treatment. Some ostomates, like some polio victims and others who are visibly stigmatized, are often forced to admit their inadequacies due to the extent

of their impairments. In spite of being severely disabled, they may strive for normalcy. In Goffman's terminology, a phantom acceptance is thus allowed to provide the basis for a phantom normalcy. Some members of society are able to contend with the most drastic of physical abominations. Others elect various patterns of escape and in the most extreme cases resort to suicide. The difficulties which affect the ostomate often stem from the fact that the ostomate himself often shares the deviant labels applied by so-called normals. Thus, when an ostomy condition develops, the patient may be open for attack from within as well as from without. First impressions often become crucial in determining an individual's future potential and acceptance. (4) The problem of acceptance and/or renegotiation of identity becomes a crucial factor for the ostomate as well as for many other involuntary deviants. Acceptance can be enhanced by concealment.

The majority of individuals affected by stigma desire to alleviate its negative consequences. Many discover that they are unable to rid themselves of the spoiled identity which society assumes to be "given".

Society condones some patterns of concealment. Generally speaking, an individual who conceals a physiological blemish in order to attain acceptance tends to be admired, but those with criminal backgrounds and those who have formerly been labelled subversive tend to be used as monumental 'whipping boys'.

What has been analyzed in this investigation is the identity-formation process and renegotiation measures experienced by those who become functioning ostomates. As illustrated, the richest and most significant theory and research on the identity-formation process has been undertaken by those who follow in the tradition of symbolic interactionists such as Mead, Cooley, Goffman, Glaser and Davis.

For the ostomates studied, their subsequent functioning is in part a consequence of an understanding of the social meaning attached to being an ostomate. Some ostomates discover that their roles are changed fundamentally. Others find that their conditions are in fact not disabling and for many, becoming an ostomate alleviates more difficulties than it creates. Perhaps as a consequence of a concern for the twenty percent of ostomates who encounter difficulties in adjusting to their altered status, there has been a tendency to overlook the fact that eighty percent of the ostomy population achieve gains in terms of increasing life expectancy and eliminating painful conditions. However, the majority of ostomates, like many other involuntary deviants, are affected by stigmata and therefore may encounter identity stress.

An ill person may resume his role when cure is effected, but for the disabled and handicapped segments of society, the result of being so affected is to be assigned a deviant role. In the rehabilitative process, the form which the deviance will take is

outlined in spite of the efforts to alleviate its significance. Rehabilitation can be viewed as a socialization process, the purpose of which is to prepare the ostomate to play a type of deviant role.

The attitudes of patients to the placement of an abdominal stoma tends, initially at least, to be those of revulsion, disgust, horror and alienation from themselves and, in many instances, from others. The assault on human dignity and body image for many ostomates is severe. The stoma presents a continually wet surface and, at least, makes continual sexual contact messy. According to Freedman:

. . . the loss of a breast can be overcome, since the erogenous component of nipple stimulation is a minor one, but the attachment of a collecting device, however artfully disguised under clothing, leaves no retreat in the bedchamber (1975:648).

The continuous care that the stoma often requires changes many patients into emotional cripples as they encounter physical and psychological difficulties and many, in some instances, lack the emotional support necessary, desired or expected in endeavouring to manage an ostomy condition. Ostomates tend to demonstrate varying patterns of adjustment and most tend to benefit from the availability of self-help organizations that counsel, review and invent strategies permitting patients to deal with their altered physical selves.

Ostomy surgery relieves a disabling and often life-threatening condition, but it also introduces new problems involving social and personal acceptance. It is often seen as threatening personal esteem and disturbing or altering one's body image. Ostomates initially

wish to deny their condition and subsequently feel angry. They often endeavour to bargain in order to avoid the consequences of their condition and this process is followed by depression and finally, in at least eighty percent of the ostomy population - acceptance. Ostomates react to their (perceived) identity-spoiling conditions with a variety of responses including humour, self pity, compassion, apathy, apprehension and withdrawal.

Depression is a standard reaction. In a comparable examination of thirty-five patients with permanent colostomies following abdominoperineal resection for carcinoma of the large bowel, Druss et al.'s (1968) findings are less optimistic than ours. They found that depression, shame and helpless anger in the postoperative spheres were common. In the first year, regaining bowel control through a successful colostomy training was associated with the utilization of obsessional defences, whereas patients unsuccessful in re-establishing bowel habits became fearful, isolate and unable to handle the responsibilities of everyday life. These findings corroborate earlier work by Sutherland et al. (1952) with a similar group of cancer patients in whom feelings of unacceptability, self-directed anger and social withdrawal were universal in one form or another following abdominoperineal resection and the formation of a permanent colostomy.

As with the Druss et al. data, we found it difficult to predict which patients will and which will not respond positively during their post-surgical periods, except that most adjust reasonably well. We

found that acceptance of and adjustment to one's condition is related to one's ability to manage the condition from a physical perspective and successful management is often enhanced by being able to disguise the flawed "identity". Added to this, positive interpersonal relations, education as to how to manage one's ostomy, association with others who have successfully coped with the consequences of being an ostomate, are also beneficial to adjustment. Medically it appears that the best technology is available and being applied in managing the physical aspects of ostomate status. Theoretical and research development is of more immediate concern in the social aspects surrounding identity formation in cases of spoiled identity.

IMPLICATIONS FOR FUTURE RESEARCH
ON THE STUDY OF IDENTITY RENEGOTIATION FOR INVOLUNTARY
DEVIANTS

A fairly serious maladjustment rate among ostomates and a significant suicide rate indicates a potentially productive area for research in endeavouring to alleviate the difficulties associated with serious cases of maladjustment. Maladjustment has been extensively used to illustrate the usual by contrast in sociology and does not only extend to individuals noticeably afflicted by medical procedure and/or damaged by disease but affects many individuals who have been labelled as deviants by various segments of society.

Ostomates are perhaps one of the best illustrations of the dramatic effects of involuntary deviance on identity because their stigma arises from two fundamental alterations of ability to perform bodily functions which in most societies tend to be strictly regulated - the sexual and the evacuational. As such the renegotiation of new identities as experienced by people with these stigma under such intense social focus can contribute significantly to our understanding of the process of identity formation of those who belong to that segment of society defined as "involuntary deviants".

This study attempted to study the corporate life of the ostomate as an illustration of involuntary deviants who are usually required to renegotiate their identities in order to alleviate the consequences of spoiled identity.

FOOTNOTES

- (1) Because of the limitations of the sample as described in Chapter III, more research is required in the rehabilitative potential and adjustment patterns illustrated not only by ostomates who are not members of ostomy associations but indeed by other segments of the "disabled population" who refuse or who are unable to belong to their own "mutual benefit associations".
- (2) Perhaps the best example was the insurance executive who initially was able to contend with the physical consequences of being an ostomate, but who subsequently committed suicide because of the social ramifications resulting from his acquired status.
- (3) Identity anomia refers to a state in which an individual with a formerly established identity finds this identity compromised in his own terms or in the definitions of others as a result of what he has become or of what he is thought to have become. Some individuals subject to these ambivalent pressures choose to attempt to maintain their previously-established identities while others adopt a variety of adaptations encompassing the definitions of their newly-acquired and in the case of ostomates, involuntary status.

- (4) A young ostomate does not regard himself as a desirable prospective mate and in fact most normals tend to absent themselves from a romantic relationship with an ostomate. A survey of twenty-seven undergraduates in September, 1976 (thirteen males and fourteen females) indicates that only three males and four females would readily accept dates with ostomates.

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APPENDICES

APPENDIX A

RECOMMENDATIONS

ISSUES AND OBSERVATIONS

It is not the immediate goal of this research to make specific recommendations. However, it would be negligent not to put forward suggestions that can be extracted from the data.

The consequences of an ostomy have a psychological impact that extends to every significant aspect of living and is not simply confined to the patient learning a different mode of evacuation. Effective management of one's ostomy cannot be achieved unless the intense psychological impact is clearly recognized and dealt with. According to Sutherland et al.:

There are, however, patients whose basic methods of adaptation render them so vulnerable to the stress of surgical procedures or their sequels, that even extensive psychotherapy would seem to be without avail. But the patients for whom psychic devastation is the price of survival are few. By and large, whenever serious curtailment of function or activity occur, with the single exception of sexual impairment in men, it represents a failure of management (1952:869).

Even a satisfactory counselling program and adequate information may not be able to provide the necessary support for some to enable them to be successfully rehabilitated.

Due to the ramifications of this surgery, not only is invalidism common, but also severe and extensive depression that induces some individuals to contemplate suicide. It must be admitted that the majority of

individuals in society at one time or another contemplate taking their own lives, but various works as those of E. S. Shneidmann (1960, 1963, 1967) indicate that this is a normal reaction to depression and anxiety. When people undergo ostomy surgery some become so upset that they develop suicidal depression. The situation becomes more difficult when it is realized, especially by the surgeons and other medical personnel involved, that the only means to survive is via ostomy surgery.

Rehabilitation of the ostomy victim is not easy from a technical point of view as a person's reactions to the handling of his or her own waste and to the subsequent spoiled identity is almost impossible to measure objectively. Rehabilitation of the ostomate requires a consideration of these sixteen issues and recommendations:

1. Pre- and Post-operative Counselling

Successful rehabilitation begins prior to surgery and utilizes concerned medical and paramedical personnel in a coordinated team effort. Pre-operative counselling should take into account the psychological preparation for the surgery. This part of the procedure is just as necessary as pre-operative physiological preparation of the patient's body systems to optimize the patient's adjustment and adaptation after the surgery. Although it is difficult to relieve the patient from the fears and apprehensions associated with having this surgery, it is important to inform the patient of the problems and situations he may expect to encounter in his post-operative recovery period.

During this preliminary stage, and at all times during the

hospitalization period, medical personnel must be aware of the acute anxiety faced by patients and they should also realize the trust and reliance placed upon them by the patients.

Pre-operatively, patients have fear of damage and death ensuing from their disease and the surgery itself, even though many of the patients are unable to verbalize these feelings. Successful socio-psychological counselling before surgery may relieve the panic, despair and confusion that occur. Psychiatric and psychological intervention may be necessary in order to prevent or at least alleviate depression and invalidism.

Only a few medical and paramedical personnel and family members are able to discuss with the patients the issues and concerns which they immediately face. Patients need to express their fear of death, grief, loss, anger and frustration and the opportunity should not be denied them. Many of the patients in this study expressed the concern that they felt abused by the fact that they could not frankly discuss their situations with their doctor or family.

I didn't have any advance counselling. The doctor told me what was wrong and what my operation would be - if you consider that counselling. My wife and family and myself never had any counselling to speak of. The doctor told both of us that I had cancer and it had to be removed. He was quite brief in the explanation ... I don't think, however, that he mentioned at all the subject of appliances and routines and strangely enough, I don't think that aspect of the event ever went through my mind before I was faced with it ... I did not understand most of the explanation at the time. I guess because the appliances weren't even mentioned that they thought they'd take care of my reactions afterwards.

I think that prior to an ostomy operation, everyone in one's family should be counselled. It would help; it gives them confidence. They should get it before the operation, rather than face the fear of coming home afterwards. Some people I know just can't cope with the idea. (1)

In theory, counselling should constitute a major input in the pre- and post-operative environment, however, few of the patients in this study (i.e. eight out of thirty-five) maintained that there was an actual program or semblance of a program to which they were directed in order to understand the problems and prospects of their surgery. The surgeon (in three of the cases) and the family doctor (in the other cases) endeavoured to have the individual either "plugged in" to an Ostomy Association or to answer the questions himself, or to provide a situation whereby the patient and also the members of his family were adequately counselled. This function should be handled by competent and skillful people; yet even some surgeons are hesitant to inform their patients of the consequences of surgery. For example, when a man is about to have an operation for an ileal conduit and/or cystectomy (removal of the urinary bladder) and wishes to know the chances of remaining sexually potent, he should be told that this type of ostomy surgery will probably render him impotent. If the patient has not been informed beforehand, this creates a dilemma for the paramedical personnel caring for him after his surgery but it seems reasonable that his doctor should be the person to convey this difficult information. Some doctors wish to escape the "social pressures" of this type of surgery. One male who was interviewed angrily protested that:

... if that S.O.B. had told me that this would happen to me, I would have rather died. Who the hell does he think he is? How can they screw up my body like that? (1)

Another patient who was interviewed further complained that:

If only he had the guts to tell me. We had one child, we are trying to adopt another but we've been waiting five years! I have read the fact that they can store sperm - why didn't they tell me? Sometimes I've thought of killing him! (1)

Another patient interviewed before his surgery commented:

They tell me I'm going to be all right. I'm having a conduit but everything is going to be O.K. - the doctor assured me of this. (1)

Obviously, this is not going to be the case. The patient appeared to have little or no knowledge about the results of his surgery (i.e. possible impotency). He is twenty-seven years old, married and with two children.

How does one relate the type and consequences of "drastic" surgery? The medical and paramedical personnel have had only a limited opportunity to prepare the patient physiologically and emotionally for surgery. Even when the individual has the realization that he will require surgery over a relatively long period of time (as in the case of a person suffering from chronic ulcerative colitis) and knows that sooner or later he must live with a stoma, the difficulty for most is apparent. Some surgeons feel that it is very important to assess the patient's readiness to learn and accept and then plan accordingly. It is sometimes asserted that some patients should not know in advance what will happen to them as those patients are believed to be unable to cope. After the surgery there is no choice. According to a stoma therapist:

You cannot tell patients everything. The amount of information depends to some extent on the individual patient. But there must be an honest explanation, I believe, framed in terms that will be understood and beneficial to the patient. Semantics are crucial; let me give you an illustration. I knew of a patient who was required to undergo an ileal conduit because she had cancer of the bladder. The surgeon told her that she would have to wear a 'bag' for the rest of her life after the operation. The patient could not accept this and was in a state of what I would categorize as shock, absolutely refusing to submit to surgery. Her dismay obviously was not only a consequence of the type of surgery, but an important thing was revealed to her in terms of the fact she would have to wear a bag!

One has to be very careful because if you remark to a patient that they must wear an appliance after surgery which will take care of their bodily wastes, perhaps they can come to grips with their situation much easier. In other words, one has to be very cautious in approaching these patients. (2)

On the other hand, there is the view expressed by doctors Winkelstein and Lyons, both medical advisors for the Ileostomy and Colostomy Societies of New York. They believe that:

With some patients, groundless optimism or belittling of the ostomy itself is likely to produce adverse results - causing the shock of reality to be all the greater. Conversely, it is also inadvisable to go into more detail than is solicited. A lengthy, over-precise lecture can simply increase anxieties. With others, however, details can allay various concerns that will arise from insufficient clarification (1971:4).

These doctors believe the most effective answer is to demonstrate an appliance in use by having another ostomate come for a visit.

When I went to the hospital, I did ask what the appliance would look like, and I did not say anything about the stoma - I was scared! I knew it would be there, but I didn't want to ask. I didn't want to know - I was afraid! (1)

It appears, then, that even when patients are briefed on the details of their surgery, it is difficult for most of them to comprehend the explanation. As one patient stated:

They said something about a stoma. I forget.
When you are under that kind of pressure - who can
remember? (1)

It may be that the best policy is to let the patient determine how much detail is to be divulged and this would be determined by the relationship between the patient, his doctor and the attending physicians. Unfortunately, because of the problems in terms of time and obligations, many physicians do not have time to be involved with the patient. An illustration of how quickly the diagnosis can be made and the operation performed on a more or less impersonal basis is revealed by the following incident:

I met my surgeon after I was sent there by my GP. He did a number of tests and then sent me to the hospital for two or three more tests. He came into my room and told me that I had cancer and he would be forced to operate as soon as possible. An hour and a half later I was in surgery! That was all I knew. (1)

There is also the surgeon's point of view.

I am not certain, although I try and spend as much time as possible with the patient prior to an operation, how much anxiety I can alleviate. In any patient, whether they know the consequences of surgery or not, even for a tonsillectomy, there is always a severe emotional reaction, regardless of pre-operative preparation.

And I believe that perhaps it is self defeating to warn the patient that this can be expected because obviously this would only add to his anxiety. I believe that it is after surgery that my position and the position of others is to reassure the patient that a response of depression is normal. But to convey this information to him in advance, perhaps adds to the difficulties that we are trying to alleviate. (3)

Lack of understanding and/or the fear of informing the patient is illustrated by another surgeon. He quite coldly said to a fifty-two-year-old patient:

Better to live than to have sex. You're too old to worry about sex anyway; at this age, why should one be concerned about sex. Isn't it just good enough to be alive? (3)

The importance of sensitive, informed and well-presented counselling during the stages encountered by the ostomate in his pre- and post-operative period cannot be overemphasized.

2. Advantages of Family Counselling

Ostomy surgery affects not only the patient but also his family and his relationships with others. Pressures, anxieties, depression and tensions are transferred from the patient to those around him. Therefore, it is deemed necessary to counsel not only the patient involved, but members of his immediate family as well. This helps to ensure that the family will understand the needs and situation which the patient experiences so that the family will be able to adequately give the patient the necessary support.

Ostomy surgery is done for a variety of conditions, but no matter how beneficial it is, even when it is curative, the surgery itself leads to significant problems for both the patient and his family. And it is very important to remember that they form a unit - the patient and his family (Schuster, 1973:7)

The interviews undertaken for this investigation demonstrated that only three in thirty-five cases had family members who were encouraged (and, in one case, almost forced) to participate in the counselling program. Yet in fifteen cases, the patients felt that various members of their family tended to heighten their anxiety and depression. Perhaps this situation could have been avoided had these families been included in a counselling program for the patient.

3. Post-Surgical Psychiatric Difficulties

Most of the psychiatric difficulties that arise occur after surgery. The psychiatrist or psychologist can serve a useful function on the ostomy team by alerting the surgeon before the operation as to the mental and emotional status of the patient and how the surgery may possibly affect him. The difficulty is that many psychiatrists seldom come into contact with ostomy patients and their role is often minimized by their lack of familiarity with the problems. Therefore, it would appear that proper training and exposure of psychiatrists to this particular field should be able to contribute valuable aid in counter-acting emotional problems that many ostomates experience.

Intelligent use of the informed psychiatrist may forestall curtailment of function, an easier job than repair of chronic deterioration (Sutherland et al., 1952:871).

In the cases surveyed, there was no psychiatric intervention until in the post-operative phase when the patient reached an abnormal state of anxiety. It appears that in the counselling process both pre- and post-operatively, psychiatric consultation could play a positive role in helping potential ostomates and/or functioning ostomates to adjust to their altered position.

4. Sex Counselling

Another important area of counselling that has been ignored is that concerning the implications of ostomy surgery on the patient's sexuality. As has been illustrated, this area of human functioning and

gratification is the least discussed of all the problems facing the ostomate. Medical and paramedical personnel repeatedly avoid counselling the patients on this matter and the patients themselves tend to suppress their anxieties about their sexual future and are afraid to discuss their problems openly. Sexual impairment in the case of the ostomate can be either organic or psychological and as such the patient needs expert professional help. It should not be assumed by either the patient or doctor that this difficulty will eventually resolve itself. The following recommendation may provide a solution for this poorly handled area.

We must not think that people are so liberal that they spontaneously ask about sexual problems themselves, especially if there are other persons in the room. We therefore believe that an expert on sex matters should have a place in follow-up organizations that nowadays are considered necessary for colectomized patients. We should find a sex expert for one or more talks with the patient and probably also for his or her partner (Geiger, 1972:2).

What is suggested is that a sex counsellor should have a prominent position in the rehabilitation programs specifically designed for ostomates. This counsellor's function should be made known to both the ostomate and his or her spouse immediately after the operation and before it if possible, so that the problems can be worked out as they develop. A program of this type could expel the current myths surrounding ostomate sexuality and it may dispel tensions and anxieties that could lead to breakdown of a marriage. It could also function to guide the young, unmarried ostomate in attempts to date, court and find a suitable mate.

5. Influence of Other Ostomates

It has been demonstrated that the person of most benefit to the new ostomate (or soon-to-be ostomate) is the functioning ostomate from the local Ostomy Association. There is a possibility, however, that although these persons appear to be successfully coping with their own situations, they may try and demonstrate techniques which are beyond the mastery of the new ostomate. At the same time, some ostomates develop difficult and negative adaptations and they may try to impose their routines, ideas and solutions to problems where these are not appropriate. Their visits with ostomates may extend to other areas of counselling and this may or may not be desirable.

A successfully rehabilitated ostomate should be included in every ostomy team, but efforts should be made to be certain that the ostomate is not disturbed himself or that his personality and habits do not clash with what is intended for the patient.

6. Post-Surgical Problems

The ostomate, in addition to having his life system altered, becomes a permanent patient in that he is subject to a number of side effects of the surgery such as hemorrhage, urinary tract difficulties, hernia, stenosis, as well as the possible recurrence of bowel obstructions or cancer. These difficulties which may occur have both physiological and psychological origins. Therefore, the patient finds himself in the situation where he may have to rely on the diagnosis of his doctor

on a permanent basis. The patient should avail himself of check-ups at regular intervals. Fear of recurrent cancer and a fear of further destruction of one's self both psychologically and physically tends to inhibit the patient from developing and maintaining a strong post-operative medical check-up program. These check-ups are seen as desirable by all surgeons and doctors.

7. Ostomate Identification

To both the social welfare and medical professions, ileostomies and colostomies present a problem. Several reasons are given for this.

The operation is new and comparatively infrequent in the general population. Thus each professional person's experience is limited (Lenneberg and Rowbotham, 1970:12).

Preliminary analysis and general discussion illustrate that the public by and large is ignorant when it comes to this type of surgery. Most people know very little and what knowledge they possess is usually inaccurate. One man who was interviewed commented:

I found that whenever I answered someone's question as to what I was doing specifically, the reply was, 'Oh, what's that?' (1)

Another man found that while he was showering at a health club, people would look curiously at his appliance and one person even asked, "Is that a hernia?"

Hence, every ostomate should carry an identification card briefly describing his method of appliance removal, skin care and listing the name and telephone number of the doctor or hospital to contact in case of an

accident or emergency. Lenneberg and Rowbotham feel that:

The ileostomy (and colostomy) are still new conditions and may not even be recognized by hospital personnel (1970:115).

If this is the case, every ostomate should definitely have some method of identification about his person at all times.

8. Ostomy Team Formation and Function

The medical profession and related paramedical personnel, in their wide variety of roles up to the present time, have failed to evolve strategems which provide a method or methods of maximizing an ostomy patient's rehabilitative potential.

Hospitals with very few exceptions have not developed a routine care program. There exists ambiguity as to roles and areas of responsibility among the members of the care-taking team (Lenneberg and Rowbotham, 1970:12).

This problem is perhaps the most serious impediment to successful rehabilitation. One envisions that under ideal conditions there should be an Ostomy Team within the hospital environment. They would be well versed and experienced in the difficulties involved in ostomy surgery and recovery - physical, social and emotional. This specialized Ostomy Team may include referring physicians, surgeons, nurses, stoma therapists, psychologists, psychiatrists, social workers and visiting ostomates from local Ostomy Associations. This group would provide an organized and educative approach to the ostomy patient's rehabilitation. A team approach is valuable in that the patient's progress from diagnosis through surgery to recovery can be carefully monitored and constantly supervised by the various team members so that the patient can receive

the benefits of professional guidance and counselling throughout the entire process.

9. The Role of the Surgeon

From a psychological perspective, the role of the surgeon must be interpreted as a positive and perhaps even a "fatherly" figure. That is, in order to successfully alleviate the patient's fears, he must be perceived as a protective figure rather than as a punishing individual. It is usual for patients to conceive of their general practitioners and surgeons as extremely powerful, important and personal support figures. Most patients expect considerable emotional support and extensive discussion both before and after the operation. In most cases, the surgeon views his role in a less personal light. The following perspective illustrates how the surgeon views his role and function.

I am only one of a few surgeons in this particular location who does perform this surgery. I spend as much time with the patient as possible, but in all honesty, I seldom spend more than two hours with a patient before the operation. During his two weeks afterwards I may see him for a combined total of forty minutes.

One just has to realize the obligations to which one is subject. I have my obligations to the patient, to my practice, to the hospital, obligations to my family, and I just cannot spend hours or days with a patient. All surgeons, and in fact all doctors and nurses, are under the same set of expectations. I know that there are some surgeons who spend a minimum amount of time with their patients. I spend as much time as I can afford in order to perform good medicine to all the patients with whom I am involved. (3)

Another surgeon expressed this viewpoint:

It is incorrect to believe that one can develop a satisfactory relationship between a surgeon and his patient. I just do not have the time! We cannot have friends. There is an importance only from a scientific point of view in the doctor-patient relationship. (3)

The expectations of both patients and surgeons are surrounded by atmospheres of ambivalence and anxiety.

The role of doctors and their relationships with patients has been explored in depth in many studies. The precarious position of physicians and surgeons can best be summarized by the following statement made by Dr. A. H. Letton:

The problem thus far considered pathogenesis, etiology, detection, diagnosis and therapy for colon cancer. It is now time to consider the individual who is the host of this tumour. It is our duty as physicians not to treat the tumour alone, but to consider the patient as a whole, that he may hopefully return to a normal, healthy and useful life.

The quotation from St. Matthew: 'For what is a man profited if he shall gain the whole world and lose his soul?' can be paraphrased to, 'For what is a man profited if you save his life from cancer and he loses his ability to live, if he loses his ability to make a livelihood, if he loses his social acceptability?' It is obviously our duty to rehabilitate these patients by teaching them how to take care of their colon and their colostomies so that they may return to a normal, useful, socially accepted life (1971:219).

10. The Role of the Referring Physician

Another important factor which can relieve immediate post-operative tension is for the referring physician to be present during the operation. This helps to diminish some anxiety and increases the patient's belief that he is in "good hands". Thus the surgeon's every procedure will be viewed by a doctor who is assumed to be personally concerned with the patient's well being.

11. Post-Operative Care

Post-operatively, the role of the surgeon, family doctor, and allied personnel is crucial in helping the patient through this difficult stage. These are the personnel who come into direct contact with the patient's physical and emotional needs. Their primary functions are to diminish the anxieties that patients face. In attempting to carry this out, these personnel must realize that they are not only performing post-surgical care, but that the patient must leave the hospital being completely trained in the methods of caring for himself. He must be made aware of what to expect when he returns home. The earlier this type of training is begun, the easier it is for the patient to readjust in the post-hospital phase of his rehabilitation. Encouraging and forcing patients to care for themselves brings forth anger and expressions of resentment towards hospital staff even though this early forcing of self-help may be advantageous to the patient in the long run. One woman commented on her treatment while in the hospital:

I was really upset when I was in the hospital. Right after the operation they forced me to see my stoma, they showed me how to keep it clean, and they pushed me to do it. I was really angry; I thought I was paying for it, or at least my insurance was paying for it and I was entitled to care. But they were extremely strict and you know what - it was a good thing! Because when I left the hospital I could look after myself. I have met several individuals at the Ostomy Association who when they went home from the hospital were complete invalids. They had had around-the-clock care and they hadn't had to do things for themselves. When the necessity of doing things emerged, they were at a loss. I've never had spillage; I can control my odours and this was because of the way I was treated in the hospital.

What I am saying is that perhaps hospitals should deal more harshly with patients in this condition. It alleviates depression, it creates hostility against them - which I guess is perhaps positive. I did it with myself and said to hell with them! I certainly learned a lot! (1)

Overprotection and "unusual" care within the hospital may be a distinct disadvantage to the patient. Another individual remarked on his care while in the hospital:

My greatest criticism in the hospital was what they did for me. They did too much! They looked after me completely and when I went home, I had to do it myself, but I had never really had to do it myself before; I had all sorts of problems.(1)

12. The Importance of Training in Waste Evacuation

Body evacuation is the most important factor in the rehabilitation of the ostomy patient.

In his case, the requirement is for a means of dealing with body evacuations. When he can do this completely successfully, he experiences no permanent physical handicap, and he neither needs permanent medical management nor retraining, nor special considerations in the environment (Lenneberg and Rowbotham, 1970:9).

Thus the person with an ileostomy or colostomy must learn a new method of body waste elimination which was previously automatic. This, according to Lenneberg and Rowbotham, is the first major step in the rehabilitation of the ostomy patient - successful management of his ostomy.

This is the sine qua non of rehabilitation; this basic task and all it entails is what makes the stoma patient different from all other patients (Lenneberg and Rowbotham, 1970:9).

From one perspective, some colostomy patients are fortunate; they are able to learn how to irrigate and this allows them to lead relatively controlled

lives. However, these advantages do not befall the ileostomy patient. Basic to the resumption of activities is the ability to handle the stoma and body waste, and this should be taught to all patients while they are still in the hospital. This function can best be handled by a trained stoma therapist.

Within the confines of the hospital the stoma therapist's role becomes crucial. This person is in an important position to help lessen the emotional anxieties and fears present in patients - by both teaching them to take care of themselves, and by providing valuable information about their conditions.

A patient's inability to learn quickly is usually not a consequence of incompetence from an intellectual point of view, but it is more related to the disruptive effects of anxiety and depression which are often heightened by the patient's first sight of the stoma and body waste. One stoma therapist who was interviewed commented on her role:

I have to give my instructions many times over without showing impatience. One thing I have discovered is the necessity of conveying the same information over and over again to the patient until he understands.

There are so many different processes available, and to keep changing appliances for patients even once or twice, can lead to untold difficulties. Those who are able to irrigate successfully really resolve much of their anxiety and self-depreciation. However, others have extremely negative feelings concerning their gas, their feces, and what other individuals think of them. These persons are concerned because they will not always appear clean.

My role is a very positive one in teaching the establishment of bowel control, so that they can resume their normal functions in all areas of life. Unfortunately, the wrong comment by doctors, nurses, family and friends can do so much

destruction that they need me and a psychiatrist to sometimes undo the damage. The odd time it cannot be done. During my practice I have had about seven patients who have tried suicide and two who have been successful. You can understand the anxieties involved and this is a danger which we must face. In all likelihood there are some who would have committed suicide anyway in this way; there is not too much that can be done. The counselling must be done prior to the surgery.

As you know, individuals have different makeups, and it is impossible in many instances to judge the consequences. You know, it is a difficult situation but when you finish the problems of colitis or cancer, more problems are renewed by the surgery. Surgeons and other individuals like myself cannot play 'God', we can only try our best. (2)

The original stoma therapists were ostomy patients who sought training in order to be able to respond to the needs of other patients. Benfield et al. suggest that the complete acceptance of the therapist is not usually possible if the therapist is new and strange to the hospital. They therefore recommend that:

... therapists should be selected from the nursing or allied health personnel of the institution whenever possible (1973:64).

Gradually, more and more vocational nurses and registered nurses have become trained as enterostomal therapists and the current trend appears to be that of registered nurses becoming trained as therapists. Benfield et al. suggest the following recommendations:

We believe that trained, competent enterostomal therapists with less formal training than registered nurses are fully worthy of support and recognition. However, we also believe that the trend toward professional registered nurses assuming the enterostomal therapist role is a healthy one that will prevail because the role of the enterostomal therapist so often requires psychological and medical insight not generally available to people with lesser training (1973:64).

These researchers recommend that enterostomal therapists should also be closely related with surgeons and that these services should be hospital-based wherever possible. The reason for this is that they

have found repeated instances where patient care has significantly benefited by the stoma therapist being able to consult a surgeon or physician with ease and regularity. Currently, less than half of the therapists in the United States are hospital-based (Benfield et al., 1973:65).

Furthermore, training programs without instructors trained in teaching techniques and without active physician participation are to be condemned, since the success of ET (Enterostomal Therapy) depends upon competence and maturity (Benfield et al., 1973:65).

The emphasis should be on a well-structured, adequately funded, formal training program. Benfield et al. (1973) recommend that every hospital which regularly has ten or more hospitalized patients with intestinal stomas should have an enterostomal therapy program and those hospitals that have fifteen or more stoma patients need to have one or more stoma therapists on their staff.

These researchers conclude their study of enterostomal therapists by stating:

We hope that large hospitals will see this need and that small ones form consortia in which they share the services and costs of ET programs. Thereby, the general levels of enterostomal care will be elevated from what it is currently to a level that is more acceptable to patients and physicians (1973:65).

13. Problems Associated with Appliances

Basic to the ostomy patient's adjustment is his physical ability to properly utilize the available appliances. One important basic change

is adjustment to the appliance. In Lenneberg's study, she found that forty percent of the population she studied indicated that they had appliance problems; fifty-four percent had skin troubles and forty-six percent had problems with odour (1970:11). In the study at hand, it was found that twelve of the participants had trouble with their appliances, fifteen had skin problems resulting from poor appliance fitting and thirteen had problems with odour. Lenneberg's conclusion was that the influence of appliance failures on the rehabilitation of the ileostomy patient was profoundly disturbing. Learning to manage one's ostomy successfully is the most fundamental aspect of a person's rehabilitation. It only follows then, that the perfection of rehabilitation will depend to a great extent on technological advances in appliance design. The prevention of personal failure on this clinical level (i.e. ostomy care and management) is entirely possible for the colostomy and ileostomy patient with the knowledge and equipment available today to appliance researchers. However, at the present time:

... technical development of prosthetic devices is only partially efficient, which causes difficulties for almost every patient at some time (Lenneberg and Rowbotham, 1970:12).

14. Medical-Paramedical Communication Problems

Amongst doctors there has always been a noted hesitancy to consult one another. Consultation may be viewed in a positive perspective as a process during which the symptoms of patients can be discussed and re-examined with the goal of obtaining an accurate and precise diagnosis. Some physicians demonstrate considerable reserve when it comes to

consultation. Those who demonstrate a willingness or who make a habit of trying to consult with others are sometimes looked upon negatively by their colleagues. It appears that undue consultation or the desire for this consultation may be seen by the surgeon involved or by others as a sign of lack of knowledge, if not incompetence. Therefore, the possible fear that one may seriously compromise one's status by excess or overt consultation may hinder or inhibit some physicians from seeking expert advice.

There is also a gulf in terms of open consultation between medical and paramedical staff. Often physicians and surgeons regard other paramedical staff members as service workers. The term they tend to use is not "consultation", but "direction". One statement from a surgeon interviewed illustrated this phenomenon: "I tell them what to do and they are expected to do it. I know what is best for my patients."(3)

Many nurses, psychiatric social workers, and other paramedical persons are in a better position to have greater insight into particular problems of the patient whom they see more often than the attending surgeon. Because this communication gap exists between these two groups of hospital personnel successful consultation between them seldom occurs. If these individuals were able to consult openly many patient problems could be minimized.

Some paramedical personnel have distinctly recognized roles. The social worker becomes an important individual in terms of being able to provide arrangements for convalescence. Social workers can also deal with job problems and placement changes when necessary. The psychiatric

social worker is trained to recognize problems in interpersonal and family relationships and is in a position to help alleviate many of these as they develop. The psychiatrist and the psychologist are in similar positions. Their roles may become crucial, especially for those who have a great deal of difficulty in adapting.

APPENDIX B

THE HISTORY OF OSTOMY SURGERY

Although the first recorded colostomy was credited to a French surgeon, Alexis Littre, in 1710, he only suggested how it might be done; he really did not make the first colostomy. After observing the postmortem examination of a six-day-old infant who had died from an intestinal obstruction, Littre suggested bringing the bowel to the abdominal wall (Sterling and McIlrath, 1970:80).

The first colostomy that was attempted took place in 1776 and it was performed by another French surgeon - Pillore, in Rouen, France. The patient suffered from an obstructing carcinoma of the rectum and so Pillore performed a cecostomy based on Littre's original description, but unfortunately the patient did not live long after the operation.

In 1784 a surgeon named Chesleden unknowingly performed one of the first colostomy operations on a woman named Margaret While in England. She suffered from an obstructed umbilical hernia, causing the colon to protrude at the umbilicus (navel). Chesleden trimmed off this protruding colon and she lived many years after, "voiding excrements through the intestine at her navel" (Devlin and Plant, 1969:231).

The first successful deliberate colostomy operation was performed by Duret in Brest, France in 1793. He formed a colostomy to correct an imperforated anus in a three-day-old infant who lived for forty-five days after the operation (Devlin and Plant, 1969:231).

Duret also reported one of the first complications - a prolapse. (4)

By 1880 surgeons had learned that if they opened the abdomen it was usually fatal for the patient. Therefore, a surgeon named Amussat conceived of the idea of a lumbar colostomy. In this procedure, a cut was made under the ribs and just in front of the left kidney on the patient's back. As can be imagined, a colostomy on one's back was not very easy to manage and most inconveniently located for irrigating and changing appliances. However, it was out of sight and was considered safe at that time. This method became widely used in the nineteenth century but was gradually abandoned as its disadvantages became apparent.

Originally, a colostomy was referred to as a preternatural anus by its early researchers in the field and for many years it was called by that name (Turnbull and Gill, 1973:42).

Slowly the colostomy became an accepted method for relieving obstruction in the colon and rectum and surgeons began studying the possibility of ileostomy for treating small intestine obstructions. A surgeon named F. Henrotin first suggested this procedure in 1893 but it was not until 1903 that F. B. Lund first reported an ileostomy method for small bowel obstruction (from complicated appendicitis). It was not until 1913 that J. Y. Brown performed the first external ileostomy. His procedure of dividing the bowel, closing the end section of it and establishing an end-type ileostomy through the abdominal incision, was used without much modification until the 1950's (Sterling and McIlrath, 1970:80-81).

Problems of water and electrolyte (salt) imbalance usually occurred and resulted in cramping pains, profuse watery discharge, and

vomiting when the ileostomy was made. This "ileostomy dysfunction" was caused by partial obstruction of the stoma. Because of these complications, F. W. Rankin advised in 1931 against colectomy until the ileostomy became better established (Sterling and McIlrath, 1970:81). Therefore, while colostomies were being made since the early 1900's, ileostomies were not performed with frequency until the late 1940's. Ileal conduits have been performed only since 1950 (Lenneberg and Weiner, 1973:7). It is still not possible to document data on the long-term survival rate of the ostomy population. Lenneberg (1973) points out that there is a fairly high mortality rate associated with certain diagnoses while others reveal a survival rate as expected for the general population. Dr. A. G. Parks carried out a study of long-term prognosis of ileostomy patients and concluded that the death rate for ileostomies (in his sample study) was 0.15% per annum due to complications arising from the ileostomy (1965:793-794).

Prior to the development of modern surgical techniques, ostomies of all types were considered to be high-risk surgical procedures. Before the early 1950's, the life of an ostomate was not entirely pleasant due to the fact that the appliances were not leak-proof, many were malodorous and provision was not made for protecting the skin from irritating discharges from the stoma. Therefore, because the surgical techniques and post-operative management of such surgery had not been adequately developed, the mortality rate was fairly high among these patients. Often the stomas were placed so that they could not be fitted with a satisfactory appliance.

For these reasons, gastroenterologists in the past seldom advertised ileostomy or colostomy for patients with ulcerative colitis (Turnbull and Crile, 1951:239).

Dr. J. E. Dunphy thinks back on his past and recalls the following:

... I think back to the early days of the operations of colectomy, when I was an intern and a resident. At that time, an ileostomy was regarded as a fate worse than death. I can remember many distinguished physicians literally refusing to have their patients operated upon because of the tragic result of having to live with an ileostomy. And I remember the earliest days and the difficulty we had learning how to use appliances. ... (A)t that period of time the psychiatrists were saying that patients suffered from colitis because of their nervous systems; they were really sort of crazy people who couldn't face life and so they developed chronic diarrhea (1972:19).

In the last few years, advances have been made in the post-operative management of ostomy patients and this has resulted in a striking reduction in both morbidity and mortality rates after the surgery. Mortality rates declined rapidly from 1949 on.

For example, in the past two years (September 1949 - 1951) we have performed subtotal colectomy with simultaneous ileostomy twenty-two times as an elective procedure for chronic ulcerative colitis and removed the lower sigmoid colon and rectal stump as secondary operations in twenty-seven cases without a fatality. Rehabilitation of the patient occurred promptly after removal of the colon as exemplified by one patient who gained thirty pounds in the first thirty days, and no patient has failed to make a satisfactory social adjustment following the ileostomy (Turnbull and Crile, 1951:239).

It is significant that these dramatic results, at least from a physiological point of view, have taken place in general for ostomy patients. Many of those who die do so because of neglectful diagnosis and/or contraction of other diseases such as pneumonia, infections and other afflictions which generally affect those more advanced in age.

The findings of two doctors, R. B. Turnbull and G. Crile, although applying directly to ileostomies, can also be generalized to apply to all those with ostomies. These findings were reported as follows:

1. Prolonged conservative treatment of intractable ulcerative colitis is both dangerous and unsatisfactory.
2. The mortality rate from cancer of the colon ... exceeds the risk of colectomy.
3. One stage colectomy with simultaneous ileostomy is the safest and most effective treatment for acute toxic ulcerative colitis or for the severe intractable chronic forms of the disease.
4. There is no place for ileostomy alone in the treatment of ulcerative colitis.
5. In acute toxic ulcerative colitis, the mortality rate among patients having one stage ileostomies and colectomies is only one-third that of those receiving medical treatment or having ileostomies alone.
6. In chronic, nontoxic forms of ulcerative colitis, there has been no mortality in a consecutive series of twenty-two elective one stage ileostomies and colectomies, followed in most cases by removal of the rectal stump.
7. Since a properly made and placed ileostomy fitted with a modern type of appliance enables the patients to make satisfactory social and economic adjustments, there is no longer any reasons to deny the benefits of one stage ileostomy and colectomy to those whose lives are threatened or whose social and economic activities are limited by ulcerative colitis (1951:244-245).

As this particular passage demonstrates, the technical difficulties involved in the surgical procedure have been substantially lessened. Now the problems that result from ostomy surgery tend to stem more from social and emotional difficulties than physiological factors directly

related to the surgery. It is these psychological and emotional problems that now must receive the focus of attention of all those directly concerned with ostomy surgery.

APPENDIX C

TYPES OF OSTOMIES

The diagrams that follow are pictorial illustrations and brief descriptions of the various types of ostomies. There are also diagrams of a complete, intact intestinal and urinary tract which are included to be used as points of reference from which to see the changes made in these body systems by ostomy operations.

There are three basic types of ostomies: the colostomy, the ileostomy and the urinary ostomy. There is only one type of ileostomy but there are several types of colostomies and urinary ostomies. The type of ostomy that one requires depends on the disease or affliction that necessitates the surgery. In general it must be remembered that most ostomy surgeries take place on a more or less emergency basis. That is, the patient has had very little time to accommodate himself to the need for surgery.

The descriptions that follow may use medical terms that are unfamiliar; please consult the glossary in the Appendix.

fig. 1

THE INTESTINAL TRACT

- A - Mouth
- B - Esophagus
- C - Stomach
- D - Small Intestine
- E - Cecum
- F - Ascending Colon
- G - Transverse Colon
- H - Descending Colon
- I - Sigmoid Colon
- J - Rectum
- K - Anus

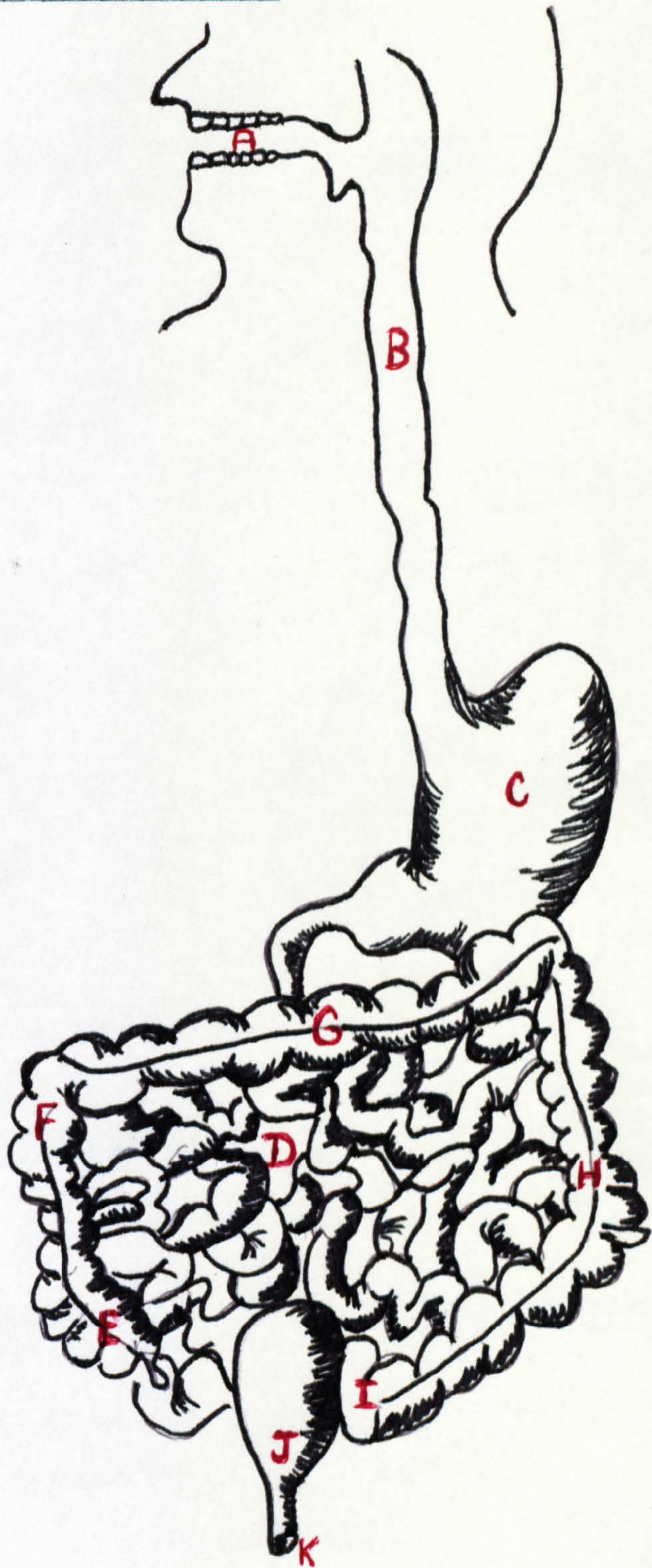


fig. 2

SIGMOID COLOSTOMY

A sigmoid colostomy is similar to the descending colostomy in all respects except that it is located in the sigmoid colon, which is just a few inches lower in the intestinal tract, below the descending colon. It therefore produces slightly more solid and regular fecal discharges and it is the easiest of all the ostomies to manage. In this case, only the rectum and the very end portion of the large bowel are removed.

It is probably the most frequently performed of the colostomies.



fig. 3

DESCENDING COLOSTOMY

Located at the end of the descending colon, this colostomy is therefore made on the lower left side of the abdomen. This colostomy can be made as a double-barrel, or single-barrel opening, but the single-barrel or "end" colostomy is more common. An "end" colostomy may have a permanent stoma that is flush with the skin when the mucosa is turned back on itself and sutured to the skin. Or the stoma may protrude slightly beyond the skin surface and a "stump" is made.

This type is sometimes called a "dry" colostomy because the stool is firm and formed because only the end section of the large bowel has been removed. Although there is no voluntary control, the discharge can be regulated through irrigation and enemas to prevent "unscheduled" movements. In this instance, the patient may be able to do without a bag or appliance if a dependable irrigation pattern becomes established.



fig. 4

TRANSVERSE COLOSTOMY

This type of colostomy is usually made in the upper abdomen, either in the middle, or a little to the right. The consistency of the discharge varies, depending of how far away from the small intestine the stoma opening is made. The nature of the discharge (e.g. firm or semi-liquid) is unpredictable, but most run all the time with a soft or loose stool that contains irritating digestive enzymes.

Control by irrigation is possible in some cases, but not the majority. Therefore, the patient will almost certainly require full time use of an appliance.



fig. 5

DOUBLE-BARREL COLOSTOMY

The double-barrel colostomy is so called because there are two stomas, one active, and one inactive. It is usually a temporary measure to bypass a small section of injured or inflamed lower colon. The surgeon cuts the bowel in two and creates two stomas; the upper one diverts feces to the outside, while the lower, inactive one preserves the opening of the bypassed segment until healing is completed. Usually about six to eight months later the bowel ends are rejoined and the stomas are closed.

This double-barrel method is usually used for descending and transverse colostomies.



fig. 6

CECOSTOMY OR ASCENDING COLOSTOMY

The cecostomy is made on the lower right side of the abdomen and the stoma is flush to the skin surface and may contain a drainage tube, which directs the very liquid feces and gas into a receptacle. The stoma will close by itself in a few days if the tube is removed. This ostomy may also be made not to close by itself, and in this case, a bag rather than a tube is used to collect the discharge. Because it is so close to the small bowel, the fecal material is watery, it flows continually, and it is very rich in digestive enzymes so that a tube or pouch must be used at all times.

This type of colostomy is the most difficult to manage.

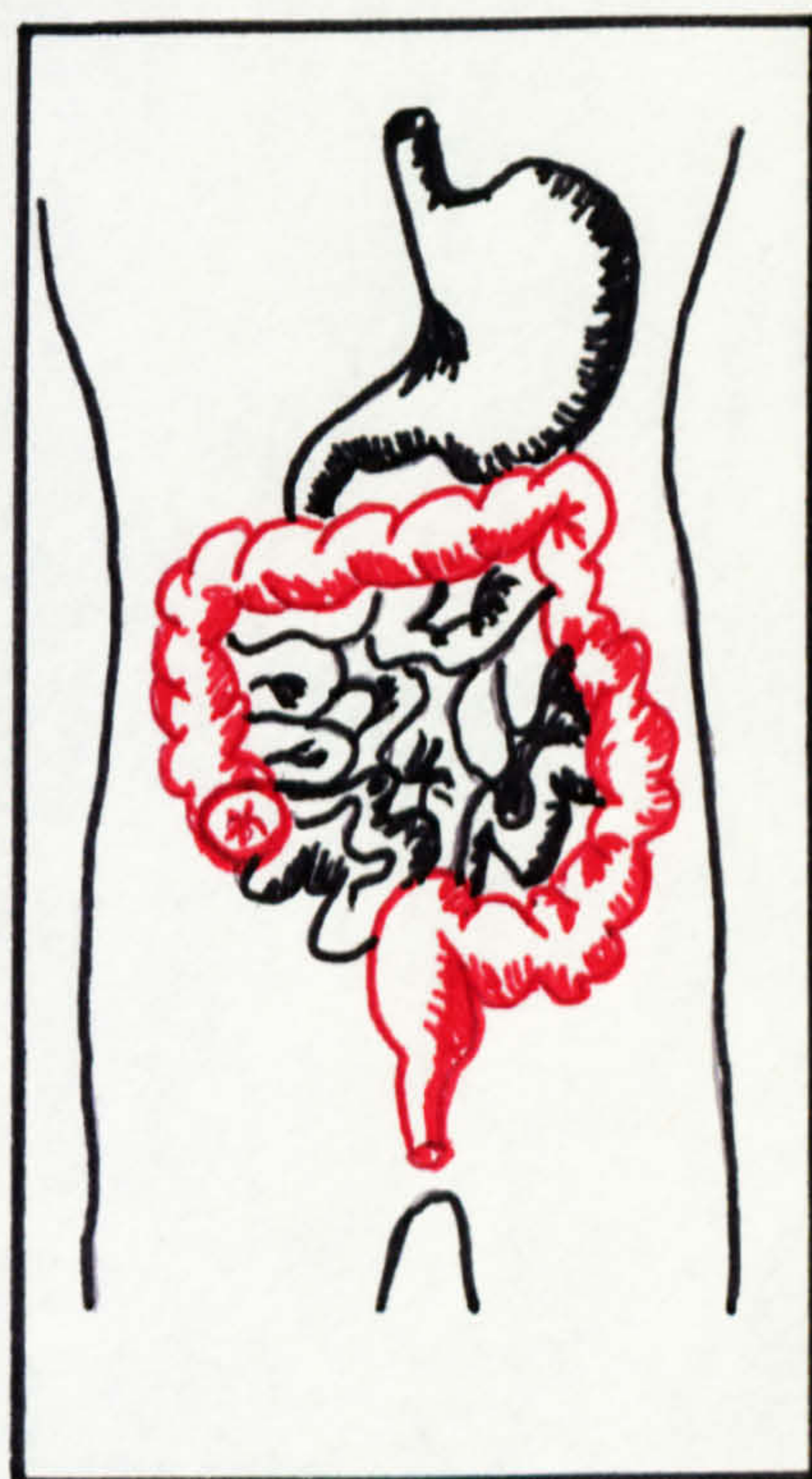
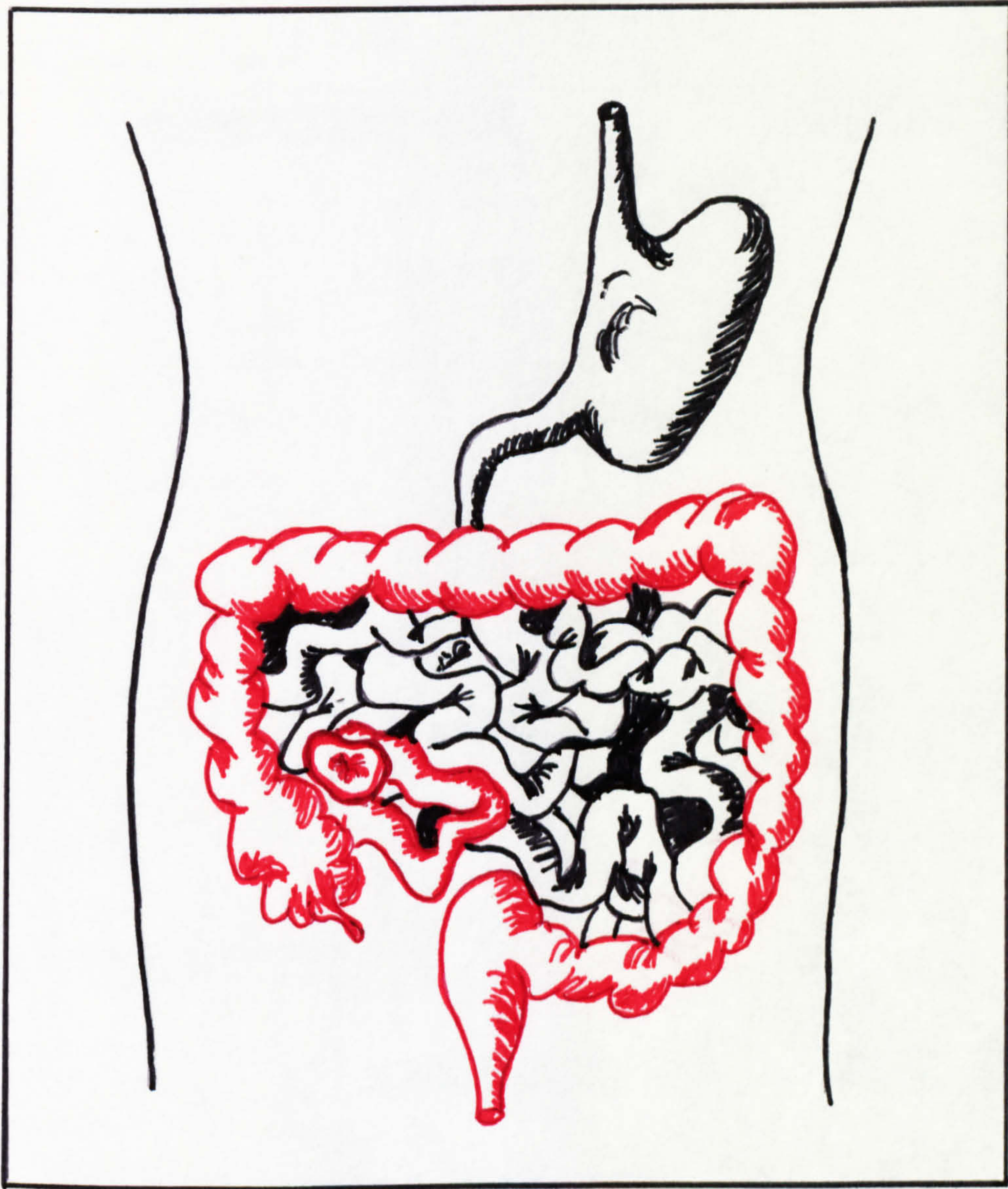


fig. 7

LOOP COLOSTOMY

This is also a temporary fecal diversion procedure more commonly done for the transverse or sigmoid colon. The surgeon lifts an intact loop of the bowel through the abdominal incision. To give it support, he places a plastic bridge or rod underneath it. The bowel on top of this loop is longitudinally cut and feces is released through this incision. It may remain open for as few as ten days, or as many as nine months. This surgery may be performed in advance of a planned emergency procedure to relieve obstruction to temporarily decompress the obstructed colon.





An ileostomy involves the removal of the large bowel, the rectum, and the ileum (last section of the small intestine). As far as bowel control is concerned, an ileostomy is untrainable. Discharge is unpredictable and the stool is a semi-paste and contains digestive enzymes. Therefore, an appliance must be worn at all times.

fig. 9

THE URINARY TRACT

- A - Kidney
B - Ureter
C - Bladder
D - Urethra

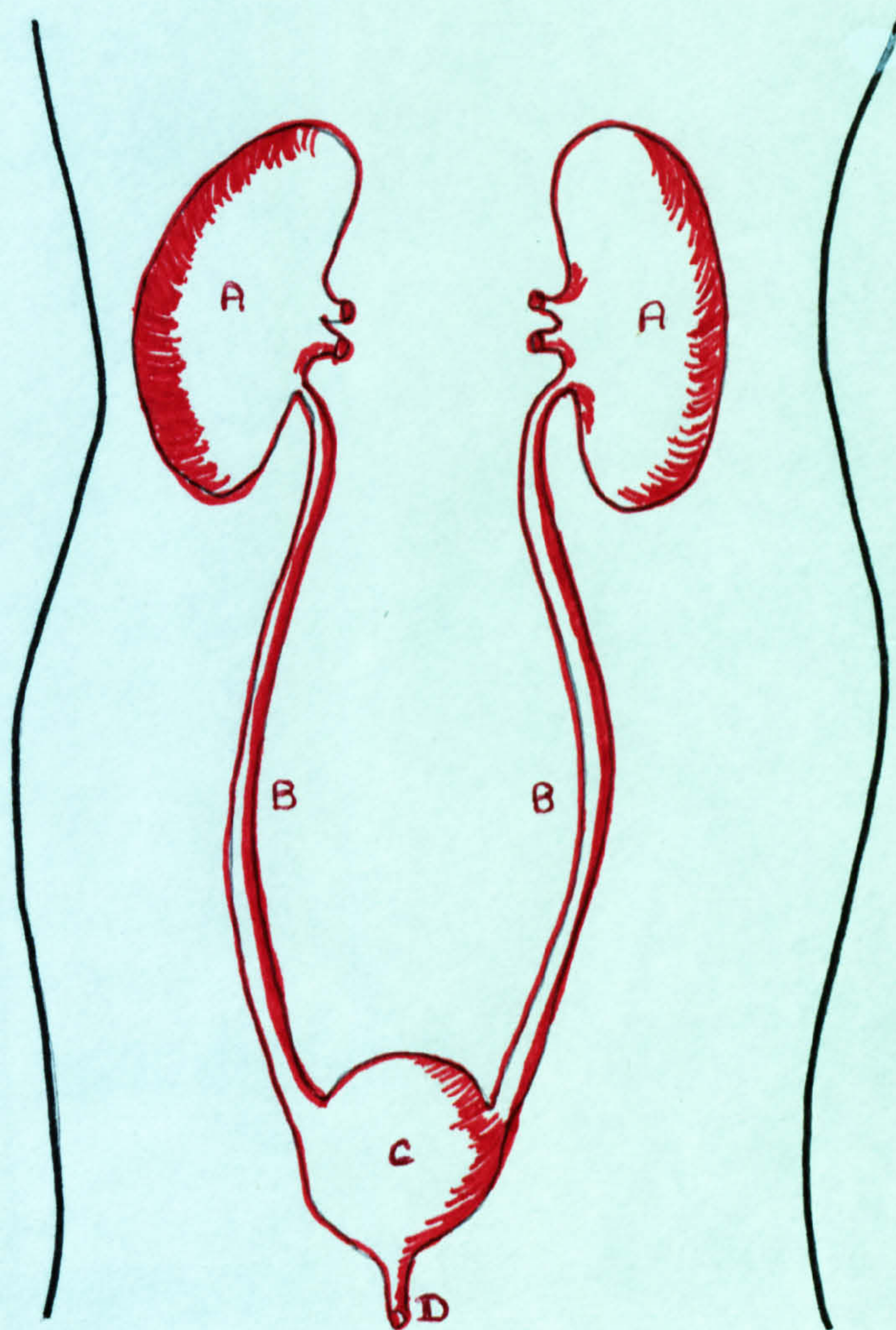


fig. 10

CUTANEOUS or BILATERAL URETEROSTOMY

A ureterostomy is not common today if the ostomy has to be permanent. It is usually performed when the urinary bladder has developed an inoperable condition, or in elderly or otherwise poor risk patients. This method involves less extensive surgery and requires far less time than the ileal conduit. Cutaneous urinary ostomies are a popular temporary or permanent treatment for birth defects. In this operation the end of the ureter is brought to the wall of the abdomen to allow the urine to flow from the kidneys to the outside of the body through the stoma, and thereby bypassing the removed bladder. It may be a single ureterostomy where only one stoma is made for one ureter, or it may be a bilateral (as shown) ureterostomy with both ureters being brought to the skin and a stoma made on the left and on the right side of the abdomen. An appliance is worn to collect the urine.

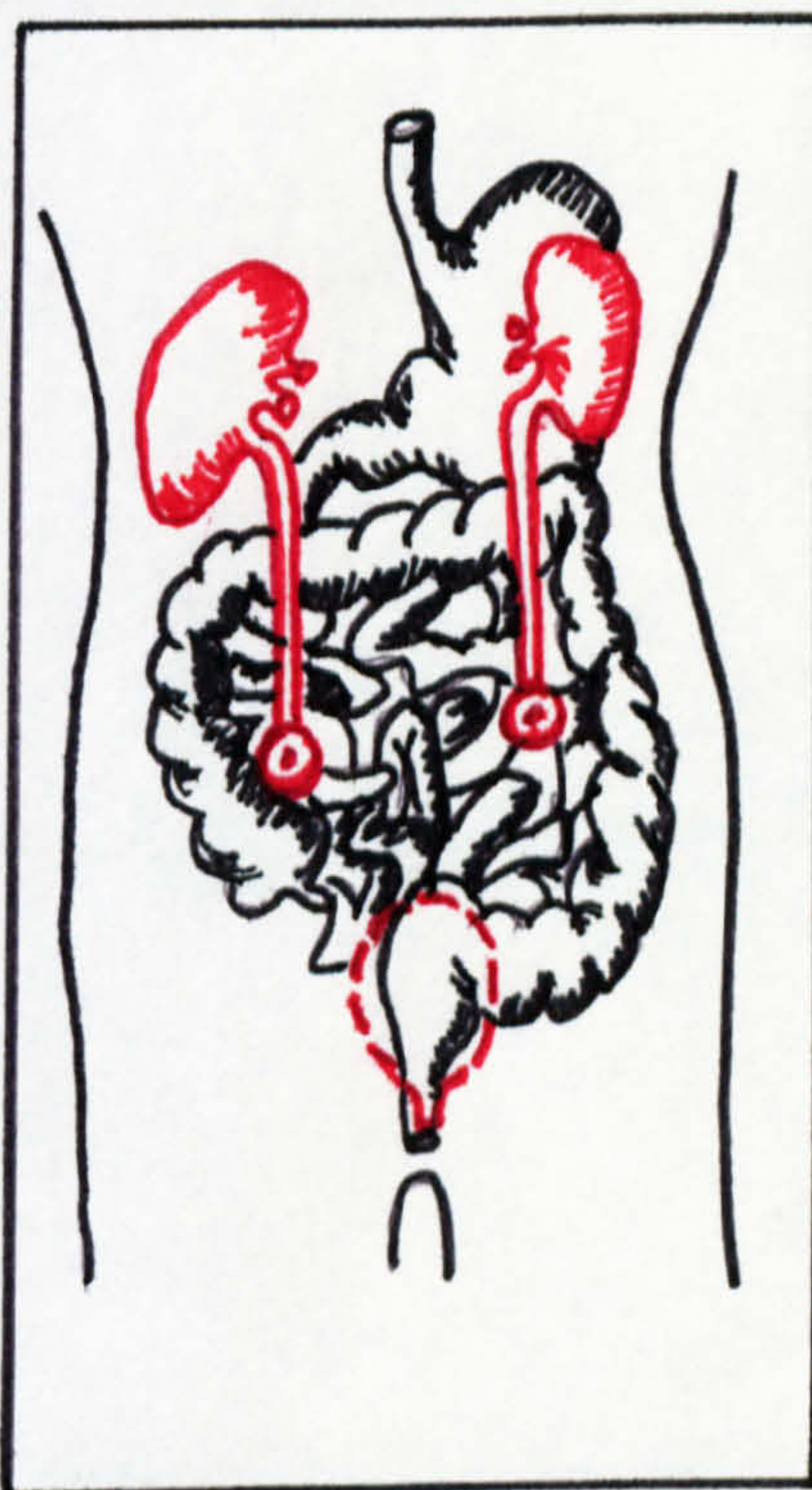


fig. 11

ILEAL CONDUIT or ILEAL BLADDER

The ileal conduit is also referred to as a "Bricker Loop" or "Ileal Loop". It is theoretically a urinary ostomy and is performed when the patient's bladder can no longer be used because of disease or defect. A bowel resection is performed to "borrow" a short segment or conduit (8 to 10 inches) of the small intestine (or ileum). The end of this section is closed to preserve the blood supply and the ureters are attached to the sides of this ileum section. The other end of this segment is then brought to the outside of the body through a stoma in the abdominal wall; it is turned back and sutured to the skin. The troublesome bladder is removed, but the bowel is rejoined and continues to function normally. The urine therefore passes from the kidneys into the ureters and ileal conduit and out of the stoma into the appliance. This method creates a single stoma and minimizes the danger of infection migrating upward to the kidneys. It also, in most cases, results in sexual impotency for the male patient.

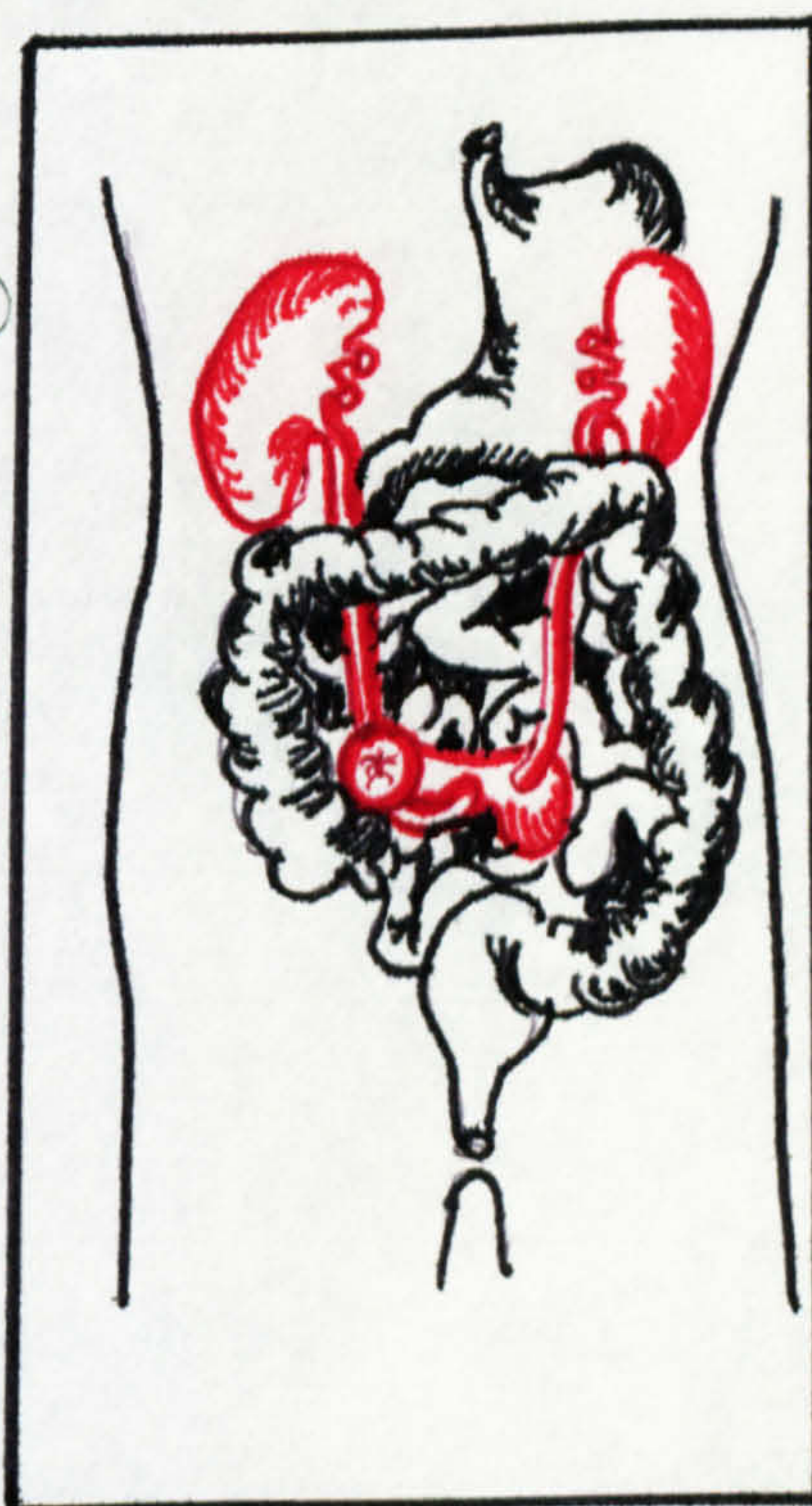
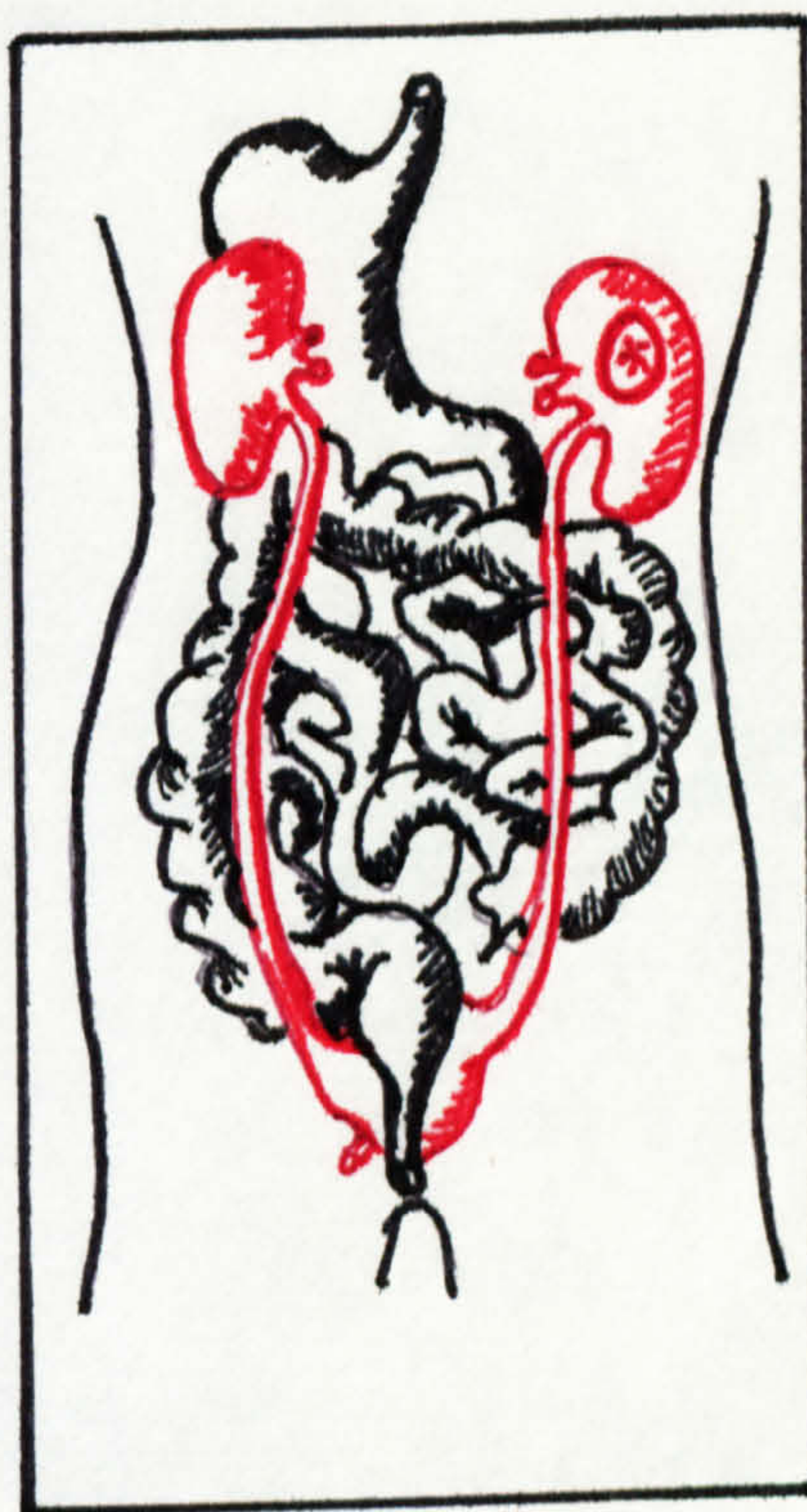


fig. 12

NEPHROSTOMY (Back View)

In this operation, the surgeon cuts an opening in the posterior or back of the kidney and inserts a tube into the kidney. This may be done on one or both kidneys so that the urine will bypass the ureter and bladder which are diseased or deformed.

This is usually a temporary measure of draining the kidney in order to promote healing of the bypassed ureter(s) and bladder. The tube or tubes exit on the patient's flank and a leg bag is worn to collect the urine.



(back view)

fig. 13

VESICOSTOMY

This procedure is used to treat some cases of trauma or deformity at birth. It is a form of urinary ostomy which diverts the urine away from the urethra by bringing the bladder forward and suturing it to the abdominal wall. An opening or stoma is created for the bladder between the umbilicus (or navel) and the pubic bone, and this is where the urine drains from the body into an appliance. Generally it is hard to fit this type of urinary diversion with an appliance.



fig. 14

TRANSURETER OSTOMY

This is a urinary diversion procedure in which one ureter is brought through the abdomen, while the other ureter is joined internally to the externalized one, so that there is only one stoma opening on the abdomen. The bladder is removed when this is a permanent measure or it is temporarily bypassed when the ostomy is only temporary.



fig. 15

DOUBLE-BARREL URETEROSTOMY

This procedure is similar to the construction of a transureteroureterostomy, but instead of joining one ureter to the other, both are brought out to the abdomen at the same place on the abdominal wall. Therefore, the patient has to contend with two stomas very close to one another on his lower abdomen.

This is a urinary diversion procedure and the bladder may or may not be removed, depending on the permanence of the ostomy.

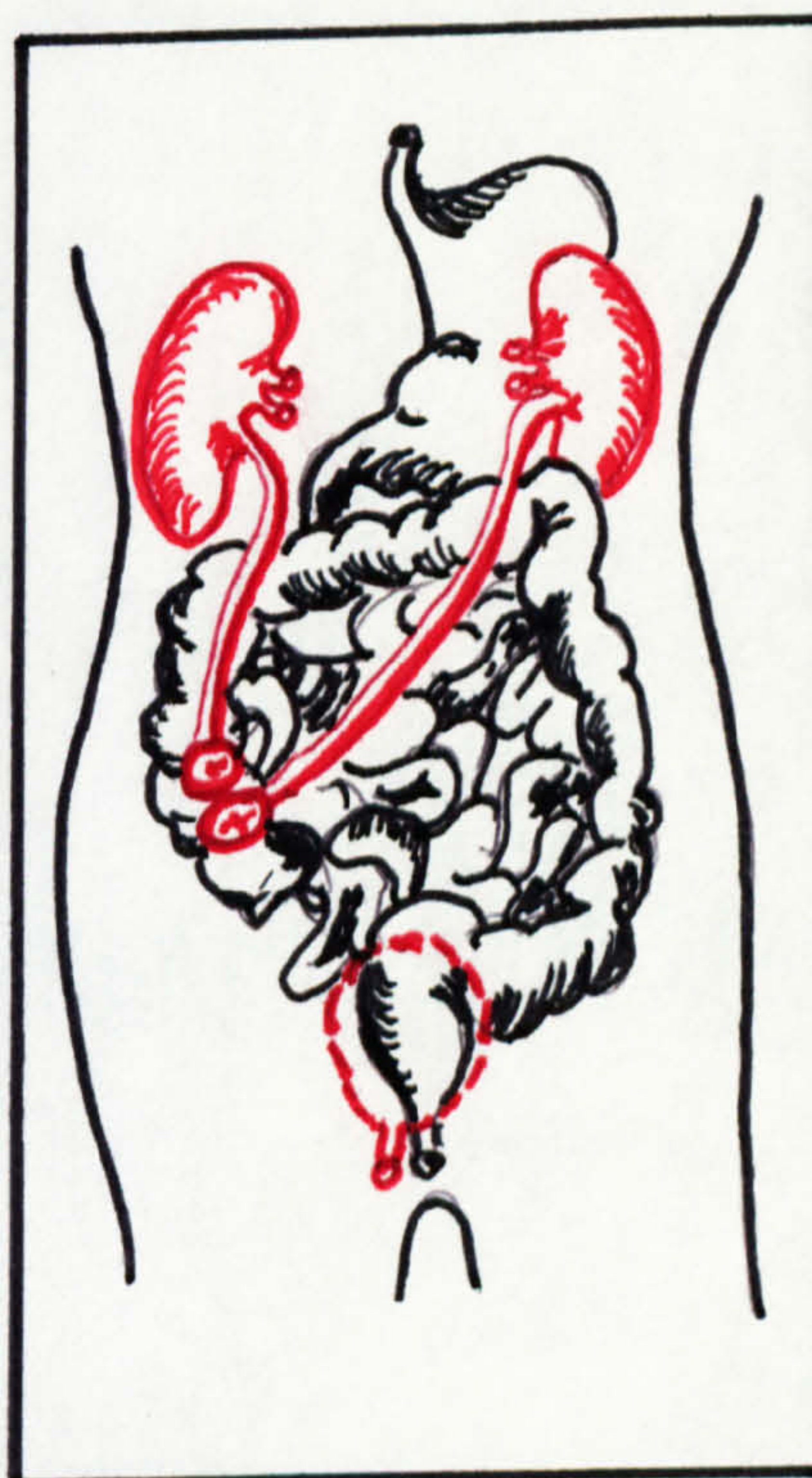
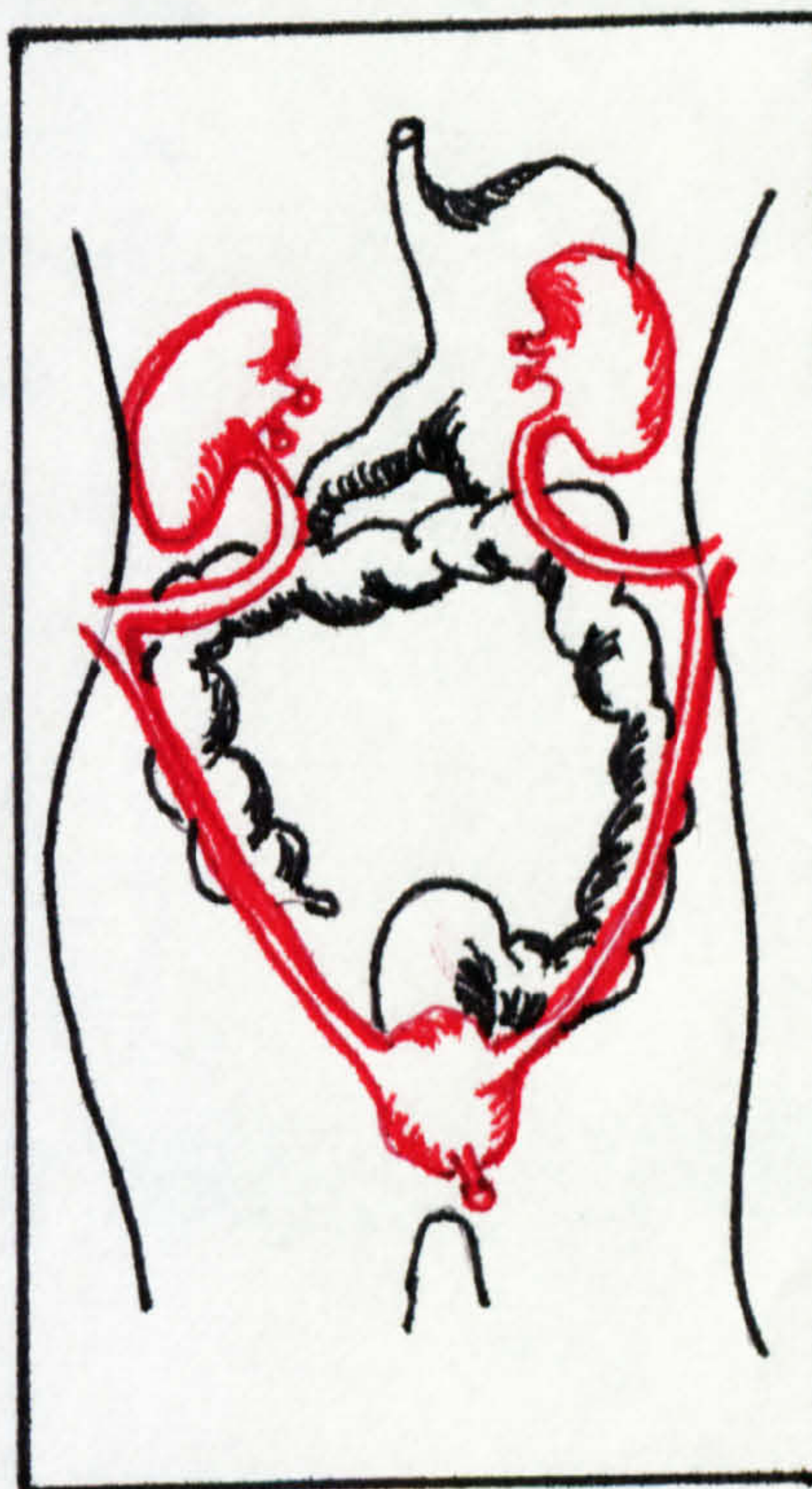


fig. 16

LOOP URETEROSTOMY

This is a temporary operation normally done only in early childhood, which allows the urine to escape from one or both kidneys as quickly as possible to the outside, without going through the bladder. Each ureter is kept connected to its lower portion, but it is brought directly to the outside of the body, as close to the kidney as possible. The stomas, one on each side, are located high on the patient's flanks.

This measure gives the bladder a rest and once it has healed sufficiently, the stomas are closed and the bladder can be used again.



APPENDIX D

DIAGNOSIS

If symptoms are severe, the patient is examined in the hospital, but the usual procedure for the preliminary diagnostic tests is for them to take place within the surgeon's office. The following tests are usually administered: a barium enema; a gastro-intestinal series; endoscopy; intravenous pyelogram; a peritoneoscopy and laparoscopy; rectal examinations; colonoscopy; esophageal-hydrochloric acid production tests; motility studies of the esophagus; histalog stimulation test; basic gastric secretory level - basal gastric acid output; insulin stimulation study or what is known as the "hollinder test"; biliary drain study or "Lyon's drainage"; malabsorption studies such as microscopic examination of the stool for fat, quantitative determination of fecal fat content; dextrose tolerance test. These tests may also be followed by an esophageal cytology, a gastric cytology and pathology.

APPENDIX E

THE HOSPITAL PHASE

Physiological Preparation for Surgery

If, after a series of diagnostic tests and evaluations, an individual is scheduled to have a colostomy or ileostomy, he must first be placed on a strict regimen including diet, purgatives, mechanical bowel cleansing and antibacterial therapy. These measures must be taken in order to inhibit the colon flora and decrease the risk of infection during and after the operation.

But, these bowel cleansing measures may cause inadequate absorption of vitamins. Therefore, supplemental multivitamins, vitamin C and vitamin K are given pre-operatively. Vitamin K is particularly necessary to compensate for the inability of the cleansed bowel to synthesize its own vitamin K due to *E. coli* suppression by antibiotics and daily purges. The purgative and enemas may exhaust and dehydrate the patient; therefore, fluids and electrolyte supplements are given before surgery to compensate for these losses from the bowel preparation and from the strict diet. Fluids and electrolytes can be given orally but when this is not possible, they are administered intravenously. Accurate intake and output records are kept, and the patient is asked to keep a stool count (Gutowski, 1972:262-263).

This rigorous pre-operative preparation is continued for several days and also includes the following procedures.

Hyponatremia, hypokalemia and hypoproteinemia are common in many patients with colon and rectal cancer because of frequent stools and diminished absorption. Sodium, potassium and protein must therefore be replaced before surgery. The patients are placed on a modified bowel preparation which usually consists of bowel cleansing and sulphur drugs. In addition, because most patients have been on cortisone therapy for a number of years, extra cortisone must be given before surgery to prevent post-operative collapse from stress and adrenal failure. Because of their large cortisone doses, these patients present a greater risk of infection post-operatively (Gutowski, 1972: 264).

APPENDIX F

FACTORS ASSOCIATED WITH STIGMATIZED
AND NON-STIGMATIZED AFFLICTIONS

	<u>Type I</u> Short Term Acute	<u>Type II</u> Long Term Non-Stigma- tized Ill- ness	<u>Type III</u> Long Term Stigmatized Illness	<u>Type IV</u> Mental Illness
<u>Clarity of Symptoms</u>	Clear and un-ambiguous to lay public and physician	Unclear to lay public and to physician until a number of sophisticated diagnostic tests are made.	Clear to lay public although they may be unable to interpret them. Clear to physician once diagnostic aids are used.	Varies widely. Ambiguous for both public and physician.
<u>Medical Diagnosis</u>	Highly certain and reliable as the underlying biological processes are well understood.	Usually certain and reliable. The unfolding of the biological cause of the disease is fairly well established.	As for Type II	Uncertain and unreliable as the processes are not well understood.
<u>Medical Treatment</u>	Effective and curative. Illness is reversible.	Effective to moderately effective but not curative. The disease process may be halted or controlled but not reversed.	As for Type II	No unequivocally effective treatment. Sometimes reversible but often not.

	<u>Type I</u>	<u>Type II</u>	<u>Type III</u>	<u>Type IV</u>
	Short Term Acute	Long Term Non-Stigmatized Illness	Long Term Stigmatized Illness	Mental Illness
<u>Physician's Role</u>	a) to identify the disease b) to legitimate temporary release from social obligations c) to certify the short-term impact of the disease	a) As in Type I b) to legitimate indefinite release from social obligations c) to aid in the definition of the long term impact of the disease	a) As in Type I b) to legitimate permanent release from social obligations c) As in Type II, especially the rehabilitative process	a) to certify the individual as different b) to legitimate others' definition of the individual as being incapable of fulfilling social obligations. c) to construct a social identity and ways of acting acceptable to others
<u>Impact on Self Conception</u>	Minimal as the label is temporary even though it may be all-pervasive at the time.	Variable, depending on the degree to which the illness is internalized. However, there is always some effect since the label persists.	Considerable and unavoidable. The illness often becomes the central organizing aspect of identity for both the individual and others.	Variable, ranging from slight to severe. The extent to which the label 'mentally ill' becomes central for the individual and others varies widely.
<u>Social Consequences</u>	In short run, individual is released from a wide range of social obligations while retaining most of his rights. Minimal long run consequences.	Short run consequences as for Type I. Long run consequences are variable and to some extent under individual's control.	Severe due to visibility of the physical consequences. The individual cannot exert much control over placement into spoiled or stigmatized category. Illness inevitably becomes disability.	Vary widely. At best may be short run and minimal; at worst an all-pervasive and permanent discrediting of the individual as a competent and normal actor.

APPENDIX G

OSTOMY SURGERY

The objective in rectal and colon surgery is to remove the cancerous tumour along with its avenues of spread or to reduce the inflammation or bleeding of certain other afflictions of the bowel, so that the patient may lead a physically more healthy life.

The site of the stoma is determined by several factors: the type of ostomy to be performed (which in turn is dependent on the site of the disease or affliction, the physique of the patient (e.g. height, weight, bone size, musculature), his age and sex. The stoma is usually placed to the right or left of the navel but not so far over that the appliance will be hampered by the hip bone. It may be placed at the waistline level for the male (so that his belt may act as a supporting measure) and below the waistline of the female (so that the appliance will not bulge under a skirt). When the site of the stoma has been decided and the patient has undergone the five or six days of pre-operative preparation (i.e. bowel cleansing) then he is taken to the operating room and the operation is begun.

The incision is made and the diseased bowel and rectum are removed and the anus is sutured closed. The end of the bowel is pulled up to the skin level of the abdomen and supported there by a glass or plastic rod pushed through its mesentry. For a colostomy, the bowel is opened longitudinally and the edges of the bowel are sutured to the

skin of the abdomen to form the stoma. The intestine is rearranged inside the abdomen and the bowel is fixed so that it will not retreat or prolapse at the colostomy site.

When the ileostomy is made, a disc of skin is excised from the abdominal wall and then the ileum is brought through the hole, turned back on itself and sutured to the skin margin. This provides a stoma about one inch in diameter and projects one to two inches out of the abdomen. This protruding spout of the stoma is necessary to ensure that all the fluid goes into the appliance and does not trickle back onto the skin because the most troublesome problem of ileal fluid is the enzymes contained in it, which damage and erode the skin around the stoma. In an ileostomy operation all of the large bowel is removed and the anus is closed.

The surgery generally lasts about two hours on the average, but may take as long as three or four hours if serious complications arise. It usually requires two surgeons, an assistant surgeon, an anaesthetist and two or three nurses to perform this operation.

On returning from the operating theatre, the patient should have an adhesive, see-through bag attached to the stoma and this is left on for the first 48 to 72 hours in order that the nurses can carefully monitor stomal activity and the healing of the stoma itself (Devlin and Plant, 1968, 1969; also a surgeon consulted for this study).

The magnitude of certain types of ostomy operations must be appreciated. According to Carbary:

Cancer of the colon and rectum will claim more victims this year than any other type of cancer, except superficial skin cancer. It will kill more people than any other type of cancer except lung cancer. Nearly half of the estimated 99,000 victims will die. Yet, almost three out of four patients could be saved by early diagnosis and prompt treatment.

The five year survival rate for colon-rectum cancer is seventy-one percent if the disease is treated while it is still localized. Chances for survival drop to forty-three percent once there is regional involvement (1975:21).

It seems that the importance of this surgery has been grossly underestimated and poorly received. With so many people being afflicted by colon-rectal cancer each year, one would think that any surgical procedure that was successful in eliminating this widespread and destructive disease would be considered a valuable medical innovation.

Colostomy operations for cancer of the rectum have been carried out for many years, but with increasing operability rates and resuscitation, more are surviving for longer periods. Ulcerative colitis and Crohn's disease of the large intestine appear to show a true increased incidence, at least in the western world, and as yet there is no medical cure. Colectomy, usually with ileostomy, offers the best prospect for long survival (Todd, 1971:478).

Many people still fear and are repulsed by the thought of this operation. However, it should be realized that ostomy surgery is a very important lifesaving or life-preserving operation, despite the myths that surround it.

In the past ten to fifteen years morbidity and mortality associated with total proctocolectomy and ileostomy have declined progressively. The number of patients restored to normal health as a result of removal of diseased bowel and the establishment of a permanent abdominal stoma continues to increase ...

... Despite these facts, both patients and physicians continue to procrastinate in making and accepting the decision to proceed with proctocolectomy and the establishment of a permanent ileal stoma. As a result, unfortunately, many patients are refused the appropriate surgical attention until major complications have occurred which may jeopardize their chance for a successful recovery (Roy et al., 1970:77).

The modern surgical aids of anesthesia, blood and fluid replacements, chemotherapy and antibiotics have made the ostomy operation much safer than before. Significant improvements have been made in the design and management of appliances and these have considerable potential for enhancing the future prospects of ostomy patients.

Regarding the acceptability of ostomy surgery, Beahrs did an extensive study of 497 patients seen during the years 1951 - 1965 at the Mayo Clinic in Rochester, Minnesota. His conclusions were:

It must be recognized ... that mortality in association with colectomy and ileostomy does exist (about five percent), and that there is some morbidity associated with the procedure...

... (T)he quality of life with an ileostomy is certainly acceptable and compatible with normal living for almost all. There should no longer be fear on the part of physician or patient in the establishment of an ileostomy, when indicated (1971:463).

APPENDIX H

MAJOR COMPLICATIONS FOLLOWING OSTOMY SURGERY

Major complications are a direct result of any type of ostomy surgery. They very often require further surgery for correction and therefore naturally impede a person's successful rehabilitation. Some of the major complications following ostomy surgery are: stenosis, herniation, prolapse, retraction, fistulization, perforation, bleeding and dermatitis.

Stenosis is a tightening of the stoma. It is caused by a natural scar tissue formation at the junction of the skin and mucosa. With the employment of modern surgical techniques, and by turning back the mucosa of the stoma, surgeons feel that there is less chance for primary stenosis than formerly (Lenneberg and Rowbotham, 1970:33). Stenosis is one of the most common causes of malfunction of the ileostomy. It leads to cramps, diarrhea and excessive fluid loss and possibly serious illness and death if not treated properly. This complication is extremely rare in colostomy patients who routinely dilate the stoma when they irrigate.

Herniation occurs around the stoma and is one of the more frequent complications. It involves rupturing of the abdominal wall around the stoma opening and is much less common with ileostomy than with colostomy. In order to correct this it is sometimes necessary to relocate the stoma.

Bleeding is usually a minor problem incidental to irrigations or local irritations. Dermatitis or inflammation of the skin is more common with ileostomy and can develop into a severe and painful inflammation that may require hospitalization if it is not properly looked after in its early stages. This difficulty usually results from a poorly fitting appliance which allows too much spillage onto the skin.

Prolapse is a very frightening experience for the patient. The small intestine virtually falls out of the body, turning itself inside out (Lenneberg and Rowbotham, 1970:35).

Usually prolapse takes place very slowly and is recognized by a gradual lengthening of the stoma. Some degree of prolapse is acceptable, but excessive prolapse may interfere with the function of the stoma and proper appliance fitting. In this case, a prolapse must be reduced surgically. The complication is much less common with ileostomy than with colostomy.

Retraction is the opposite of prolapse and involves the pulling in of the stoma. It can be caused by several factors. It may be due to the breaking of the sutures holding the stoma to the skin or to the unexpected internal tension causing the stoma to pull back. Most commonly, it is caused by excessive weight gain by the patient. True retraction occurs after the operation and must be corrected immediately to prevent loss of stoma and internal failing. Correction usually involves minor surgery.

Perforation is by far the most serious complication. It usually occurs as a result of trauma during irrigation of the colonic stoma. Thus, it can be seen as a potential threat to the irrigating

colostomate. It can be eliminated by teaching irrigating colostomy patients the proper technique of irrigation including the careful insertion of the cathetude so that the puncturing or perforation does not occur.

Perforation is heralded by the onset of sudden and excruciating pain with the failure of fluid to drain from the colostomy. The proper treatment is immediate laparotomy, resection of the bowel, cleansing the abdomen and establishment of a new stoma (Sterling and McIlrath, 1970:84).

Prosthetic Problems

Prosthetic or appliance problems are considered the least serious technically, yet they are often the ones most frustrating to the patient and can therefore pose a serious impediment to successful rehabilitation.

A prosthesis or ostomy appliance must be worn if the patient is to lead a normal life. Without an appliance a person is virtually incapacitated. Successful rehabilitation is therefore dependent upon the patient receiving a proper appliance and proper instruction as to its care and maintenance.

Skin problems can be seen as directly related to the appliance itself. An improperly fitted appliance will allow the fecal matter to drip onto the skin and cause severe irritation; it may also rub and irritate the skin, causing raw skin, blisters and rashes.

Odour is a problem to all ostomates at some time or another. It deeply concerns many people. It may be a case of the improper cleansing equipment, the type of food eaten, the state of health of the intes-

times and often the concomitant taking of medicines.

Odour control is often achieved by wearing a proper fitting appliance, eating bismuth subcarbonate and the simultaneous using of a liquid deodorant in the appliance (Rowbotham, 1971:224).

Flatus (or gas), especially noisy emission, is extremely embarrassing and a major cause for some ostomates in avoiding social contacts. Pryse-Phillips found that in a follow-up study of twenty middle to old-aged ostomates, the odour of bowel wind was a far greater fear than the physical presence of the stoma or the sudden loss of bowel control.

The reactions of the six patients who were most affected by the fear of smelling were normal in kind, but abnormal in degree; sometimes the fear of smelling reached delusional intensity or was associated with olfactory hallucinations (1971:29-30).

One patient in the Pryse-Phillips study was convinced that she emitted a foul smell after her operation and would not allow any of her friends into her house. When she detected the odour coming from the arm chair where she used to sit, she burned it despite the fact that her husband said it had no smell.

Any failure in the appliance, meaning that the patient cannot rely completely on his appliance to perform as expected, causes physical and social insecurity. This is a handicap which, in addition, takes its psychological toll. Living with the knowledge that at any moment the appliance might become loose and one might soil oneself, influences behaviour.

To have an odour is socially embarrassing, as are uncontrollable

flatae (or gas or wind). Sore skin about the appliance makes the wearing of the appliance both difficult and painful, doubling one's troubles. As Lenneberg and Rowbotham note, the ostomate can never relax his vigilance over his appliance, odour or skin.

A telling bit of behaviour between ostomates is the inevitable question the older ostomate asks the newer one immediately after saying 'How do you do.' It is: 'How are you getting along with your appliance? Do you have any trouble?' In this way he acknowledges that trouble is always just around the corner and he well knows the endless physical, social and emotional ramifications of even a little bit of trouble (1970:31).

APPENDIX I

GLOSSARY

ABDOMINOPERINEAL RESECTION

A surgical procedure in which the sigmoid colon and the entire rectum and anus are removed. The end of the remaining colon is then brought out as a permanent colostomy. The rectal wound then heals.

ANTIBIOTICS

A chemical substance (e.g. penicillin) produced by a micro-organism which has the capacity to inhibit the growth of, or kill, harmful micro-organisms in the body. They are primarily used in the treatment of infectious diseases in man.

APPENDICITIS

This is an acute inflammation of the appendix. The appendix is a vestigial organ of no use to human beings. The symptoms are pain in the lower right portion of the abdomen, fever and nausea. Vomiting, constipation and diarrhea may also occur. Immediate surgery is usually necessary (i.e. appendectomy).

APPLIANCE (or Prosthesis)

The pouch or device of a reusable or disposable type that is worn to collect discharges from ostomy stomas.

BARIUM ENEMAS

A solution of barium sulfate (i.e. a water insoluble salt) and water used as a contrast material for x-ray photography of the digestive tract. The enema is injected into the rectum and x-rays are taken as it passes through the digestive tract. Disorders occurring in the tract are made visible on the x-ray film by barium sulfate.

BENIGN

Not cancerous; not malignant. Having a favourable prognosis.

BISMUTH SUBCARBONATE

This is an odourless, tasteless, white salt that is insoluble in water. It is used as a protective antacid in gastrointestinal diseases and as an astringent to arrest hemorrhages, diarrhea or other discharges.

CARCINOMA

Cancer; malignant growth.

CECOSTOMY

An opening in the cecum, located on the lower right side. Evacuation is involuntary and cannot be controlled by irrigation. Usually temporary - to rest the colon.

CHEMOTHERAPY

The treatment of, or prevention of, disease by chemical agents.

COLECTOMY

The partial or total removal of the colon (large intestine).

COLON FLORA

The growth of bacteria in the colon (e.g. E. coli). This is a type of bacteria that is not harmful to man but is quite beneficial as it aids in the breaking down of food products in the intestines.

COLONOSCOPY

The use of a sterile sigmoidoscope during an operation to visually examine the colon for the presence of polyps. It is done through two or three small openings in the colon.

COLOSTOMY

This is a surgical opening of the colon (large intestine). It may be temporary or permanent.

CONGENITAL

Present or existing at the time of birth, as a deformity, disease or tendency.

CONSTIPATION

This is the difficult or infrequent passage of stools. It may be a sign of obstruction of the colon caused by a tumour or a cancer.

CORTISONE

A hormone from the adrenal cortex that is largely inactive in humans until converted to cortisol - a steroid that is produced commercially by synthesis. Used as an acetate to treat acute infections, shock, allergies.

CROHN'S DISEASE

This is an inflammatory condition of the digestive tract, in most cases causing a swelling in the terminal (end) ileum. Although the mortality is low, recurrence and continuing illness is common. The patient has a history of vague, often right-sided abdominal pain, and sometimes attacks of nausea and vomiting. Surgery may be needed in severe cases.

CYSTECTOMY

Excision of a cyst or of a fluid-containing structure. Excision of the urinary bladder (i.e. complete or total) or resection of the bladder (i.e. partial cystectomy).

DIARRHEA

Is an abnormal frequency and liquidity of stools. The passage of frequent soft or watery stools may be associated with low, cramping abdominal pain and a feeling of urgency. Leaves the patient feeling weak and fatigued.

DIVERTICULITIS

This is an inflammation or infection in one or more of the diverticula (small sacs on the colon). Symptoms are low, cramping, abdominal pain and tenderness in the area of involvement. Diagnosis is made on the basis of x-ray, but in some cases it is difficult to tell this condition from cancer on a colon x-ray.

E. COLI (Escherichia coli)

A group of normal bacteria constituting the greater part of the intestinal flora (i.e. inhabiting the intestine) of man and all vertebrates. They are usually beneficial and nonpathogenic, but pathogenic strains are common and can cause urinary tract infection and severe diarrhea.

-ECTOMY

Excision (cutting out) of an organ or part. Used as a suffix to indicate excision of the structure or organ designated by the root to which it is affixed; for example, appendectomy, tonsillectomy, colectomy.

ELECTROLYTES

Normal chemicals of the body such as salt, needed to maintain proper balance. When the electrolytes are out of balance, the patient may become ill and weak and needs to take chemicals by mouth or through the vein.

ENDOSCOPY

The general term for visual examination of any hollow organ. See colonoscopy, proctoscopy, sigmoidoscopy.

ENEMA

Enemas are most commonly given to flush wastes from the lower bowel and are usually just plain water injected into the rectum.

EXCORIATION

Any superficial loss of substance, such as that produced on the skin by scratching. In ostomy it commonly refers, when it is present, to the red, raw-appearing, sore skin area surrounding the stoma. It is usually caused by enzymes in the fecal matter or by urine eroding the skin surface, or abuse of the skin by scrubbing or scratching.

FAMILIAL POLYPOSIS (Multiple Polyps)

A rare disease that runs in families. Here the colon and rectum contain innumerable polyps. This is a different condition than the mere presence of a small number of polyps in the colon. Familial polyposis requires regular medical supervision of all members of the family because of serious complications and tendency to malignancy.

FECES

Bodily wastes which are discharged through the anus or colostomy and/or ileostomy stomas.

GASTROENTEROLOGIST

A physician specializing in the study of the stomach and intestines, and their diseases.

GYNECOLOGY

That branch of medical science which especially concerns itself with the reproductive organs of the female. It deals with the health, disease and treatment of female reproductive organs from infancy through advanced old age.

HERNIA

A protrusion (bulging) of a loop or knuckle of an organ or tissue through a structure which usually contains it.

ABDOMINAL HERNIA

The protrusion of an internal organ, such as the colon, through the abdominal musculature. This can happen around the stomal area or at the stoma site. The ordinary femoral hernia is a protrusion in the groin.

HYPOKALEMIA

An unusually low potassium concentration in the blood - generally resulting from excessive vomiting or diarrhea. It is a symptom of gastrointestinal disorders.

HYPOPROTEINEMIA

An abnormal deficiency of protein in the blood.

HYSTERECTOMY

The surgical removal (excision) of the uterus in the female, usually because of tumour (cancer) growth.

ILEAL

Pertaining to the ileum or lower part of the small intestine.

ILEITIS

Inflammation of the ileum, also called regional ileitis, Crohn's disease and regional enteritis.

ILEOSTOMY

A surgical opening in the ileum portion of the small intestine. The entire colon and rectum may be removed, or the entire colon but not the rectum may be removed, leaving the lower portion of the rectum. The end portion of the ileum is brought through the abdominal wall to form a stoma, usually on the lower right side of the abdomen. Through it, feces are eliminated. An appliance must be worn at all times to catch feces and control odour.

IMPERFORATED ANUS

Without the normal opening - an abnormally closed anus. Congenital closure of the anal opening, usually by a membrane structure.

IMPOTENCE

Occurs in the male only; the inability to achieve or sustain an erection.

INCONTINENCE

The inability of the bladder to hold urine causing uncontrollable dribbling or wetting.

INTRAVENOUS PYELOGRAM

A pyelogram (i.e. x-ray picture) of the renal pelvic and ureter. A contrast material is injected into the patient intravenously (i.e. through the vein) to permit the radiographic visualization of the kidneys as they excrete the material. This is a method to detect urinary tract disorders.

IRRIGATION

Washing of a wound or a cavity using a stream of water. An enema. Colostomies are often managed by "irrigations". The term is used here in the sense of an enema; the water distends the bowel and causes peristalsis (movement of the bowel) which expels wastes.

INTESTINAL OBSTRUCTION

This refers to any condition which interferes with the passing of intestinal contents through the bowel passageway. The most common cause is adhesions (e.g. internal growth of scar tissue resulting from previous surgery). Symptoms are cramping, colicky, severe, sharp abdominal pain, abdominal distention and vomiting.

LAPAROTOMY

The operation of cutting into the abdominal cavity through the loin or flank.

MALIGNANCY

The condition of being dangerous; a cancerous growth.

MESENTRY

A membranous fold attaching various organs to the body wall, e.g. the peritoneal mesentry attaches the small intestine to the body wall of the back.

MUCOSA

The mucosa of the intestine is the mucous membrane lining the digestive tract. The mucous membrane is a protective membrane lining those cavities and canals communicating with the air. It is kept moist by the secretions of various mucous glands.

MULTIPLE POLYPS

See Familial Polyposis.

OBSTRUCTION

Blockage or clogging of an organ resulting in loss of flow through the area and building up of back pressure. In an ostomy, obstruction can be caused by impaction of fecal matter, collapse of organ, or tightening around organs caused by adhesions or growing in of abdominal muscles where the stoma comes through.

OSTOMY

A surgical opening. The shortened form of a description for the three basic types of ostomies: ileostomy, colostomy and urostomy. An ileostomy involves the small intestine. A colostomy - and there are several types - involves the colon. A urostomy involves the loss of the bladder or its function.

PERINEAL

Pertaining to the perineum. The perineum is that area between the legs; it includes anal area, scrotal area (men) and vaginal area (women). In an ostomy operation where the rectum is removed, it refers to the anal area.

PERINEAL RESECTION

The surgical removal (or excision) of the rectum.

PERITONEOSCOPY

An examination procedure used to detect cancer, polyps, ulcers and inflammation of the bowel. A proctoscope is inserted through an incision made in the abdominal skin and abdominal wall, into the peritoneal cavity (i.e. the space between the intestine and the abdominal muscles) and it becomes possible to view the liver, part of the stomach, intestine, colon and the ovaries. The results of this procedure are valuable in determining whether disease is present in any of these organs.

POLYP

A small projection inside of the bowel; it is often mushroom-shaped or it may be flat. It is usually benign but can be malignant. Note: The question of whether benign polyps in ordinary people ever "turn into" cancers is not settled. Most surgeons routinely remove accessible polyps when found. Approximately five percent of adults will have a polyp of the rectum or colon. Small polyps cause no symptoms but large ones may bleed causing blood in the stool and cramping pains.

PROCTOCOLECTOMY

Procto - designating a relationship to the rectum or hind parts.

Colectomy - excision of a portion of the colon, or the whole colon.

Proctocolectomy - the surgical removal of the rectum and colon.

PROCTOSCOPY

The direct visual examination of the anus and rectum by means of a hollow metal tube called a proctoscope. This instrument is one foot long and half an inch in diameter. It is equipped with a light source at one end. It permits the inner lining of the bowel wall to be seen directly so that cancer, polyps and ulcers of the bowel can be readily diagnosed.

PROSTHESIS

See appliance

PURGATIVE

A drug that produces evacuation of the bowel; a cathartic that stimulates peristaltic action of the bowel.

RESECTION

Surgical removal or excision

SIGMOIDOSCOPY

Visual examination with a ten-inch (or longer) lighted tube (sigmoidoscope) of the anus, rectum and lower part of the sigmoid colon.

SPHINCTER

A ring-like muscle surrounding a passageway of an organ and able to open and close. The sphincter in the anus makes possible bowel control. The bladder sphincter controls urine flow. These muscles make voluntary control of body waste elimination possible.

STOMA

This open (or end) portion of the remaining intestine or ureter which is retained outside of the body on the abdomen. That portion of the intestine or ureter which is seen on the abdomen after an ostomy operation has been performed. It is usually bright red in colour. There are no nerve endings in the stoma, therefore it is not a source of pain or discomfort.

THALIDOMIDE

This is a chemical agent used commonly in Europe as a sedative and hypnotic in the early 1960's. It was discovered to be the cause of serious congenital abnormalities or defects in the fetus (e.g. gross limb deformity) when taken by a woman during early pregnancy. Its use has since been discontinued.

TONSILLECTOMY

The surgical removal of infected and inflamed tonsils. Not a major surgery - relative uncomplicated and usually done on children.

TRAUMA

A physical injury caused by a mechanical force, such as a blow, a twist, a knife or a bullet. Psychic trauma is an injury to the subconscious mind by emotional shock.

TUMOUR

Tumours of the small bowel are rather rare. Benign tumours or polyps may produce symptoms of obstruction if they become large enough. Diagnosis is made on the basis of x-ray examination and treatment is surgery. Malignant tumours are more rare than benign tumours, and the symptoms are also primarily those of obstruction. In addition, hemorrhage and malnutrition with increasing weight loss is common. Treatment is surgical removal of the tumour with as wide a margin of surrounding tissue as possible.

ULCERATIVE COLITIS

It is an acute or chronic inflammatory disease involving usually the descending colon and the rectum, characterized by bloody diarrhea (i.e. hemorrhage) and perforation. It is accompanied by ulcerations or lesions of various sizes in the area of involvement and there is an increased risk of malignant cancer. Diagnosis is made on the basis of x-rays and proctoscopic examination.

URETER

The fibromuscular tube which conveys the urine from a kidney to the bladder. It empties into the base of the bladder and is from 16 to 18 inches long.

URINARY DIVERSION

Any one of a number of surgical procedures which diverts the urine away from a diseased or defective bladder.

URINARY TRACT

The system in the body comprised of the kidneys, ureters (tubes connecting kidneys to bladder), bladder, and urethra. Urine is made in the kidneys, passes down the ureters, accumulates in the bladder and passes outside through the urethra.

WOUND

An injury to the body caused by physical means, with disruption of the normal continuity of the body structure. Relative to operations, it refers to the area where an incision or excision was made, such as "perineal wound" where the rectum is removed.

APPENDIX J

PATIENT QUESTIONNAIRE

AGE:

SEX:

EDUCATION:

OCCUPATION OR PROFESSION:

MARITAL STATUS:

ORIGINAL COMPLAINT (medical symptoms):

DIAGNOSIS:

1. How was it conveyed to you?
2. What was your initial reaction?
3. How did you convey it to:
 - a) your family?
 - b) your business associates?
 - c) your friends?
 - d) any casual acquaintances?
4. What were your feelings when you were made aware of the diagnosis?
5. How have these feelings changed?
6. How long has it been since you had the operation?
7. What counselling procedures or advice was given by your physician once you were notified of your situation?
8. Did your physician suggest that you seek any type of professional counselling?
 - a) from him?

- b) from other paramedical personnel?
 - c) others (specify)?
9. What pre-operative counselling did you and/or your family receive?
 10. What post-operative counselling did you or your family receive?
 11. What were your initial reactions once you had had the surgery?
 12. What were the reactions of your family?
 13. What were the reactions of your fellow workers or the people with whom you work?
 14. Did you ever feel hostile to the ways in which you were treated by family, friends, fellow workers and others? Specify and discuss at length.
 15. Once your diagnosis had originally been made, did you contact other physicians and surgeons to get "second opinions"?
 16. How did you acquire your surgeon?
 17. Were you covered by insurance?
 18. Does your "handicap" now inhibit you in any way? Specify.
 19. Has your "handicap" prevented you from promotions or other opportunities which would be open to a "normal" individual? Specify and discuss.
 20. Do you think organizations of and for the colostomy victim serve a useful purpose? Discuss.
 21. Has the operation interfered with any of your traditional life patterns. Social, economic, sex, etc. Specify and discuss.

PATIENT QUESTIONNAIRE

Part 2

1. What type of surgery did you have?

a) ureterostomy	d) ileal bladder
b) colostomy	e) other
c) ileostomy	f) don't know
2. For what condition was the surgery performed?

a) accidental injury	f) ulcerative colitis
b) cancer or tumour	g) diverticulitis
c) birth defect	h) not certain
d) polyposis of the colon	i) other
3. How much time prior to your surgery were you under a physician's care?
4. How much time was spent in hospitalization before the operation?
5. How long before surgery did you know of the condition?
6. Were you provided with information as to the nature of the surgery and its results?
7. Were the explanations of your surgery clear and concise to the extent that you understood exactly the nature of the surgery to be performed?
8. Prior to surgery, did the doctor or someone else suggest that you work with:

a) a social worker	d) a specialized counsellor
b) a psychologist	e) other
c) an ostomate club member	f) none of these.
9. After your surgery, did your physician or anyone else put you in consultation with any of the above people (e.g. as in question 8)?
10. Have you had any surgery since your ostomy?

a) revision of stoma	f) removal of colon
b) drainage of abcess	g) other
c) relief of obstruction	h) yes, but uncertain as to the nature of the treatment
d) resection	i) not at all.
e) removal of rectum	

11. If your rectum was removed, how long did it drain afterwards?
12. Rank the following individuals as they helped you most to prepare for your surgery:
- | | |
|--------------------------------|--------------------------------------|
| a) physician | e) hospital nurse |
| b) surgeon | f) visiting public health nurse |
| c) social worker | g) member of an ostomate association |
| d) family members
(specify) | h) other (specify). |
13. Which of the above individuals helped you most after your operation? Indicate in terms of numbers (i.e. 1-8) and make relevant comments when necessary.
14. Rank the areas in which you encountered the most difficulties after your surgery. Specify where necessary.
- | | |
|---------------------------|--------------------------|
| a) family relations | g) social life |
| b) other social relations | h) recreation activities |
| c) economic independence | i) marital life |
| d) routine of care | j) travel |
| e) diet | k) sexual adjustment |
| f) appliances | l) other (specify). |
15. Place of birth?
16. Religious denomination? (optional)
17. What was your marital status before your operation?
18. What is your present marital status? Are you contemplating a change?
19. If family difficulties occurred after surgery, what were the basic causes? Specify.
20. Do you think this discord could have been alleviated? Specify.
21. Do you think individuals undertaking this surgery should receive counselling? Specify.
22. Do you think individuals undertaking this surgery should receive any

23. Have any of your social habits with regard to the following categories been altered since surgery?
- | | |
|-------------------------|--|
| a) contact with friends | d) other social pursuits (political economic, union, etc.) |
| b) economic research | e) drinking patterns |
| c) athletic pursuits | f) other social outlets. |
24. Are there any activities you have curtailed or eliminated since surgery? Specify.
25. How many children do you have?
26. How many of these children have been born since your surgery?
27. What was your age and weight prior to surgery? or at the time of surgery? What is your weight at the present time?
28. Describe your present state of health:
- | | |
|--------------|----------|
| a) excellent | d) fair |
| b) very good | e) poor. |
| c) good | |
29. Before surgery were you:
- | | |
|-----------------------|---------------|
| a) employed full time | c) unemployed |
| b) employed part time | d) other. |
30. At this time are you:
- | | |
|-----------------------|------------|
| a) employed full time | d) retired |
| b) employed part time | e) other. |
| c) unemployed | |
31. How soon after surgery did you resume your work?
32. If you have changed jobs since surgery, was the surgery responsible for this change?
33. Have you ever been refused a job position because of your surgery? Specify.
34. Have you ever encountered stigma (social or physical insult or abuse because of your surgery)? If yes, by whom and under what conditions?
35. How many days have you been absent from work as a result of your ostomy and/or connected illnesses?

36. Have you ever received any services from the National Employment Service with regard to:
- a) counselling or advice
 - b) education
 - c) training
 - d) physical restoration (rehabilitation)
 - e) job placement
 - f) other
 - g) no services received.
37. Have you, since your operation, requested help in finding a job from others:
- a) National Employment Services
 - b) friends
 - c) family
 - d) others (specify).
38. Do you feel handicapped because of your ostomy? Specify.
39. Do others view you as being handicapped? Specify - to what degree are you seen as handicapped?
40. Do you tell your friends and acquaintances of your surgery?
41. If your answer to the above question was "no", specify your reasons.
42. Has your ostomy affected you negatively in any way since your surgery? Specify.
43. Have you applied for health insurance since surgery?
44. Were you accepted as a normal person (patient)?
- a) yes
 - b) accepted, but with higher rates
 - c) rejected.
45. Have you applied for life insurance since surgery?
46. Were you accepted as a normal person?
- a) yes
 - b) accepted, but with higher rates
 - c) rejected.

47. Having answered all of the above questions, do you feel that there is any other information that should be conveyed either to me as an investigator or to those who are going to have, or have recently undergone, ostomatic surgery?

Thank you for your time and consideration.

Mark Nagler

FOOTNOTES

- (1) Statement by ostomate, personal interview.
- (2) Statement by enterostomal therapist, personal interview.
- (3) Statement by surgeon, personal interview.
- (4) Refer to glossary in the Appendix for definition of this and other medical terms as they are mentioned.

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