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THE UNIVERSITY OF ALBERTA

WOMEN'S LIVED-EXPERIENCE OF PELVIC EXENTERATIVE SURGERY

by

BEVERLEY ELEANOR EDWARDS

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE

OF DOCTOR OF PHILOSOPHY

IN

COUNSELLING PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

SPRING 1987

ISBN 0-315-37615-5

THE UNIVERSITY OF ALBERTA

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NAME OF AUTHOR BEVERLEY ELEANOR EDWARDS

TITLE OF THESIS WOMEN'S LIVED-EXPERIENCE OF PELVIC EXENTERATIVE SURGERY

DEGREE FOR WHICH THESIS WAS PRESENTED DOCTOR OF PHILOSOPHY

YEAR THIS DEGREE GRANTED SPRING 1987

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled WOMEN'S LIVED-EXPERIENCE OF PELVIC EXENTERATIVE SURGERY submitted by BEVERLEY ELEANOR EDWARDS in partial fulfilment of the requirements for the degree of DOCTOR OF PHILOSOPHY in COUNSELLING PSYCHOLOGY.

W Hague

Supervisor

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John Lorrent

External Examiner

Date October 29, 1986

DEDICATION

Eleanor Medley-Hepburn (1874-1958)

Gordon Edwards-Cragg (Oct. - Nov. 1970)

Allan Edwards-Cragg (June - July 1972)

Gordon C. Edwards (1903 - 1986)

The tapestry of my life is enriched by many. I choose to dedicate this dissertation to four of the weavers: my grandmother, two of my sons, and my father. With them and through them I have come to know the incredible gifts of life, both brief and enduring; the pain of loss and the experienced affirmation that indeed there is life after death. Their's has been a transformational weaving in my yet to be completed tapestry. As I speak of completions I'll close this dedication this way.

Well, Pop, it is finally done! God Bless.

ABSTRACT

The study investigates the lived-experience of women who choose to have pelvic exenterative surgery as a treatment for persistent cervical cancer. The exploration is phenomenological in nature. The intent is to provide an indepth understanding of the experience of women who live with the impact of a massive and disfiguring surgery designed to rid them of recurrent malignant disease. Four women participated in a longitudinal study that spanned from presurgery through to a minimum of forty-eight months post-surgery. The women participated in multiple audio-taped conversations with the author. The women and the author became co-researchers of the phenomenon. Analysis of the conversations yielded firstly, descriptive narratives of each woman's experience, and secondly, themes that identify the underlying structures of the exenterative experience. The identified themes are: personal posture, decision-making, being patient, speaking with another, body consciousness, mutilation, loss, re-arrangement of life priorities, survival and transcendence. These themes are then discussed in relation to theoretical positions taken in existential-phenomenological psychology.

ACKNOWLEDGEMENTS

There are many people who have contributed directly or indirectly to this exploration. Their influence is woven into the words of the text. I would like to acknowledge those individuals who have been most directly involved.

Firstly, I wish to thank Mia, Laura, Margo and Pam who allowed me to come into their lives and to tell some of their story. Their willingness, openness, courage and trust in exploring their experiences has been a gift.

Secondly, I wish to acknowledge my examining committee who shared their strengths and talents with me at various times in the research process:

Dr. Bill Hague (Supervisor), for his encouragement "to write in the way I spoke of the experiences." His support, stimulating questions and prompt and thorough reading of my drafts are greatly appreciated;

Dr. John Osbourne, for his enthusiasm and appreciation of this study, his thorough critiquing and suggestions regarding extension of the discussion;

Professor Doris Badir for her receptiveness to the study, her encouragement in the end stages of the writing, and her involvement with me at various stages throughout my "graduate career";

Dr. Len Stewin for his continued interest and involvement in my research and progress over an extended period of time;

Dr. John Lamont (External Examiner) for his thoughtful reading of this text, his questions and his affirmation that these were powerful stories that needed to be explored and told.

I wish to also thank a number of other people for their contribution in the process of this dissertation coming to be:

Drs. Max van Manen and Tom Maguire whose earlier involvement in the research helped me to clarify and articulate my own research position;

Dr. Michael Taylor, colleague and friend, who initiated the idea of my involvement with the women who would undergo pelvic exenterative surgery. I respect his skill and value his caring and warmth;

Mrs. Judith Abbott who carefully translated my handwritten jottings into this text, was flexible in meeting my timelines and did all of this in good humor;

My husband, Don, whose loving encouragement is ever present. I appreciate the stimulating conversations, his listening to each draft, and his willingness to facilitate the changed responsibilities as I absented myself from home in the final writing stages.

Finally, I would like to acknowledge our six children who provide both chaos and balance to all my activities. In particular, I acknowledge Geoffrey whose birth and growth during this research has enriched our family's life. His ability to invite us into the joy of the moment is his gift.

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PROLOGUE

This research explores the experience of living with pelvic exenterative surgery. This is a surgery that removes massive amounts of pelvic tissue in an attempt to render women free of persistent malignant disease. It is not a common surgery. Although there is an adequate body of literature about the surgical aspects of the experience and a smaller body of literature about the post-operative adjustment to it, there is no literature that addresses the ongoing lived-experience of women who choose this surgical option.

The experiences of four women are the core of this study. The methodology may be called phenomenological. In order to come to an understanding of their experience I have involved myself with each of these women in an ongoing way. This has spanned a five year period of time. I have followed their journey from pre-surgery through the many varied crises, transitions and adjustments that followed. I took an involved rather than detached posture in endeavouring to understand the pelvic exenterative ~~experience~~. I am convinced of the impossibility of being an unbiased observer. The challenge was to balance my participation so that it was neither embedded nor detached. To use Gadamer's (1975) terms, there was a dialectical tension between "participation" and "distanciation". I wanted to come close enough to the women's experience so as not to misunderstand them and yet not be so totally enmeshed with them that I had no critical perspective. As researcher my task was to attempt to describe and interpret the lived reality of women who undergo exenterative surgery; to provide an accurate narrative that allows you, the reader, to gain an understanding of the experience of these women. In order for you to assess the validity of this narrative, my intent is to provide you with sufficient access both to the women's own words as they speak of their experiences and of my personal vantage point as interpreter of their experience. The conversational nature of this study will find its fulfillment if what results is a new conversation between you and the words of this dissertation.

I. INTRODUCTION

Within the shadows
A voice of who I was
And who I am —
A stranger, even to myself
My reflection frightens me
Still, I exist;
You — with your strong, straight spine,
Your clear keen eyes —
You and I,
We share this place,
Come . . .
Draw closer . . .
Listen . . .
To the voices from the shadows.

Jennifer Snair, 1983[1]
(Voices from the Shadows;
Women with Disabilities Speak Out)

The Emerging Question

Q. Do you do sexual counselling?

A. Yes.

Q. Do you know anything about pelvic exenteration?

A. No.

Q. Would you consider working with me with women who may undergo this surgery?

A. I don't know. Let me think about it. I'll get back to you.

This is a distillation of a conversation that took place in June of 1981 between myself and a gynecological oncologist [surgeon]. At the time I was just completing my first six months of working as the only psychologist at a cancer clinic. The surgeon had also joined the staff at about the same time. The "I don't know. Let me think about it. I'll get back to you" took four

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[1] cited in Ferguson—Mathews (1983).

months. In the meantime the surgeon performed two pelvic exenterations. During this time I searched out and read whatever information was available about the psychosocial/sexual aspects of exenterative surgery, finding that there was little published information. Many of these studies gave me statistics about survival time, occupational recovery, degree of sexual function, pre-post marital relationship status and emotional functioning as measured by standardized assessment instruments. I read the medical information that decribed the surgical aspects of the surgery. I listened to the surgeon describe the process that would "disembowel" these women only to glance down and see myself protecting with my arms my own abdomen and genitals as he spoke. As a woman, I struggled to understand the impact and meaning of this surgery to one's sense of female personhood. I spoke with the nurses who were debating the pros and cons of exenterative surgery. Many had never seen an exenteration. Some had, many years earlier, nursed women who had undergone the surgery with less rigourous pre-surgical diagnostic criteria, only to see them die after a short period of time. The theme of many of the vocal nurses had been "I'd never go through that — enough is enough" or "How can he — a young, single male — do that to women?" During this time one of two women who had undergone the exenterative surgery was not healing and indeed was dying. The staff were doing their grieving. Throughout this time I also had the opportunity to work collaboratively with the surgeon as he provided medical treatment for other women who were living with various gynecological malignancies. I grew to appreciate his willingness to share information, to collaborate in treatment goals, to teach others and to learn from them, and to seek out and be open to treatment options. I observed his respectful way with the women who were his patients.

During these four months I learned that a pelvic exenteration is a massive and mutilative surgery done for persistent pelvic cancer. Without the surgery these women's projected survival would be less than a year. With surgery they had a 30—60% chance of long-term survival; that is disease free five years after surgery (Morely & Lindenauer, 1976). The literature indicated differing degrees of quality of life after surgery and in all cases acknowledged a difficult adjustment to it. There were indications that with support from a co-ordinated multidisciplinary team, women's adjustment to the surgery could be enhanced (Fisher, 1979; Lamont, DePetrillo & Sargeant, 1978; Sewell & Edwards, 1980; Yarbrough, 1981). I began to recognize that for these women that the core of the decision to have this surgery was survival. I would need to use my skills to support them and their families as they made the necessary cognitive, emotional, sexual and social adjustments that were precipitated firstly with the possibility of the surgery and eventually with the consequences of the surgery itself. I continued to probe my own responses to the idea of this surgery. I knew I was ready to say "yes" and offer my own skills as part of the team who would offer their resources to these women and their families. There was so much I did not know about the specifics of the experience of having a pelvic exenteration but I had therapy skills and information I felt confident were applicable. I had my first meeting with a woman who was a candidate for a pelvic exenteration in December of 1981. I consciously participated in this encounter both as therapist and educator. My role as a researcher took form as my own questioning continued.

Perhaps this gives sufficient background to contextualize the research question that emerged for me. This study originated with the question "*What does it mean to a woman to undergo a pelvic exenteration?*" and commenced as an exploration of the life-experiences of women who had undergone this surgery as treatment for their recurrent pelvic cancer. *The New Webster Encyclopedia Dictionary* (1980) defines experience as practical wisdom taught by the changes and trials of life. On my first encounter with a woman preparing for a pelvic exenteration I became acutely aware of my lack of practical wisdom about the exenterative experience. I had knowledge about the surgery, experience with illness, information about her prognosis and the projected rehabilitative process, but her *searching* questions rapidly exposed the shallowness of my knowledge. I had researched the area of pelvic exenterative surgery in preparation for and anticipation of my role on the health care team. The encounter invited me into the research. Perhaps it might be best explained in the difference between knowledge and wisdom or information and understanding. Bain (1986) states that "one must have an assumed understanding, a preunderstanding in order to have the knowledge of not knowing, in order to form the question." (p. 27) Polanyi (1958) distinguishes between propositional and tacit knowledge. It was tacit knowledge — that which comes from not only the knowledge of reason but also the knowledge of experience that I sought. You are invited to reflect on a portion of Jennifer Snair's poem,

You and I
We share this place
Come . . .
Draw closer . . .
Listen . . .
To the voices from the shadows.

The research grew out of desire to come, to draw closer, to listen not only to the voices from the shadows but also to share this place by co-creating an opportunity and a medium through which together the voices of their experience did not need to remain in the shadows but could be heard and the meaning of the experience be brought to light.

B. Some Methodological Considerations

Mages and Mendelsohn (1980) state: "we know most about what happens in the acute phases of the disease — the beginning and the end of natural history — and relatively little about the long-term adaptation made by those patients who are surviving with their disease" (p. 258). Vera (1981) reflecting on the specific surgical procedure of pelvic exenteration concludes:

> The procedure elicits negative attitudes in surgeons and patients alike because of the radical mutilation and consequent psychological, sexual, and social adaptation required of the patient. Thus, questions as to whether it should be utilized do not stem from its medical indications or technical aspects, to which considerable attention has been devoted, but from doubts concerning the quality of life it offers to the patient. (p. 355)

The research has grown out of a desire to pay attention to the quality of life afforded exenterative patients, to learn from them about the adaptations that are required and to grow in understanding of the lived-experiences of these women. The question then emerged, how best could one gain a deeper understanding of these women's experience of living with illness — to understand the meaning it had for these women, each in their own unique context. In endeavouring to answer this methodological question for myself I became acutely aware of two of my own biases. Firstly having had both the experience of being ill and the experience of being a "health care" and at times an "illness care" professional in a medical setting, I believed that often in the course of healing disease we may indeed fail to heal persons. Stated more emphatically, Cassel (1982), a physician, suggests that in the process of curing disease, medicine may simply create patients. As a psychologist my second bias grows out of the awareness that often psychological research employs a model that seeks to discover causality rather than to grow in understanding of human experiences. As a clinician, I often experience large gaps between research and practice. Giorgi (1970) suggests that traditionally research in psychology has allowed method to dictate what its content should be. As I reflected on these biases I knew that I wanted to approach the question in such a way that I did not begin the process by distilling out the possible richness and complexity of these women's experiences. I wanted to learn from them. They were the *experts*. I also believed that in order to understand their experience of illness and disease intervention, the research would need to address the personal meaning the experiences had for each woman.

The Legacy of Natural Science

A brief examination of the historical legacy of the natural science research model in medicine and psychology would provide a context in which to place the current resurgence of holistic medicine and the newly defined speciality of health psychology, both of which have implications for this study.

> It is not enough for us to do what we can do; the patient and his environment, and external conditions must contribute to achieve the cure.
>
> Hippocrates (460-377 B.C.)

The tenets of Hippocratic medicine, the foundation of western medicine, have been to foster healing of the whole person — to restore integrity to the body, mind and soul. Bergsma and Thomasma (1982) suggest that: "The conventional wisdom that illness affects the whole person is rarely denied outright. Rather its meaning, therapeutic implications and relevance to physicians are at issue. Even the most ardent reductionists will pay lip service to the importance of the *whole* patient." (p. X) Proponents of holistic health care (Bergsma & Thomasma, 1982; Benner, 1985; Buytendijk, 1974; Cassel, 1982; Millon, Green & Meagher, 1982) express concern over what might be termed reductionistic thinking and treatment that they believe to be rampant in health care services. The thinking of Descartes in the early seventeenth century significantly influenced current research and practice in medicine and the social sciences. The adoption of Cartesian thinking put an end to the distinctions of a body and a soul within a unified individual. It led to conceiving of the body and soul as separate entities. This dualistic approach to man opened the way for "science to escape the control of the church by assigning the non-corporeal, spiritual realm to the church leaving the physical world as the domain of science" (Cassel, 1982, p. 640). In this milieu, science as a discipline flourished. Knowledge of the human body increased dramatically as information about human anatomy and physiology was amassed. With ever increasing specialization in the medical field, human illness was often approached in ways which now not only conceptually separated the body and the soul but began to reduce the body into separate biological systems. This approach is now coming under serious re-examination. This challenge to the perceived practice of medicine is stated succinctly by Cassel (1982):

> It is not possible to treat sickness as something that happens solely to the body without thereby risking damage to the person. An anachronistic division of the human condition into what is medical (having to do with the body) and what is non-medical (the remainder) has given medicine too narrow a notion of its calling. Because of this division, physicians may in concentrating on the cure of bodily disease, do things that cause the patient as a person to suffer. (p. 640)

Benner (1985) further addresses the distinction between bodily disease and human illness. She identifies disease as concerned with biochemical, neurophysiological functioning at the cell, organ, tissue, and system level. On the other hand, illness is the human experience of dysfunction. Health and illness are lived-experiences and are accessed through perceptions, beliefs, skills, practices and expectations. Personal meaning in all its complexity is a fundamental dimension of personhood and there can be no understanding of human illness without taking it into account.

Within the discipline of psychology the same enthusiasm for what has been termed the positivist approach to research and practice has been present. Psychology as a recognized discipline and profession has a much more recent history than medicine. Psychology in its struggle to be recognized as a science also embraced the reductionistic model of human existence. Wilhelm Wundt, in the latter part of the nineteenth century "gave birth to scientific psychology and baptized it with the experimental method" (Colaizzi, 1978, p. 50). The scientific investigation of psychological phenomena proceeded by eliminating human experience. Clinical psychology as it began to emerge accepted the Cartesian dualism and focused its attention on the "mentally" disordered. Millon et al. (1982), in their comprehensive presentation of the historical and philosophical development of health psychology, note that there were some significant efforts in the second decade of this century to co-ordinate the perspectives of physicians and psychologists. By the 1930s, a small number of psychologists were working in university medical centres on projects in neurological and psychophysiological research. (Watson, 1953) These numbers remained small until the 1960s when "there was a growing awareness among physicians that an increasing number of ailments seen in everyday practice reflected the ravaging effects not of infectious agents or ordinary bodily decay but of pernicious styles of life and habits of behavior." (Millon et al., 1982, p. 3) The late 1970s saw the establishment of the Society for Behavioral Medicine, formed by joining health professionals from both medicine and psychology. At about the same time the American Psychological Association (1976) addressed the contribution psychology could make in bridging the mind-body dichotomy, indicating a need for scientific formulations and clinical practices that addressed the problems of illness.

> No other discipline is better suited and equipped than psychology to discover, delineate, and demonstrate the organismic nature of humans and to encourage an ever-broadening realization that humanity's total functional health is threatened when either side of the interactive mind-body equation is neglected. Any program for health care and illness management can achieve comprehensiveness and integration only as there is respect for the functional unity of the individual. (p. 271)

In working toward a synthesis of mind-body it is important to recognize that valuable contributions have been made both in the field of medicine and psychology by those researchers who separated their studies into those realms. In the area of health care, though, this paradigm does not appear to be the most satisfactory. Scofield (1979) states:

> It is a conceptual convention that has facilitated scientific inquiries more than it has encouraged a truly comprehensive medicine . . . . Specialization and focus on body *or* mind has made for effective and progressive programmatic research. A small number of illnesses have been viewed as "psychosomatic" and only a very few physicians and psychologists have been attracted to the complex interface of the physical and the mental. Recent years have seen an increasing appreciation for the need to study the reciprocity between psyche and soma as there has been growing awareness that the individual's health status is a personal gestalt to which situational/environmental and mental/emotional conditions contribute in a complex interactive fashion. (p. 450)

It is within this context, a desire to understand the *personal gestalt* of women who undergo exenterative surgery, that the question is rervealed and from which the research proceeds. A research paradigm which acknowledges the unified nature of being-in-the-world is indicated.

Phenomenological Inquiry

Phenomenological inquiry, founded upon ideas developed by Edmund Husserl (1859-1938), provides a method of investigation that seeks to understand the human condition, manifest in concrete lived situations. As a human science it differs from the natural science paradigm in that it does not seek to explain behavior but rather to understand it. It does not look for causal relationships that measure the physical, observable aspects of the situation. People are not viewed as objects in nature whose behavior is determined by environmental contingencies. It does not seek to discover "the laws" which govern human behavior.

Husserl (1962) called for a turn "to the things themselves". His concern was not with the world as interpreted by scientific fact and theory but the uninterpreted world of experience and language, the *Lebenswelt* or life-world. It is the world as lived by the person. In translation, the hyphenated term "life-world" attempts to capture the interrelatedness inherent in the word *Lebenswelt*. Neither man nor his environment can be understood in isolation. They both co-constitute each other. It is via the world that the meaning of a person's existence emerges for both self and others. The converse is also true. It is each individual's existence that gives individual world meaning. Man is not *in* the world but *of* the world.

The *Lebenswelt* is seen as the ground from which all phenomenological investigation proceeds. No assumptions are made about underlying causality of the life-world. It is seen as direct and immediate in human experience, truly the beginning. Naive experience is not based on anything else. The lived-world is not constructed and the hypotheses, theories and causal thinking of natural science are seen as higher order, less basic, derivatives of the lived-world.

Basic to Husserl's (1962) approach to understanding human experience is the notion of "phenomenological reduction"; coming to the essential "structure" of the phenomenon. He suggests that it requires a process of "bracketing"; an attempt to suspend or put in abeyance one's preconceptions and presuppositions. As this is done, new assumptions emerge to the level of "reflective awareness" and so they too can be bracketed. The aim is to move toward a "transcendental attitude" in understanding the phenomenon. The structure of the phenomenon is understood through a process of bracketing that moves the interpreted closer to the essential nature of the phenomenon. The structure of the phenomenon is the commonality running through the many diverse appearances of the phenomenon.

Simply stated, the aim of phenomenological inquiry is to articulate the essence, the structure, the form of human experience. Contrasting phenomenological inquiry with the natural science paradigm, description through disciplined reflection then replaces the experiment as the method and structure replaces cause and effect relationships. (Valle & King, 1978)

Heidegger (1962) in his discussion "The Phenomenological Method of Investigation" presents a definition of phenomenology by refering to the Greek roots of the word: *phainomenon* or *phainesthai* and *logos*. The word phainesthai connotes "that which knows itself, the manifested, revealed." The *pha* akin to *phos* means light or brightness, "that in which something can become manifest, can become visible." Phenomena then are the "totality of what lies in the light of day, or can be brought to the light, what the Greek identified simply as 'what is'." (Heidegger, 1962, p. 51) *Logos* is "that which is conveyed in speaking." Heidegger (1962) says that in a deeper sense *logos* has the function of letting something be seen. It points to the phenomena. Smith (1983) states that *logos* (speaking) is not really a power given to language by its user but a power which language gives to the speaker, a means of being seized by what is made manifest through it." (p. 51) Phenomenology then as the combination of *phainesthai* and *logos* means letting things become manifest as what they are. The act of phenomenological investigation and interpretation is to bring something from concealment into clarity. (Smith, 1983)

Phenomenological methodologies have been variously described and applied. Colaizzi (1978) in addressing the interface between phenomenology and psychological research states: "there is no such thing as THE phenomenological method. Instead the phenomenologist employs descriptive methods, with the emphasis on plural. *Each particular psychological phenomenon, in conjunction with the particular aims and objectives of a particular researcher, evokes a particular descriptive method.*" (p. 53)

Giorgi (1975) has clearly outlined the fundamental criteria underlying phenomenological inquiry. There is fidelity to the phenomenon as it is lived, allowing anything that the subject feels is worthy of speaking about to be registered as data. It also requires the researcher to make her perspective explicit. The point of departure for the research is the everyday lived world of individuals prior to theoretical interpretations. Phenomenological research depends on the power of language so that the subject can communicate her experience. Paramount to this approach is that the situation is expressed from the subject's viewpoint. The research proceeds within an interpersonal context with a dialectical exchange between subject and researcher. The basic unit of research is the lived situation, part of which is the research situation. All the contextual factors are presumed to be interdependent as meaning units are discovered and thematicized. The phenomenological approach endeavors to formulate key terms after dialoguing with the data. This is not done a priori in order to direct the search. The method requires an engaged researcher, not merely an observer. Finally the phenomenological approach explores meaning by investigating the qualitative aspects of the phenomenon.

C. The Research Question and its Organization

"What does it mean to a woman to undergo a pelvic exenteration?"

The nature of the question is such that it seeks a deeper understanding of and demands insight into these particular women's experience of being-in-the-world. The question asks *what* rather than *why*. The question points to *understanding* rather than *explanation*. It requires women to speak of their experience and for me as a researcher to be involved in this dialogue, not simply observe it. This research initiates an exploration of the subjective meaning of being a woman and undergoing a massive pelvic surgery that is mutilative and may be curative of persistent malignant disease. The exploration does not evolve out of an ideology but rather begins from women's experience as they choose to reveal it. It focuses on what women actually do, their responses, what they feel and what they perceive; the despair and the hope, the pain and the pleasure, the fear and the courage, the trust and the mistrust, the anger and the joy, the horror and the acceptance, the change and the sameness of their everyday being-in-the-world. Chapter II provides a context for this exploration, a further background to the question as it emerged for me. Most significantly it provides an overview of the available literature related to the psychosocial aspects of pelvic exenterative surgery. In reviewing this literature some questions were answered for me; many more emerged. It is intended that Chapter II speaks to the relevance of the research question and answers the query: Why does this question need to be asked?

Chapter III describes the research process, how the question was explored. The intent was to gather rich descriptive data that would allow you, the reader to enter into the lived-experience of these women. It describes the process through which I as therapist and researcher participated in the gathering of the data. Colaizzi (1978) describes this as "dialogal research." Through dialogue the meanings and reality systems behind the phenomenon are explored. It allows an exploration of the phenomenon without objectifying the participants. It values individual perceptions and experiences. It values "not knowing" on the part of the researcher, an openness and humbleness in the face of what is revealed. It acknowledges the contribution of both participants of the dialogue in the construction of the resulting "truth". (Bain, 1986) Chapter III provides the first opportunity to directly encounter the women whose experience is the research. They are described using a medical summary format. This is how they may first become known to the many health care givers who interact with them. The intent of the research is to provide a gradual unfolding or deepening of the understanding of these women's being-in-the-world. The chapter includes a description of and demonstration of the way I began my own reflective process of the transcribed conversations and case notes.

The following chapters are a presentation of the developing understanding of the phenomenon of living with a pelvic exenteration. In order to come to a deeper understanding of the phenomenon, I chose to present three layers of analysis: firstly via descriptive narratives, secondly via a thematic discussion, and thirdly via a personal reflection on the research process.

Chapter IV addresses the first level. It presents descriptive narratives of each of the women. The intent is to allow you, the reader, to enter into the lived-experience of these women. You hear the words of each of the women as they reveal their own very personal experiences of living with illness, of living with uncertainty and change, of being a woman, a lover, a wife, a mother, a worker, and a friend. The decision to present narratives of each woman grew out of a desire to portray and acknowledge the individuality of each woman — her richness and beauty. As I met with, spoke with and listened to the women I came to a deep appreciation of their courage and their strength and of their willingness to struggle and to move on. They shared their despair and anger, their faith and their hope. These women have many things in common and yet they are uniquely individual. In order to facilitate hearing the sameness and the difference of each woman the narratives are presented using a recurring format. Throughout the conversations there were common concerns and transitions on which the women focused their attention. These are ordinary women facing an extraordinary adaptive challenge.

Chapter V presents the themes as they emerged for me from my conversations with these four women. Benner (1985) refers to this process as translating the language of phenomenological events into the patterns or concepts that might be called the language of understanding. The process is intended to add to experience and to deepen understanding. It is my hope that this pays tribute to their experience and speaks to the *heart* of their being-in-the-world.

The Epilogue represents a stepping back and reflecting. It maps some of my journey. It presents my personal reflections upon my participation in this endeavor — a glimpse at my being-in-the-world as the research evolved.

II. BACKGROUND TO THE RESEARCH

This chapter provides a background to the study of the experience of living with the impact of pelvic exenterative surgery. Initially a brief description of the surgical procedure will be presented. That will be followed by a review of all the available published studies on the adjustment to pelvic exenterative surgery. Those studies published prior to June, 1981 provided me with my initial introduction to and understanding of this surgical procedure.

In order to place this oncological intervention within a broader context, there will be a brief presentation of the literature that has reviewed more generally the psychosocial impact of cancer on patients and their families.

With this overview of the currently available literature I would anticipate that you, the reader, may begin to formulate your own reactions to and questions about what is the lived-experience of women who choose to undergo this extensive surgical procedure with the ultimate hope of being rendered free of malignant disease. The existing information is limited and often addresses biological functioning. The intent of this research is to add to the further understanding of the exenterative experience, complementing the existing information.

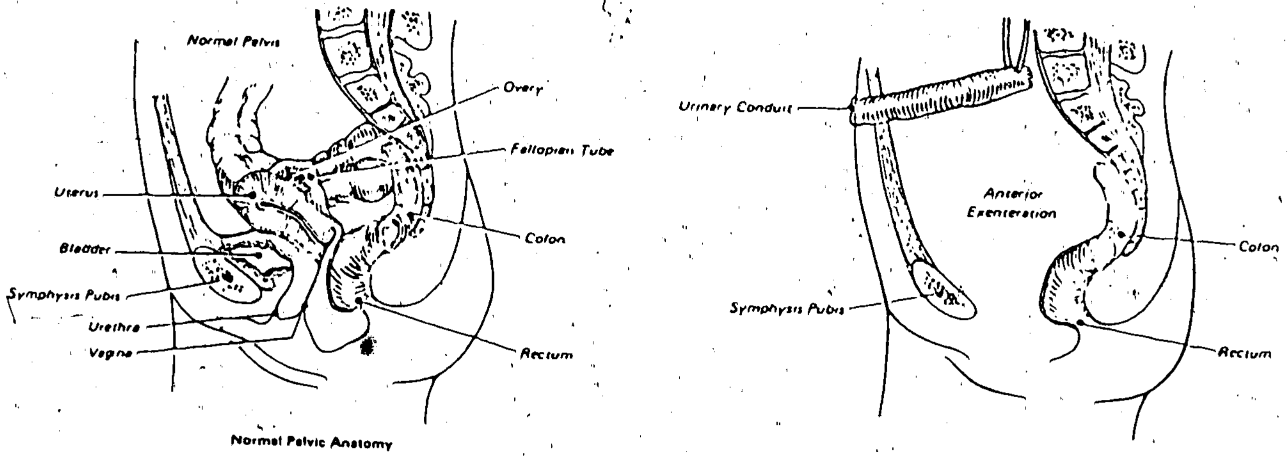
A. Pelvic Exenteration

Pelvic exenterative surgery was first described in the literature by Brunschwig (1948). More than three decades later the procedure still evokes controversy in the medical community. Turko, Benedet, Boyes and Nickerson (1977) in reviewing medical records in the province of British Columbia over a 22 year period concluded that this surgical procedure has a small but definite role in the management of certain types of pelvic cancers.

Pelvic exenteration is a surgical procedure aimed at providing a cure for invasive gynecological cancer. This is not palliative surgery. The goal of the surgery is to render the woman free of pelvic cancer. The procedure is extensive. A total pelvic exenteration entails "the en masse removal of the rectum, distal sigmoid colon, urinary bladder, distal ureters, internal iliac vessels and their lateral branches, all pelvic reproductive organs and lymph nodes, and the entire pelvic peritoneum with accompanying pelvic peritoneum, levator muscles and perineum." (Bricker, 1970, p. 14) Postoperatively she may expect to have a colostomy, an ileo-conduit and possibly a reconstructed neovagina (see Figure 1). In lay terms, a woman will have had her bowel, bladder, uterus, ovaries, and vagina removed. After surgery she may have external appliances to collect urine and fecal matter and through tissue grafting a new vagina may be created.

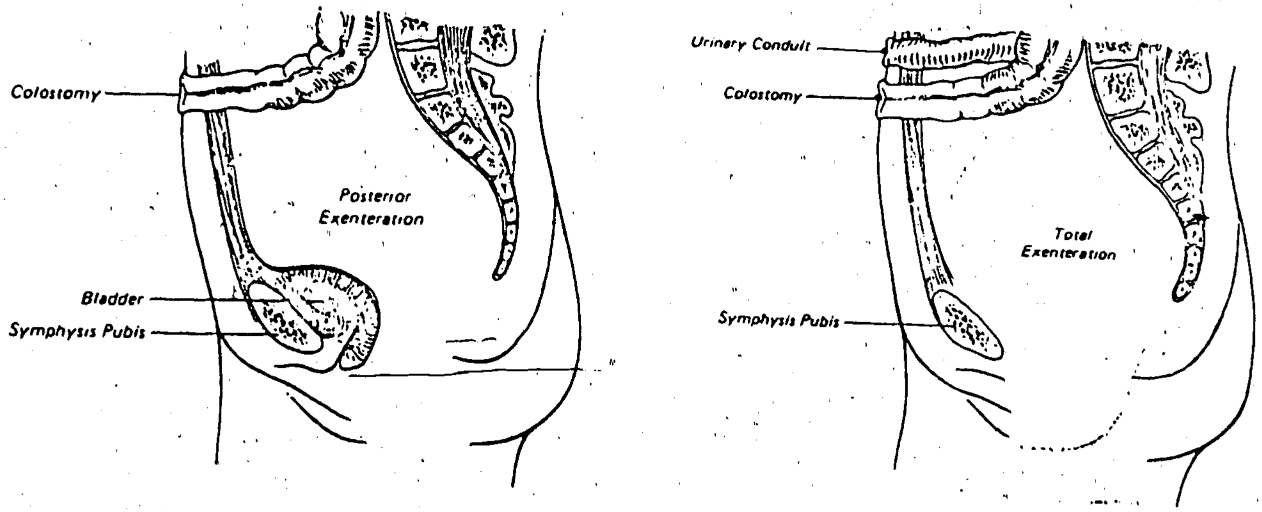
All women considered for this surgery are carefully screened to ensure that they do not have malignancy outside the pelvic cavity. Most women will have been previously treated, either surgically or by radiotherapy for their malignancy and now have either persistent or recurrent disease.

The surgical procedure may take eight to twelve hours to complete and postoperatively there will be a three to six week hospitalization. This is followed by an extensive convalescent period out of hospital.



Normal Pelvic Anatomy

Anterior Exenteration



Posterior Exenteration

Total Exenteration

Figure 1. Examples of pelvic exenterations (from "A patient teaching aid for the pelvic exenteration patient" by Katherine Crosson, *Oncology Nursing Forum*, 1981, *8*, 4, 55).

B. Adjustment to Pelvic Exenterative Surgery

The following is a chronological review of the studies of the psychosocial and psychosexual adjustment of women to pelvic exenteration surgery.

In order to investigate adjustment to pelvic exenteration surgery, Brown, Haddox, Possada, and Rubio (1972) studied 15 of 19 surviving women out of a population of 57 who had undergone this surgery at the University of Virginia in the period between 1954 and 1966. Interviews were conducted over a three year period at times when the women returned for three to six month physical checkups. The mean time since exenterative surgery was 4.15 years with a range from .2 to 12 years. These interviews were non-directive, psychoanalytically oriented and included administration of psychological instruments including the MMPI, the Rorschach, Human Figure Drawing, and the Miale-Holsopple Sentence Completion Tests. The intent was to assess:

1. social adjustment following the operation;
2. psychological adjustment to mutilation, especially the desexualization and the loss of bowel control following colostomy;
3. correlation of personality factors and the course of malignancy; and
4. the role of psychiatric support in the responses of these women.

These findings indicate that 40% reported change in social habits and 80% returned to their job. They identified 23% of the group as having aberrant MMPI profiles and concluded that this departed very little from estimates of mental illness in the general population. After exenteration 73% indicated no present sexual interest. Further to these findings the researchers suggested that supportive psychotherapy that occurred coincidentally to the investigation may have further improved the lives of the postexenteration patient.

Dempsey, Buchsbaum and Morrison (1975), using a structured interview, followed 16 patients who underwent a pelvic exenteration. Their intent was to determine factors that influenced patients' social, physical and mental recovery and their acceptance of the procedure. Patients were interviewed both pre- and post-operatively. The most common reason given by patients for agreeing to exenterative surgery was the desired continuation of family relationships. The family, particularly the husband, was an important factor in the patient's acceptance of surgery and also was significant in providing emotional support post-operatively. These findings associating family relationships with the management of illness related anxiety are also supported by Dyk and Sutherland (1956).

Dempsey et al. (1975) concluded that satisfactory levels of psychological and physical well-being are achieved within four months of exenterative surgery and that the long term physical, social, mental and occupational recovery is good. They found a significant loss of sexuality following pelvic exenteration. In conclusion "... the quality of life after exenteration is very satisfactory. The negative reaction of many physicians to pelvic exenteration is unfounded" (p. 333).

With a well defined team intervention, Lamont, DePetrillo, and Sargeant (1978) reported on the psychosexual rehabilitation of 12 exenterative patients. The team consisted of two oncologists, an anesthetist, an enterostomal therapist, and a psychosexual counsellor for the patient and her partner. All patients were seen pre-operatively by all team members and then followed post-operatively at regular intervals. Ten of the women had vaginal reconstructive surgery, one refused the reconstruction, and one did not require the surgery because half the vagina remained intact after exenterative surgery.

Lamont et al. (1978) reported that of eight women who were assessed to have good sexual adjustment pre-operatively, seven resumed sexual activity and were assessed as having good post-operative adjustment. They concluded that "exenterative surgery need not contradict coital activity, but patients need to be encouraged to explore options to coitus and possibly evolve a philosophy of sexuality which includes lovemaking as a series of options or a smorgasbord of pleasure." (p. 242) Further, they proposed that loss of sexual function is more likely to be associated with feeling unattractive, a lack of information, or a lack of support in dealing with post-operative psychological reactions.

Fisher (1979) in her study of six exenterative patients identified that while their general patterns of life continued, there were many unresolved psychosexual problems three to ten years post-operatively. Five of the six patients considered themselves to lack femininity and expressed concern regarding their appearance. Half of the women felt they lacked practical information concerning stomal care; however, half reported their partners assisted them with this care. Three patients terminated their relationship with their partner after surgery. Five patients reported terminating any kind of sexual contact with partners after having reported a normal sexual relationship pre-operatively. All patients seemed unaware of alternative forms of lovemaking.

Sewell and Edwards (1980) in comparing pelvic exenteration patients to patients undergoing either a Wertheim hysterectomy or radical vulectomy, found a significant difference six months post-operatively between exenteration patients and the other two patient groups in the following ways: body image, altered sexual relationship after surgery and frequency of intercourse after surgery. All three groups showed a significant decrease in the aforementioned with exenteration patients indicating the greatest change. There were no significant differences between and among the three groups on self-esteem, general well-being, Rotter's internal-external control, or social adjustment measures.

Vera (1981) interviewed 19 women post-operatively to assess their social, sexual and psychological adaptation after pelvic exenteration. This population was selected from 25 women who had had this surgery during a ten year period prior to the study. Two of these women declined participation, stating they wished they had never had the surgery, and four other women died as the study progressed. A 176-item questionnaire was used as the interview basis. The time interval between surgery and interview varied from 6 months to 9 years.

The data indicated that there was a negligible incidence of psychiatric disorders, a significant loss of sexual life, poor occupational recovery and decrease in social activities. When asked their most difficult post-operative adjustment, six women reported stoma care, seven considered changes in physical appearance most distressing, four mentioned loss of their partner, one stated loss of sexual life and one woman was unable to identify one particular difficulty. In spite of these significant changes, women tended to indicate that their quality of life was above average, with a trend toward improvement. They faced the future with marked hope.

Anderson and Hacker (1983), in a descriptive study, examined the psychosexual adjustment following pelvic exenteration of 15 women. At time of interview, average time since surgery was 5 years 6 months. All patients were clinically free of disease. The data were collected through one hour semi-structured interviews followed by completion of a questionnaire battery designed to assess psychological distress, psychosocial adjustment, and sexual functioning.

Results indicated that as a group they were mildly distressed and depressed. These women reported active and satisfactory levels of social and free time activities. Sexual functioning continued as the area of greatest difficulty. On this dimension, they resemble severely sexually disfunctional healthy women. They reported greater sexual anxiety and a much lower level of sexual satisfaction than do sexually dysfunctional women.

For virtually all the women in the study there was a significant disruption in sexual activity. Two important subgroups were identified — those who were satisfied and those who were dissatisfied with their present sexual situation. For the sexually active satisfied group (N=4), the vaginal reconstruction had gone well and they were able to maintain a satisfactory level of activity. In the sexually active dissatisfied group (N=3) they reported disruption in the frequency, variety of activity, level of arousal or problems with the neovagina (e.g., length insufficient, cavity too large, painful intercourse, chronic discharge). In the non-sexually active group there were those who were content with the end of sexual activity (N=4) and those who were not (N=4). This latter group also includes two women with neovaginas: one without a partner and one who was uncomfortable with resuming sexual activity even though she had an interested partner. Anderson and Hacker (1983) concluded that "objective evidence indicates that reconstructive surgery does not significantly enhance body image; however, incidental reports from patients lead these investigators to believe that it may have a positive impact, as individual women have reported not feeling like a woman until reconstructive surgery was performed." (p. 337)

All patients reported they would go through this surgery again in order to survive. There was not consensus that they had received adequate preparatory information. All patients undergoing reconstructive vaginal surgery indicated that discussions of sexual functioning were inadequate.

It is interesting to note the variation in reported adjustment to exenterative surgery. In all studies the sample was small. Many of the studies involved retrospective recall and often group data were reported when women were at differing stages of post-operative adjustment. Not all studies indicated vaginal reconstruction status. Fisher (1979) reports poor adjustment to surgery whereas Brown et al. (1972), Dempey et al. (1975) and Anderson et al. (1983) report good adjustment except in the area of sexual functioning. Sewell et al. (1980) would support this finding. Vera (1981) found both poor sexual and occupational recovery after exenterative surgery. Lamont et al. (1978), providing a systematic intervention protocol, report a much better sexual rehabilitation profile of their patients. Derogatis (1980) when speaking about gynecological malignancies in general states: "they are unique because not only do they inflict pain, suffering and the potential for death, but carry with them a special ability . . . the capacity to devastate the feminine identity." (p. 10)

Both Lamont et al. (1978) and Anderson et al. (1983) stress the significance of vaginal reconstructive surgery as a significant factor in sexual rehabilitation. Further to this, they stress the importance of education and support of patients and their partners regarding psychosexual matters. Morley, Lindenauer and Youngs (1973) concluded from their respective specialties of gynecology, surgery and psychiatry that "when the surgeon removes part or all of the vagina during pelvic exenteration, he is obliged to consider some type of vaginal reconstruction as part of the rehabilitation program." (p. 996)

Several writers (Fisher, 1979; Lamont et al., 1978; Morley et al., 1973; Sewell & Edwards, 1980; Yanbrough, 1981) stress the importance of pre-operative intervention by a multidisciplinary team. At this phase and throughout treatment, intervention includes both support and teaching for the patient and her partner. Major concerns initially are survival and comprehension of the physical changes that will occur. Post-operatively, as the patient begins to recover from the surgical insult, the patient begins to hope for complete rehabilitation, and the concerns regarding psychosexual functioning begin to emerge (Lamont et al., 1978). Fisher (1979) states that "her social and sexual value system remains intact, and all adaptive changes and orientation to new behavior must occur within this context." (p. 224)

C. Psychosocial Impact of Cancer

In order to view the exenterative literature in context, it may be important to briefly review some of the literature which addresses more generally the psychosocial impact of cancer. All writers reviewed in this area begin with two principal tenets: 1) the diagnosis and treatment of cancer is a stress to patients and their families and 2) management of this stress should be an integral component of comprehensive medical care.

Crisis theory states that the degree and character of psychosocial distress depends on the specific meaning of the stressful situation, previous exposure to similar distress, the adaptiveness of the individual's coping mechanism, and the support received from others (Capone, Good, Westie, & Jacobson, 1980; Caplan, 1964). Krant (1981) states "that the 'stress' of cancer is primarily related to the fear that one's life is being altered in an irrevocable manner such that desired and cherished values, roles, and adaptive functioning will be reduced." (p. 608) Adaptive functioning appears to be influenced by: 1) a belief in one's personal power to influence favorably other important people as well as life's events; 2) a belief in control over one's personal destiny; 3) a sense of comfortable belonging to a particular group or unit; and 4) a belief in a limitless future. (Krant, 1981)

Mages and Mendelsohn (1980) propose three dimensions on which psychosocial aspects of cancer can be viewed. Firstly, cancer is an ongoing process that unfolds over a considerable period of time and in several stages. Secondly, cancer produces enduring personal change which needs to be viewed in the context of the individual's life stage and previous history. Thirdly, the psychological developments at any given point in the process are integrated around the patient's need to adapt to the issues imposed by the concrete realities of the illness.

With a growing number of cancer treatment options available it is becoming increasingly important to determine the quality as well as the quantity of life they offer to the patient. Both tumor and treatment are seen as affecting quality of life and there are many studies which now look at the impact on patients of various treatment protocols. It is generally agreed that quality of life is a complex construct. Most researchers agree that it is subjective in nature and incorporates both the physiological and psychological aspects of body functions, work and activity, and relationships (Newton, 1979; Mages & Mendelsohn, 1980; Schmale, Morrow, Schmidtt, Adler, Enelow, Murawski & Gates, 1983; Presant, 1984). Presant (1984) developed an assessment tool designed for patients to measure their own quality of life. He found that "physicians were relatively incapable of adequately describing patient quality of life" (p. 572). Correlations between patient and physician scores were very poor not only on overall quality of life scores but also on subscores for symptom control, physical well-being, and psychosocial well-being. He concluded that there is a need for the patient to play a major role in describing her quality of life rather than relying solely on physician assessment.

Schamle et al. (1983) designed a study which examined the well-being of individuals who were considered to have survived their cancer. They studied cancer patients who were a mean of three years past their last cancer treatment and who were considered medically healthy with no evidence of cancer. When compared to a matched sample of healthy controls it was found that the cancer patients had a significantly lower sense of self-control and more general health worries. They concluded that the quality of survival is greatly influenced by the patient's increased sense of vulnerability both psychologically and physically.

With advances in cancer treatment, and with more patients surviving their cancer for extended periods of time, it becomes increasingly important to determine the quality of this survival. There has indeed been a shift toward research aimed at gaining a better understanding of the social and emotional impact of cancer and its treatment (Holland, 1984). The importance of the shift is underlined by Ware's (1984) assertion that "there is more to life than not dying" (p. 2307).

D. The Relevance of the Research Question

The review of the literature pertaining to pelvic exenterative surgery underlines the difficult adjustment that is present for women who choose this surgical procedure. Lamont et al. (1978) report on the outcome of a systematic intervention program offered exenterative patients to assist them in their post operative adjustment. All other studies reviewed attempt to assess women's adjustment to exenterative surgery and the quality of life it affords. These studies often employ standardized assessment tools and structured interviews and frequently include extensive retrospective recall on the part of the women being studied. Only two of the studies (Dempsey et al., 1975; Lamont et al., 1978) follow the women both pre and post operatively. Adjustment to the surgery is influenced by the woman's own perceived quality of life following surgery. As discussed in the literature, quality of life is a complex construct. Attempts by researchers to measure it have had variable success. The assessment by professionals of patient's quality of life has not correlated highly with patients' self assessment.

The research question, *What does it mean to a woman to undergo a pelvic exenteration?* and the methodology chosen to explore this question are relevant in that they will provide qualitatively different information regarding the experience of pelvic exenterative surgery. This study complements other existing studies. It will be longitudinal in nature, following women through critical transition points in their experience with the exenteration. It is the women who will speak of their experience, evaluating their ~~quality of life~~ and determining for themselves what is significant to speak about. Most importantly the meaning of this surgery in the women's lives will be studied. In this way it will contribute new information providing an indepth description of the experience of exenterative surgery from the woman's (patient's) perspective.

III. A WAY TO UNDERSTANDING WOMEN'S EXPERIENCE OF EXENTERATIVE SURGERY

What does it mean to a woman to undergo a pelvic exenteration? The question emerges out of a desire to grow in understanding of the lived-experience of and the personal meaning for women whose lives are transformed by pelvic exenterative surgery. We bestow meaning on life events, each of us in our fashion. We may declare life meaningful, meaningless, a struggle, a joy, and so on. In the same way, events may be unbearable, a challenge, horrific, an opportunity, a punishment or a gift. We construct meaning based on our own unique life experiences, our past, our now, and our belief in what may come. We act and interact based on this rich subjective view of ourselves and our world. Benner (1985) states: "meaning resides not solely within the individual nor solely within the situation but it is a transaction between the two so that the individual both constitutes and is constituted by the situation. Therefore, the unit of analysis is the transaction." (p. 7)

This dissertation grew out of a question that sought understanding rather than explanation. It is my hope that the process will generate deeper and perhaps new understandings of the phenomenon of pelvic exenteration and that these understandings can be used to inform our actions and provide new possibilities for these who are or may be involved. Barritt, Beekman, Bleeker & Mulderij (1979) state: "research which describes human experience inorder to better appreciate it gives the chance that better decisions will be made in the future" (Chapter 2, p. 2). Accordingly, this dissertation and the process of its coming to be is phenomenological in nature.

A. Researching Lived-Experiences

> If we really want to know how people feel, what they experience and what they remember, what their emotions and motives are like, and the reasons for acting as they do . . . why not ask them?
>
> (Allport, 1942, p. 37)

As we attempt to understand human experience, often there seems to be a rift in the language and understanding of science and the language and understanding of ordinary persons. The traditional scientific approach in its pursuit of objective data collected by impartial observers may be bypassing a rich ground for understanding human experience. In my turning to the phenomenological approach it is my contention that a different kind of knowledge is arrived at. It is the knowledge or understanding which emerges out of dialogue with others. Together a shared world of meaning is created, where concensus is the criterion for validity and understanding is not intended for prediction but rather leads to enhancement of the possibilities for action and interaction.

I will now situate the methodological approach I have used in endeavoring to come to an understanding of women's lived-experience of pelvic exenterative surgery. The phenomenological approach, as elucidated by Giorgi (1970, 1975) provides the starting point for this study. The point of departure is the gathering of descriptions that are anchored in the lived-experiences of the women. These decriptions come from the women themselves and the methodology utilizes both retrospective recall and simultaneous description of their ongoing experience. With the phenomenological approach the focus is on the phenomenon; that which appears exactly as it appears to the one to whom it appears (Aanstoos, 1986). Once these descriptions are gathered, the aim of the analysis of the data is the explication of the essential structures of the phenomenon. The findings of the analysis then take the form of descriptions of the general psychological structures of the phenomenon.

Giorgi (1975) is one of a number of contemporary phenomenological researchers who chooses not to use his personal experience during an investigation, at least in the sense that it becomes an explicit part of the research. He does engage in reflection on the phenomenon prior to the investigation but endeavors to suspend (bracket) his presuppositions once the investigation begins, in an effort to approach the phenomenon openly and in order to grasp it intuitively. My approach is a departure from this. As the dialogue with the women occured over a five year period and my role was as both researcher and therapist, bracketing off my experience did not seem like the most productive way of coming to an understanding of the phenomenon. Embodied in the research in such a way as to develop a deep understanding of the nature of the phenomenon, I as researcher, attempt to describe and interpret the lived-experience of the women who undergo pelvic exenterative surgery. My preunderstandings, rather than being suspended as possible bias, are acknowledged as my gateway to the phenomenon and as a point of reference throughout the research. In dialogue with the women and later with the conversation protocols, it is my preunderstandings that become enriched, a process that eventually sets the stage for the more concrete statement of the findings.

Other phenomenological investigators (Alapack & Alapack, 1984; Lifton, 1976; Merleau-Ponty, 1962; Sullivan, 1980; von Eckertsberg, 1978) suggest models that include the researcher's experience in the investigation. Basic to these approaches is the thesis that "truth" is intersubjective in nature. Merleau-Ponty's (1962) approach to phenomenological description is that the describer is embodied and involved in the experiential field which includes "motility, spatiality, gesture and expression." Sullivan (1980) in drawing on the writings of Gadamer (1975) states; "the interpreter of a text comes to knowledge of the text by a sympathetic rather than a detached posture. Sympathy assumes bias as a necessry pre-condition for understanding." (p. 56) Although Gadamer refers to written texts per se, Sullivan (1980) contends that these principles are important in interpretation (i.e. understanding) of persons and groups of individuals. Gadamer (1975) states: "To try to eliminate one's own concept of interpretation is not only impossible, but manifestly absurd. To interpret means precisely to use one's own preconceptions so that the meaning of the text can truly speak for us." (p 358) von Eckartsberg (1978) in an approach he refers to as "dialogal existential-phenomenology" states that the researcher has to rely on the intersubjective character and shared meaning that common language and common experience provide. He claims this type of research can initiate personal and intersubjective growth while one's understanding of the person and the phenomenon deepen. Alapack et al. (1984), in taking a more extreme position inspired by Kierkegaard's notion that "all understanding is self understanding" (Nordentoff, 1978, p. 2), suggest we must enrich "our understandings expansively and comprehensively in contact with other equally legitimate interpreters. Ultimately we must come full circle to speak responsibly about the whole *In our own name*." (p. 48) Lifton (1976) challenges investigators to make their own subjectivity clear and conscious, to try to understand it and use it as part of the conceptual structure. Further, he states:

> We in the psychological professions always function within this dialectic between ethical involvement and intellectual rigour, and I believe that bringing our advocacy "out front" and articulating it makes us more rather than less scientific. Indeed, our scientific accuracy is likely to suffer when we hide our ethical beliefs behind the claim of neutrality. I view this dialectic of advocacy and detachment (again, Buber's distance and relation) to have great importance, even in the most "clinical" of situations. (pp. 155-156)

In summary, the method employed in this study focuses on the women's life-experiences with stress on the specific data gathered from the interviews. The interviews are a cooperative dialogue between the women and myself. Descriptions from the women are sought, but the interviews also include description from my (researcher/therapist) experience of the phenomenon. My research role is to actively listen to the women's description of their experience and to accurately interpret it to others. My therapy role is to facilitate introspection and support change in the women; and to advocate for them. The conversations which form the basis of this study depart from traditional phenomenological interviews in that they occurred *in vivo* (in hospital wards, in medical examining rooms, halls, homes, etc.) Therefore, there were varying degrees of privacy, just as was the women's experience. Some of the conversations took place in a group composed of the four women and myself. In group, the women frequently found support to speak about aspects of their experience that they may not have previously articulated. The goal of this study was then to use these conversations to formulate not only a rich description of the lived-experience of pelvic exenterative surgery but also to identify the underlying structures of phenomenon. To quote Lifton (1976): "By rendering these psychological concepts in their most basic and systematic form I seek to make them more accessible to myself. If I succeed in that, I know they will be accessible to others." (p. 13)

Sullivan (1980) states: "ultimately, for the researcher's interpretation to be valid it must, at least, be a recognizable reality to those in whom the interpretation is made." (p. 67) The women participated in validating their descriptive narratives. In order for you, the reader, to assess the validity of this interpretive work, the following criteria of internal validity as outlined by Cherniss (1980) may be helpful.

1. An interpretive work should help one understand the lives of the subjects. One should better comprehend the complex pattern of human experience as a result of it.
2. The themes should maintain the integrity of the original "data".
3. The interpretations are considered internally consistent if the textual data matches them. This means they need not reveal only consistent practices and commitments of the participants.
4. The data that support the findings should be presented.
5. The reported conclusions should be consistent with the reader's own experience.

"In qualitative research, the readers must critically scrutinize the results of the thematic analysis, playing a more active role in the process of 'validation' than they normally would." (Cherniss, 1980, p. 279)

B. The Women

To provide a broader context for the women of this research it may be advantageous to locate them within a group of Alberta women who were considered possible candidates for this surgery. Pelvic exenterative surgery is not a frequently performed oncological treatment. Between June, 1981 and March, 1983, at the University of Alberta hospital, eight women underwent pelvic exenterative surgery for the treatment of recurrent or persistent malignant pelvic disease. All the surgeries were performed by the same surgeon. Besides these eight women, several other women were considered candidates for this surgery. These latter women were prepared for exenteration but the surgery was not completed either due to disclosure of distal disease (i.e. liver metastases) or in the initial surgical phase due to positive biopsies of lymph nodes or sidewall tissue. These women were then offered adjunctive chemotherapy.

Prior to my involvement in this study, two of the eight women had already had the exenterative surgery. With the exception of these two women, I have met with all the above mentioned women preoperatively. The women were referred to me by the surgeon as soon as they became possible candidates for this surgery. Table 1 provides an overview of the eight women who underwent the complete surgery. I had no contact with Jean, the second woman to have the surgery. I did not meet patient Mia, the first woman to have the surgery, until nineteen months after her exenteration. I have continued to meet with her periodically up to the present time. I met with all the other women preoperatively and then periodically through their postoperative period either until the present time or until their death.

Of this group, four women,[2] all of whom are alive four or more years after surgery, form the basis of this study. Routinely as part of the health care team, I met with each of these women. The research began to formulate as I experienced the aspects of my not-knowing as I interacted with these women. I shared that not-knowing with them and each of them agreed to participate with me in a process which we hoped would provide an inclusive description of their living with exenterative surgery.[3]

These women ranged in age from 26 to 56. All were married. One had been married for a second time. All four women had children and one had a grandchild. Three of the women, prior to surgery, were employed outside their home and had some degree of financial independence. Two of the women had completed high school while two had completed some post-secondary education. All four live in major Alberta cities. All are Caucasian. One woman was born in Canada, while the other three were born in Europe (Germany, Britain and Poland). Of these latter three, two emigrated to Canada as adults, one as a young child with her parents. All of them had persistent or recurrent carcinoma of the cervix which had not been

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[2] In Table 1 these women are Mia, Laura, Marge and Pam.
[3] See Appendix A — consent to participate.

Patient	Age at Exen-teration	Status after Surgery as of August 1986	Marital Status pre/post	Employment pre/post	Initial Diagnosis (Months prior to Exenterative Surgery)	Previous Treatment	Type of Exenteration	Neovagina (status if known)
Mia	56	62 months alive and well	M/M	homemaker part-time nurse/same	C.A. cervix (9 months)	Radium inserts External radiation	Total	Sigmoid (removed) split thickness grafts (functional)
Jean	41	deceased 9 months after surgery	M/M	unknown	C.A. cervix (11 months)	Cone biopsy Radium inserts External radiation Radical hysterectomy and attempted lymphadectomy	Anterior	Gracilus myocutaneous
Diane	39	deceased 15 months after surgery	M/M	homemaker homecare worker/homemaker	C.A. cervix (31 months)	Radium inserts External radiation	Anterior	Gracilus myocutaneous
Laura	26	51 months alive with recurrence	M/M	homemaker part-time realtor/ homemaker	C.A. cervix (14 months)	Radium inserts External radiation	Anterior*	Gracilus myocutaneous (removed)
Marge	42	50 months alive and well	M/M	homemaker part-time travel industry / same	C.A. cervix (7 months)	Cone biopsy External radiation Insert unsuccessful	Anterior*	Gracilus myocutaneous (removed)
Pam	43	49 months alive and well chronic pain	M/M	homemaker/ same	C.A. cervix (9 years 7 months) recurrence (7 years 9 months)	Radium inserts x-ray and cobalt Chemotherapy Sigmoid ureterostomies	Anterior*	Gracilus myocutaneous (non-functional)
Frances	46	deceased 12 months after surgery	D/D	homemaker/ same	C.A. cervix (19 months)	External radiation Radium inserts	Total	McIndoe Vaginoplasty, skin grafts
Louise	82	deceased 4 months after surgery	W/W	homemaker/ homemaker	C.A. cervix in situ C.A. Endometridium (38 years) C.A. vagina (1 month)	Total hysterectomy Bilateral-salpingo oopherectomy	Total	declined

* developed rectal fistula — end colostomy performed at later date.

Table 1: A Pre and Post Exenterative History of the Women Undergoing Exenterative Surgery between June 1981 and March 1983 at the University of Alberta Hospital.

cured by conventional treatment.

As a brief introduction to the four women, a medical summary for each of them is presented. Such a summary is usually the basis for their introduction to the health care professionals who interact with them. This is one of the contexts that their experience becomes known or not-known, understood or misunderstood.

Mia

Mia is a married woman with two teenage daughters. Prior to exenterative surgery, Mia worked part time as a registered nurse. At the time of exenterative surgery, Mia was fifty-six years old.

In September, 1980, after about a year of low back ache and occasional spotting, she was diagnosed as having a squamous cell carcinoma of the cervix. She had two radium inserts followed by external beam radiation. In May, 1981 she had recurrent disease.

In June, 1981 she was admitted for a total pelvic exenteration. This was done and an ileoconduit, end colostomy, and a sigmoid loop neovagina were done. Mia was the first exenterative patient done by the surgeon at this hospital. After four days in the intensive care unit post operatively, she was moved to the gynecological unit. She was discharged thirty-four days after surgery.

In August, 1982 Mia was readmitted to hospital for a second stage neovagina. The vagina had stenosed down so the sigmoid was removed. A McIndoe procedure was done using split thickness skin grafts from the thigh area. These were successful and had taken within ten days. A heavy vaginal discharge continued until March, 1983. With continuous use of a dilator the vagina has remained open and functional.

At present, Mia has no evidence of recurrent disease. She has returned to part time nursing, sometimes working four or five shifts per week, and has maintained a healthy energy level.

Laura

Laura is a young married women with two preschool children. Just prior to the diagnosis of a squamous cell carcinoma of the cervix, Laura had given birth to their second child. Laura had been working as a realtor up to the time of diagnosis. She was twenty-six years old at the time of exenterative surgery.

Laura was diagnosed in March, 1981. She had bleeding during her third trimester of pregnancy. She then hemorraged postpartum and then continued to bleed for the next three months. At this time a visual diagnosis was made. During April and May, 1981 she received fourteen radiation treatments, followed by radium inserts. She continued to have a vaginal discharge and disparunia.

Due to persistent disease Laura was readmitted to hospital. On May 3, 1982 an anterior pelvic exenteration was done with a loop colostomy, an ileoconduit, and a rectosigmoid reanastomosis. A vagina was not created at this time with the plan to do a gracilis myocutaneous neovagina one week after this initial surgery. This was not done as a rectal fistula and a deep vein thrombosis developed. Laura was discharged eighteen days after surgery.

A month later she was readmitted for the creation of the gracilis myocutaneous neovagina and an attempt to close the rectal fistula. There were no post-operative complications and she was discharged thirteen days later.

In March, 1983 her colostomy was closed. There was some loss of rectal sphincter tone and some stenosis at the anastomosis line. She was discharged a week later with no complications.

Due to a rectal fistula, Laura was again admitted to hospital in September, 1983. At this time a permanent colostomy was done. A few weeks later a recurrence of tumor was diagnosed. At this time a decision was made to go to Houston, Texas to undergo a new chemotherapy protocol. This proved to be effective in reducing the size of the tumor and reducing some of the pain.

With continuance of pain and a persistance of an identifiable pelvic mass, Laura again underwent surgery in February, 1984. At this time a hemipelvectomy was a possibility. During surgery the mass was found to be lying next to the sciatic nerve. It was removed along with the rectum and vagina. The tumor was found to be benign. The surgery left Laura with some right leg weakness and a foot drop which required a brace.

Initially there was pain relief but over a period of months the pain continued to increase. Autohypnosis training for pain management was begun. A recurrence of tumor was then diagnosed. In July, 1985 a right hemipelvectomy was performed. She also had her pelvis irradiated. She was released from hospital five weeks after surgery.

In April of 1986, Laura again had recurrent disease. Metastatic disease was found in her bowel, liver and diaphragm. At this time she is on an experimental chemotherapy protocol. She is tolerating the treatment well and it appears there is no increase in tumor size or spread at this time.

Marge

Marge is a married woman with two teenage children from a previous marriage. She and her husband had been married seven years prior to the diagnosis of cancer. She is employed in the air travel industry. At the time of exenterative surgery, Marge was forty-two years old.

Marge was diagnosed in December, 1981, as having a squamous cell carcinoma of the cervix. She had a cone biopsy and was then treated with external beam radiation with the intention of follow-up radium inserts. This was not possible and further external radiation was used. She had persistent disease and was admitted in June, 1982 for a pelvic exenteration.

Exenterative surgery was done and a loop colostomy, an ileoconduit and a rectosigmoid reanastomosis was performed. A week later a gracilis myocutaneous vaginal reconstruction was done. Post operatively Marge had a continuously elevated temperature. Several examinations under anesthetics were done to rule out a pelvic abscess. Marge was discharged thirty-two days after surgery.

In November, 1982 Marge had her loop colostomy closed and an end sigmoid colostomy was performed. There were no complications and she was discharged on the fifth post-operative day.

Due to a chronic vaginal discharge with an odor, an examination under anesthetic was performed and the neovagina was debrided and an attempt was made to widen the entroitus. Marge declined any further grafting at this time.

Marge has had recurrent difficulty maintaining the ileoconduit. In June 1986 she went into renal failure. Surgical intervention was necessary and a ureterostomy was performed.

At the time of this writing, Marge has no evidence of recurrent disease. She has periodic pain which is controlled by analgesics when required. She is convalescing from her latest surgery. Prior to surgery she was working fulltime and had maintained a healthy energy level until the biochemical imbalance occurred due to renal failure. Her intention is to return to work once she regains her strength. This return to work is tentatively scheduled in one month's time.

Pam

Pam is a married women with two grown children and two grandchildren. She was forty-three years old at the time of exenterative surgery.

Pam was diagnosed in December, 1972 with carcinoma of the cervix uteri (stage IIB). She had two radium insertions followed by a three week course of deep X-ray therapy and cobalt.

In September, 1974 she was again diagnosed as having an invasive carcinoma of the cervix. At this time, she was placed on chemotherapy. Due to some bladder involvement she underwent sigmoid ureterostomies in November, 1975.

There was no evidence of disease until June, 1982. In July, 1982 she underwent an anterior pelvic exenteration with a rectosigmoid renastemosis, gracilis myocutaneous neovagina, and a transverse loop colostomy. Due to a rectal fistula an ileoconduit was done twenty-two days later. She was discharged from hospital forty-three days after initial surgery.

Due to a continuation of the rectal fistula, Pam was again hospitalized with the intent of repairing the fistula and possibly closing the colostomy. This was not possible and a permanent colostomy was done. Due to complications she was hospitalized for eighty-five days.

At this time, Pam appears to be disease free but continues to have lower pelvic pressure and back pain. This requires a constant analgesic regime. It does not appear that adequate pain relief has been achieved. She has also used acupuncture and hypnosis in an attempt to gain better pain control. At the time of writing it appears that she may be clinically addicted to analgesics. Further treatment for this and continued pain management is in progress.

C. Co-Researchers

The women have been described in a clinical manner. Prior to meeting each woman I read their medical charts to acquaint myself with their medical history leading up to the point of exenterative surgery being offered. This was my point of entry into the dialogue that would transpire. For you, the reader, it also becomes your point of entry to understanding the women's experience. The dialectical nature of phenomenological enquiry is such that the understanding of the question emerges from our coming together; the blending of each other's horizon. This necessitates some description then of my being-in-the-world what I as interpreter historically brought to the research, as the women and I became co-researchers.

D. The Researcher: An Autobiographical Reflection

In Chapter I, I identified the process I went through as I became involved in this research. Another important dimension of the coming to the research is grounded in my own personal history and the meaning I take from it. I reflected on, what are some of the fundamental preunderstandings with which I came to the research? These are the questions upon which I reflect.

1. What are my experiences with illness?

2. Why am I working as a psychologist in a medical setting?
3. What draws me to this particular group of women?

As I reflected on my experiences with illness two particular time periods in my life came to the forefront. One as a child of five when my father became critically ill and secondly as a young woman and mother when during a period of two years, two of my children died of a genetic disorder and between their deaths we adopted another child who was also experiencing illness of a chronic nature.

I was raised in a small community in northern Alberta. I was the youngest of three children and the only daughter. My father was a pharmacist and my mother a teacher. She became an active business partner with my father in the drug store after his initial illness. For several years my father had been the only health care provider in the community at large (human and animal) until a doctor and veterinarian located there. I grew up being aware of, observing and participating in many illness crises.

During my fifth year, my father had a massive heart attack; one of many over the next thirty years. His eventual return home from hospital meant many months convalescence with complete bed rest. With my brothers in school and my mother working at the drug store, I was home alone with my father. I believed it was my *job* to take care of him. I was his "legs" getting him what he needed, notifying my mother by phone if he needed help, and relaying telephone messages between my parents so that prescriptions could be filled in his physical absence from the pharmacy. I took great pride in being able to be with my father in this way. What was a crisis in our family became for me a gift — a special time of sharing. I also had a function and believed I could contribute to the convalescent and healing process. As an adult these early memories periodically re-present themselves in my consciousness. The early learnings have added to a comfort in being with people in their illness. As a growing child, the awareness of the possibility of my father's sudden death was ever present in our family functioning.

Later at age 23, as a young mother of a two year old daughter, my first son was born, a healthy nine pound baby. After a few days at home with him I began to sense that he was experiencing some physical discomfort. Within hours of that I experienced the painful progression of having given birth, coming home with my child, to returning him to the medical setting. One month later he died in hospital, his disease undiagnosed and no understanding of what brought about his death. My recollections of this time in hospital are of apologizing for wanting to be there constantly (at that time I saw no other parents there except during visiting hours); wanting to stay out of the way of staff but wanting to stay with my child. Other children seemed more critically ill and needing medical attention. It was important to me to participate in my baby's ongoing care; to nurture him and to hopefully promote healing.

Later that year we adopted a son, a two-year old who had been in medical settings since birth and had been in hospital at the time of our first son's illness. We believed that in a stable, loving environment he would begin to thrive for he had been a non-thriving child. Indeed he did thrive and grow and create some havoc. So many experiences were new for him, having never been out of a medical setting.

Nineteen months after the death of our first son another baby boy was born, nine and a quarter pounds with a presence that seemed older than that of a newborn. Throughout the pregnancy I pushed back the fears that there would be something "wrong" with this baby. When the fears pushed their way through I would find myself fearing for my own mental health should this baby die. One month after his birth he did die. He was diagnosed as having a rare genetic disorder. He and his brother became two of only sixteen children that had been recorded in medical literature as having had this particular disorder. Strangely, having a diagnosis helped.

I had feared for my own sanity prior to his birth but the experience of his birth, life and death had quite a different impact. I lived each day with an intensity and a keenness of awareness. Time was limited and precious and this awareness enriched each moment. I no longer apologized for my needs in the medical setting. Together with the staff we met our child's needs. We were a good team. The events I feared most prior to his birth became an opportunity to complete the gestalt.

During this two year period I became acutely aware of my own vulnerability in the face of illness and my impotence in changing the course of disease. Alternatively I became aware of my own emotional and spiritual strength and resilience. It was a transformative time. I required of myself to live life less superficially and again the sense of a gift from crisis was present.

The following year I began to refocus my own professional energies. I had been a physical education and health education teacher. I decided to return to graduate school. Throughout the childrens' illnesses I became aware of how little there was in the medical setting to support the family members through the whole medical crisis. My goal was to obtain the educational preparation that was necessary to do family work in such a setting. Over the next four years my understanding of the human predicament and of counselling theory and practice grew and expanded. I had experiences in hospitals, schools, and community agencies. On graduation I chose to go into private practice while continuing on into a doctoral program. In my clinical practice I worked with a broad range of clientele concerns but continued my professional interest in the process of loss, separation, bereavement and illness. Four years later I was given the opportunity to establish a psychology service in the regional cancer clinic.

I felt enthused and prepared to work with this patient population. I felt less prepared to work with the medical bureaucracy. It was a challenge. I felt committed to a vision of whole patient care and experienced many other staff members who also viewed health care similarly. I felt affirmed in some of the changes in service delivery and program development that were occurring, in part due to my involvement. I felt frustrated by the professional guarding that periodically occured, particularly where a physician perceived an individual as "my patient". In these instances health care seemed fragmented. There were many allied professionals in the setting whose expertise was important to offer to patients as options in their total health care. It required an attitude of collaborative team work.

This brings me to a response to the third question I posed to myself. I had already had significant contact with the gynecological oncologists in my first six months on staff. As physicians they worked as a team and I found it challenging and satisfying to work with them when they referred women who were being treated for gynecological malignancies. I learned that early stage cervical cancer had a treatment response of over 90%. I felt horror as I learned of the extensiveness of the surgery that could be necessary when cervical cancer did not respond to conventional treatment. I imagined the impact it would have on these women's lives. Fortunately only a small number would have to make this choice. Fortunately it was a choice that could be offered. This drastic procedure was being done. Women were choosing it. I wanted to participate as an integral member of the health care team. The psychosocial concerns inherent in such a surgery were obviously extensive. Due to the relatively small number of women in the cancer population who would undergo this surgery, there had been little research focused on their psychosocial adjustment. The fact that potentially only a small number of women would undergo this surgery also made it possible to extensively follow each of them.

Many of the referrals I initially received on joining the staff at the cancer clinic were those persons with extensive end stage disease. These referrals often were precipitated by either patient or family distress with the news of impending death or physician distress of having nothing more to offer. These were very rewarding people to work with as they finished unfinished business in their lives and their relationships. The challenge was to assist them to live as fully as possible up to the moment of death. At the other end of the illness spectrum was the group of women who would undergo exenterative surgery. These women potentially could be rendered disease free. I looked forward to providing support in the adjustment to this extensive procedure. As a member of this health care team there was the opportunity to follow through all the stages of illness and treatment. There was a clear invitation from the surgeon to collaboratively share our expertise with each other but more importantly with the women and their families.

The answer to a query, what are the preunderstandings with which I come to this study, could indeed be a lengthy one. The three questions posed at the beginning of this autobiographical reflection though were forefront as I began the reflection. I trust their presence as significant in guiding the reflection. The reflection provided an opportunity to consciously explore a portion of my being-in-the-world as I engaged in this research. For you, the reader, it is my intent to provide texture to my research perspective.

E. The Dialogue

Dialogue takes place only among persons on equal levels, without the divisiveness of social or professional stratification: dialogal research dispenses with researchers and subjects and takes place among *co-researchers* (Friere, 1970). Addressing the concept of dialogue as it relates to research, Colaizzi (1978) states:

> The dialogal approach must take place in a situation of trust. . . . Trusting dialogal research allows the co-researcher to illuminate dimensions of their lives which previously could not be facilily questioned but which can now be interrogated; and hence ratified, rejected, or modified: realms of their existential condition are newly brought into play. . . . All human research, particularly psychological research, is a mode of *existential therapy*, or at least should proceed within the horizon of existential therapy — which, however, should not be interpreted as meaning that therapy should usurp research. (p. 69)

This discussion addresses the quality of relationship that facilitates the indepth exploration of experience. Colaizzi also addressed the issue of balance between research and therapy. Throughout my encounters[4] with the women in this phenomenon a possible research dilemma was presented. I entered into the relationship with three defined functions. These were as therapist, as educator and as researcher. As researcher there were times when I was tempted to probe for issues that either the exenterative literature or other exenterative women had raised. As therapist, I chose to interact with each woman in a manner that invited her to present the concerns and issues that were forefront for her at any particular time. It is my

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[4] I use the term encounters simply because not all of my being with these women and being with myself in this experience took place through the medium of conversation. Although most of our time together was verbal, there were several times when I was with one of the women when she was anesthetized and undergoing surgery or diagnostic examination.

belief that in a respectful atmosphere where individuals are both supported and challenged, they will explore, struggle with and develop strategies to live with those areas of their life that are significant to them. I often refer to this as *tracking*, a metaphor that for me gives an image of closely following the lead that an individual reveals as they move on their own journey. If we were engaged in therapy, my function, as therapist, was to offer my skills at the crises or decision points of their journey. As educator, my role was to facilitate a process that encouraged each woman to get the information she wanted (i.e., alternative coital positions) or clarify issues when I was aware of misinformation (i.e., "How close have they moved my vagina to my rectum?"). I perceived my role of therapist as my primary function. Because of the numerous encounters and conversations over a four year period, I believe the personal experience of the phenomenon was revealed by each woman in her own way and in her own time.

Throughout the four years I maintained case notes and whenever possible our conversations were audiotaped. The minimum direct *encounter time* I had was eighteen hours with Mia and between forty to fifty-five hours with each of the other three: Laura, Marge and Pam. Our conversations took place in hospital rooms, in examining rooms, in corridors before surgery, on the telephone, in each of the women's homes, in my office, in my home, and in community eateries. Initially trust was established through organizational relationships such as patient-psychologist. This formal relationship grew into a collaborative relationship as we explored the experiences together. The "leveling" that Friere (1970) refers to was arrived at to differing degrees with each woman.

I will briefly outline the possible sequence of contact that I had with each woman from the time she was considering exenterative surgery. Once a woman became a possible candidate for a pelvic exenteration, I would be consulted. The initial contact with each woman was made along with the surgeon as he explained the surgical procedure to her and if possible, her husband. At this point I would interact in the process by responding to questions, concerns, and fears. This joint visit provided the opportunity to convey to the women a concern for the interplay between both the physical and psychological aspects of their treatment, care and rehabilitation and for the women to experience the team relationship that existed in addressing these needs. If possible I would make a return visit within twenty-four hours to discuss the woman's and her husband's understanding of the surgical procedure, to respond to further concerns and questions that were emerging, and to begin to do a psychosocial and psychosexual history.

From this point forward we would meet frequently throughout the period of hospitalization. With one of the women, I had the opportunity to be present in the operating room throughout her entire surgery.

On discharge from hospital I was in contact by telephone and met with each woman as she attended the clinic for either regular medical follow-up or symptom management. As well as individual counselling sessions at these times, I also participated with the medical team as assessments were made regarding the physical status and rehabilitation process of each woman. Initially clinic follow-up was on a biweekly, then monthly, then tri-monthly basis. I also met at least once with each woman in her own home. Each home contact was minimally a two and a half hour session. In three of the four cases, I had contact several times with the womens' husbands. This occurred either on an individual basis or conjointly with their wives. In the case of the fourth woman, Mia, I met with her husband only once, on a home visit. Since 1984, I have maintained contact with the women individually by telephone or through meeting with all of them as a group. Two of the women have had subsequent hospitalizations and I have met with them in hospital.

For the first two years of this study, there was frequent contact and collaboration between the members of the exenterative patient care team. Subsequently, the surgeon has moved to another treatment centre in the United States and I am no longer employed by the cancer institute. Since 1984, contact with the women has been initiated directly by them or by myself.

Throughout this research process I also chronicled my own thoughts, reactions and experiences.

F. Searching for Description

All audiotapes were transcribed verbatim. Initially I had my secretary transcribing these tapes. I soon became aware of how I was missing tonal qualities, pauses, silences, laughter and so on. I then began the transcribing myself, listening, writing, and reflecting on the dialogue. Each page contained the verbatim dialogue as well as a separate column for my first response to what I was hearing. These may have been a summary statement, a paraphrase, or a reaction to what was being communicated.

These many conversations, along with case notes, were then read and reread numerous times by me. In many cases, the reading was done while relistening to the audiotapes. Again I continued to make reflective summary statements beside the dialogue. Each woman's experience was unique and her responses reflected her lifestyle, her expectations and desires, and her individual history. In the conversation though there were particular transition points and particular aspects of their adaptations to surgery that began to emerge across all the women's experiences. They were speaking about and attending to similar things. I referred to these as focal units. These focal units clustered around the following ideas: 1) the inhospital experience, 2) the transition from hospital and the constant care back into functioning in their own home, 3) their perception of the physicians and nurses and the relationship they had with them, 4) ostomy care and their perception of themselves and their relationship to others now that they were living with a colostomy and ileoconduit, 5) sexuality — both sexual function and their sexual/feminine self-image, 6) pain, and 7) philosophy of life (before and after exenteration), and how one lives with the awareness of death.

Using these focal units I again went back through the conversations. I began color coding the dialogue using these seven focal units. Specific text which pertained to each focal unit was highlighted. Periodically some text was not highlighted if the conversation was simply pasttiming and rapport-building. For example: "How do you take your tea?"

After highlighting, all the text on each individual focal unit from each woman was compiled. I then read these compilations one focal unit at a time across women. Again I wrote reflective summaries of the dialogue. On completion of this I returned to each woman's case notes and transcribed dialogue to compare my summary statements of an earlier time to those I more recently compiled. This was done as a form of internal consistency to assess whether over time the dialogue was eliciting a similar response.

Once this crosscheck was completed the challenge was to present what was emerging from the conversations in a manner that allowed you, the reader, to have both an experience of the happenings in each woman's life as well as an opportunity to hear her words as she spoke of her lived-experience. It was at this point I decided to present the experiences of each woman using, as an organizing principle, six focal units. The seventh unit, pain, appeared to be more realistically presented when it was incorporated into the six other focal units. I have entitled the focal units as follows: 1) the hospital experience, 2) the transition home, 3) the experience of self in the medical relationship, 4) living with ostomies, 5) the sexual self, and 6) the finite awareness (previously focal unit 7). Initially I had planned to present these focal units individually, illustrating them with the words of all four women. I then became very aware of how the unique expression of each woman, her special qualities and struggles would have more meaning if you could also experience her individual process and pacing, her history, her context and her style. The individual experiences of Mia, Laura, Marge and Pam are presented in the following chapter. A demonstration of the method of working with this data follows.

G. A Demonstration of the Search: An Interview with Laura and her Husband

The following is a way of making explicit to you the process I used to begin my reflection on the many recorded conversations I had with the women of this study.

The following conversation was recorded in Laura's living room. Both she and her husband were present and eager to speak about their experience and were wanting to sort out some of their responses to what had and was happening for them as they lived with the disease and the impact of the treatment. Also present were their two preschool children who, for most of the meeting, were playing in the adjacent family room. This conversation took place fifteen months after exenterative surgery.

The demonstration will include verbatim dialogue, reflective summaries, and coded focal units. The presentation and interpretation of these units will occur in the following chapters. For the demonstration the following symbols will denote the speaker. L. = Laura, S. = Soren (Laura's husband), and B. = myself. The focal units are designated as follows: (o) = living with ostomies, (h) = the transition home, (f) = finite awareness, and (s) = the sexual self. I demonstrate the focal units in this way as color coding was not feasible in this document. This particular segment of conversation does not include the following focal units: the self in the medical relationship and the hospital experience.

Conversation			Reflective Summaries
L.	(o) (o) (o) (o) (o) (o)	My biggest problem is bowel control. I need to go all day, then three days nothing. On those days I'm limited. My whole day is in the bathroom. On those days I'd like to have colostomy — can be up to twenty times a day. Other days I'm glad I had reversal. I couldn't think of a job. No problem with friends, they all know.	Lack of body control with both alternatives. Wanting to be back in control rather than controlled by bowel.
B.		How does it affect you, Soren?	
S.	(o) (o)	Colostomy didn't affect me but I know Laura's happier, so I'm pleased.	Laura's happiness a goal.
L.	(o) (o)	I get so angry when I have a bad day — it's so disruptive, I get belligerent.	Bowel is unpredictable and disruptive.
S.	(h) (h) (h) (h) (h)	Some days it bothers me. I've maybe had a hard day at work and if Laura had one of those days she just goes to her room to spend three hours. Coming home — bango, the kids are right there. That bothers me a bit.	Husband's support system has changed.
B.		So some of your support system has changed.	

L.	(f) (f) (f)	There always seems to be something coming up. Like the pain in my back and leg. I'm getting it checked on Monday.	Unpredictable — something problematic continually emerges. Never a break from concerns.
B.		Always fearful of recurrence?	
L.	(f) (f)	Oh sure. Wondering how I'll dance without a leg (haha!) Just kidding.	Gallows laughter — fear of possible outcome. Perhaps she has an intuition. Pain --> recurrence --> surgery..
S.	(f) (f) (f) (f) (f)	I always take a pessimistic point of view, then when it's checked out any news is better than what you think. The big problem is the cancer. Everything else we can deal with.	Reverse psychology. Protects self from further disappointment. Identifies difference between recurrence and rehabilitative concerns.
L.	(f) (f) (f) (f)	That's right — no big deal in comparison to that. It's just annoying — all these little things. Life isn't the way it was. Not as easy and convenience.	Life has changed, it is difficult but I'm alive.
L.	(h) (h) (h)	I've enjoyed taking time at home but I can see if in fall I want to do something I know I'll be angry if I can't.	Hoping for improved physical status.
S.	(f) (f) (f)	Sometimes she doesn't like to get things checked out cause she doesn't want to know. It's easier to say it isn't that bad, I'll be okay. I'm the opposite.	Ignores symptoms, fears diagnosis.
L.	(f) (f) (f)	Yes. I do do that. When I logically think it out I know time is of the essence. I do put it off. So we do struggle with this.	"Put off knowing". Two levels of knowing cognitive and bodily.
S.	(f) (f) (f)	That's one thing that really bothers me. She has time to vacuum, wash floors, bake, mow lawn — no time to go to the doctor.	Time for tasks, no time for medical issues. "I want a wife, not a housewife." Husband angry, scared, hurt, helpless.
B.		So you'd like to say "If you really cared about us you'd get these things checked out."	
S.		I'd like to say that I don't.	
L.	(h) (h) (h) (h) (h) (h)	Some of the relatives keep me as an invalid. Last Sunday they'd go really hysterical if I'd do anything. I can't live like that. One has to do what one can. I need to do these kinds of things. It makes your life feel normal. I have to know I can still do things I've always done.	Invalid role in-valid. Live with limitations rather than limit living.

S.	(f) (f) (f)	I totally agree with you. Nothing wrong with trying to be normal, but you're doing more now than before.	What does "trying" to be normal communicate to Laura? Is she overcompensating for losses.
L.	(f) (f)	I need to feel useful about something. You have no recourse when it comes from loving concern.	Dilemma, feeling confined by what others expect of invalid, but can't share frustrations because of their intent.
S.	(f) (f) (f) (f) (f)	My fear is the overextending could lead to recurrence. It doesn't all have to be done yesterday. It's different now. You can leave things when you hurt. One year and three months isn't that long to recover.	What is our future?
L.	(f) (f) (f) (f) (f) (f) (f)	I never consciously think I have any limitations. The only time I do is when I've had one of those days in the bathroom. I know that I'm not like everyone else now. I'm so mad, furiously mad, that I have to change plans for my bowels. Some days I don't have that time to spend on myself.	Annoyance at need to be so self-focused. Loss of control of lifestyle and own time.
B.		What are pluses in reversal?	
L.	(o) (o) (o)	I can go to bathroom like everyone else. The smell and odor in the bedroom or bathroom is gone.	I'm normal.
B.		What's it been like for you, Soren, to see Laura go through all these changes?	
S.	(f) (f) (f)	It's been easy for me. I don't ignore it. I just look at what the alternative was. There really was no alternative.	Anything is better than death.
B.		One level thankful we're with each other?	
S.		Yes. We have each other; kids, family. Very easy for me cause I'm not in Laura's circumstances. I don't know if the table was reversed if it could be easy for me. It might appear I ignore Laura's predicament. I accept it.	Hard to imagine how he'd respond if his body had the disease.
L.	(f) (f) (f) (f) (f) (f)	In the last 3-4 months, I'm starting to not be quite as grateful for all of this as I did for 6-7 months after surgery. Now it's all the other things I'd like to see. I've had enough time to get used to the idea "I'm going to be here for a while or it sure looks that way".	First six months survival issues forefront. Now quality of life issues are more important.

L.	(s)	Other things too. The vagina is useless — too	A lot of pain for no success.
	(s)	short, too painful and phantom pain in my leg.	Longing for sexual function to
	(s)	I'm not feeling good about that either. I'm	be the way it was prior to
	(s)	longing for it to be the way it was. If my	surgery. Return of sexual
	(s)	vagina was okay that would be enough.	libido.
	(s)	Everything else would fall into place.	
	(s)	Alternatives just aren't the same. The discharge	
	(s)	doesn't help. The longing has only been in last	
	(s)	month and a half. I've never really verbalized	
	(s)	that till right now. It happens every now and	
	(s)	then that I think about it.	
B.		When will it be back? Where you don't have to	
		think about it — be careful — think of	
		alternatives, not express it because you don't	
		want it to go too far, in case you can't follow	
		through in way you want to.	
S.	(s)	I'd say to be as close to the way it was, or new	Fear of causing additional pain
	(s)	ways. Worry for me is the hurting or pain to	to wife.
	(s)	Laura.	
L.	(s)	When sexual things start to happen that's not	Wanting to be able to be
	(s)	the time to say stop let's try. Soren has worked	spontaneous rather than clinical
	(s)	himself up then is supposed to get analytical -	and analytical.
	(s)	slow down. It's not fun for anybody.	I'm letting him down.
S.	(s)	We were trying but not successful from pain	She puts up with pain so I can
	(s)	aspect. Laura's biting bullet for my	feel good.
	(s)	satisfaction. We both get angry in that the	Who was the vagina for?
	(s)	vaginal surgery was worse pain wise than the	Pain - for what?
	(s)	exenteration, and it wasn't successful and	
		therefore it probably wasn't worth it.	
S.	(s)	I find it hard to understand why it hasn't	Belief - intercourse could be
	(s)	healed with no intercourse for such a long time.	harmful.
L.	(s)	There is a dilemma between wanting a	Function versus pain. There
	(s)	functional vagina and no more surgery. Anal	was no problem until desire
	(s)	sex is not okay physically and psychologically	returned. I'm alive. I will
	(s)	and clitoral stimulation is out because of	survive. Now what quality do I
	(s)	discharge. I don't feel clean. That rules out	hope for?
	(s)	options. It hasn't been a problem until last few	
	(s)	months.	
S.	(s)	It's kind of a shame cause for Laura the	
	(s)	clitoral area has always been the most	
	(s)	stimulating and that's out because of the	
		discharge.	
L.	(s)	So you get aroused - then what - it's not	I've known more. I know what
	(s)	enough. So it's not worth getting to that point.	I've lost.

B.		I'd invite you to experiment with clitoral stimulation after bathing.....	
L.	(s) (s) (s) (s) (s)	I also feel that so much has happened down there. Is it sexy from Soren's point of view? Is this a sexy part of the body or is this a problem in our lives? Everything is concentrated here. This is where the big deal has been going on.	All the surgery was concentrated in genital area. Am I sexual or neutered? Protection of self and/or partner.
S.	(s) (s) (s)	That would be a good reason why Laura sees the discharge as justification for me not touching her there.	Defence mechanism.
B.		If he doesn't find that part of my body sexy, I don't want to even find out.	The logical defense.
L.	(s) (s) (s) (s) (s) (s) (s) (s) (s) (s)	I do feel altered. I don't feel good about my body any more, I'm to the point up until yesterday I didn't give a shit about where I go. Yesterday I had good heart to heart with self. Half my problem is that I've let myself go the way I have - and that is part of feeling sexual. I know I've purposely gained weight. What I concluded is that if I lose weight, I'll feel better about myself, then more receptive to sexual things.	Weight a protection to not deal with sexual feelings of inadequacy.
	(s) (s)	Now I have to talk with Soren about his feelings about my vaginal area.	New awareness
B.		Have you looked in a mirror to see your vaginal area?	
L.	(s) (s) (s) (s)	Only once after the bowel area to see how close. Now when I have loose stool I also have it all around vagina. I think that the vaginal opening is now closer to anus. All this adds to the problem.	May mean a fistula is developing between bowel and vagina. Misunderstanding of the surgical process.
B.		You know a lot about each other but don't verbalize much.	
	(f) (f) (f)	Perhaps the old rule of not talking isn't going to solve the new problems. There is now no game plan, no repertoire from past experience.	Need game plan for new situation. Can she honor healthy-part, do good things for self? Focus now on self-nourishment.
		You deserve to feel pleasure in your body. You've had two years where your body hasn't	
	(s) (s) (s)	given pleasure. The healthy part of you is longing. That is worth honoring and acknowledging.	
L.	(s) (s) (s)	I think I understand now that I gained weight because I didn't feel good about my body, to keep Soren at a distance.	A protective layer.

B.		We see our bodies in the eyes of others. You're at a new point.	
L.	(s) (s) (s) (s) (s)	Not ready to change behaviour yet but I'm looking at it. I've got to come to a decision, enough is enough, and wanting sexual things to be back. Right now I'm not ready for anything sexual because of the painfulness of vagina.	Ready to think but not act yet.
B.		But your body periodically feels sexual. Body and head not together.	
L.	(s)	It's easier to be fat and ugly and not have to deal with it.	Good summary of protective process.

This process of reflection continued for each segment of dialogue or case note material. The presentation and interpretation of the emerging focal units will occur in the following chapters. A descriptive narrative of each woman's experience was developed out of the dialogal data.

H. Validating the Descriptions

After completing each descriptive narrative I brought these back to each of the women for them to read, to reflect upon, to comment on and to request changes. These are some of their comments.

"That's how it was. I'd forgotten. If I'd spoken about it now I'd probably not have remembered to say those things. They are important to be said. . . . It was hard to hear my thoughts about my children."

"It's very painful to go over that. I just want to put it behind me. It's the truth though. It's so much more like it was than I thought it would be."

"I can hear myself saying those things."

"Yes, it was like that."

There were few changes requested. One woman requested that some identifying data be changed and this was done. One woman asked if she could withdraw from the research. When I told her yes she said "Well, my daughter thinks this is important research. Go ahead, read it — then we'll see." After reading she was surprised how she felt her experience had been validated.

She still struggles with her ambivalent feelings about the surgery — survival vs. mutilation and my presence re-presented this. She chose not to withdraw. Another of the women stated: "Yes, that's what I said and this is what I want to say as well, that I haven't explicitly stated before." The opportunity to reflect on the summary precipitated her clarifying another dimension of her experience.

Their statements confirmed for me the significance of moving through this experience with each woman rather than having them retrospectively reflect on the events, although the objectivity of a recalled event is of less value than its subjective impact on the person recalling it (Denzin, 1970). In a sense though all conversation is reflective. Once we put words to our experience we begin to move out of the direct experiencing. It is through language that we begin to ascribe meaning and can communicate understanding. It is a means of reflecting on our reality. It serves as our primary instrument for the discovery of new meaning, for the refocusing of experience and consciousness (Bain, 1986).

I. Developing the Thematic Synthesis

From the descriptive narratives of each woman's experience I began to look for the commonalities in meanings, situations and bodily experiences. Alongside the narratives I made interpretive summary statements. The next step was to cluster similar summary statements. A unifying theme began to emerge through this clustering. The themes were non-redundant but at the same time were intricately braided throughout the women's experience. A thematic discussion is presented in Chapter V.

IV. THE WOMEN: DESCRIPTIVE NARRATIVES

This research is based on indepth conversations with four of the eight women who underwent pelvic exenterative surgery during the period between August, 1981 and March, 1983. As noted in Chapter III, these conversations occurred in hospital, in their homes, in the outpatient clinic and in my home where we met as a group. The intent of this chapter is to provide you with a sense of each woman's experience. As noted in the previous chapter, all the transcribed interviews and case notes were read and reread numerous times and the following six focal units began to emerge. These are: 1)the hospital experience, 2) the transition home 3) the experience of self in the medical relationship, 4) living with ostomies, 5) the sexual self, and 6) finite awareness. Using these focal units as an organizing framework, glimpses of each woman's lived-experience will be presented. Preceding each woman's narrative is a brief introduction to her as I came to understand her historical context on our first encounter. The complexity of encapsulating four years of these women's lives into a brief written presentation was a challenge. It is hoped that you will have a sense of some of the commonality among these women and at the same time gain an appreciation of each of them as a unique individual as each speaks of her experience.

A. Mia

Mia is a married woman, fifty-six years old at the time of exenterative surgery. She and her husband have two teenage daughters. Prior to surgery, Mia worked for over twenty years as a registered nurse on the permanent part-time staff roster. This periodically included supervisory duties.

Mia was raised in rural Germany. She was a year old when her mother died in childbirth. Her father raised her and seven other siblings. Mia went on to become a nurse and began corresponding with Gerd, who later became her husband, and who had emigrated to

Canada. "His letters were always interesting. He talked about Canada, about the facts and many little things were made very interesting."

In 1958 Mia emigrated to Canada. She and Gerd began dating and were married later. On reflecting on this Mia saw this as a very independent step. No one else from her family had left Germany.

Neither Mia nor Gerd had any relatives in Canada. Mia describes her relationship with Gerd as a close one. Much of their life is centered around their home and their two daughters. They have lived in the same neighbourhood for a long time and they socialize with and know their neighbours well. They also maintain frequent contact with friends who have also emigrated from Germany.

On speaking of her relationship with Gerd, Mia reveals: "I didn't marry him because of his looks, but he always was a very interesting fellow and still is. He's not a guy for looks but in every other way, you know, it's never dull, it's never dull. He always comes out with something. How should I say that? We can go out and have a good time. If we don't have any wine we drink cranberry juice and pretend."

I first met Mia seventeen months after her exenterative surgery. This meeting took place when I was introduced to her by the surgeon when he was seeing her in clinic for a routine follow-up. At this time she had undergone both exenterative surgery and a second surgery a year later to reconstruct the neovagina which had not remained viable after the initial surgery.

My first impression of Mia was of a pleasant middle-aged woman. She is a stout, sturdily built woman with blonde hair and fair complexion. She has retained a distinctive German accent. She had a lively expressive face and appeared to have a good energy level. She related her experiences much like a storyteller might, expanding an idea or concern with anecdotes, sometimes mixing German and English words together in a way that added to the texture of her stories. As medical staff left the room she expressed concern that perhaps she wasn't given all the information, that they perhaps gave her only information that kept her encouraged. She expressed a desire to read her chart and this was arranged. She was anxious to read the chart, somewhat agitated by her concern that information was withheld, and at the same time concerned what the staff reaction would be to her request.

As Mia speaks it may be important to recognize that her statements regarding the hospital experience, the transition home and the early recovery period are made as she reflects back on her experience several months after surgery. Her decision to have the surgery was facilitated by her trust in her primary physician. "He felt that an exenteration was the only thing he could now offer, the best chance to go on living." For Mia "to go on living" was the important factor.

The Hospital Experience

As Mia reflected on her time in hospital she immediately began to speak with caring and concern for her family. She was acutely aware of the impact it had had for them. As mother, wife and nurse there is a sense that she believes she should have prepared them more fully for what was to transpire. In the event she could not, then one of her colleagues in her profession might have. "My family didn't know what to do. The nurses should teach the family what to do; how to sit there - to take a hand." Having Mia in the role of patient precipitated new roles for other family members. As Mia speaks of her husband, Gerd, it is as though this new role has put him in a new land and he is lost and cannot find his way. Indeed this is uncharted territory for this family.

> Mia: With my heart, I should have explained a lot to him. He came this day. . . . I was in intensive care and I was sleeping. I didn't see him and he stood there for a while and he didn't know how he should act, what he should say. He didn't even know what to ask. You know, that's what he told me. But when he left I sort of heard him and then I called him by name. Well, he just walked away more or less and I confronted him with that afterwards because I felt awful. Two months later, I asked, "Why did you walk away from me, didn't you hear me?" He said, "Yes, I heard you but I didn't know what I was supposed to do. I walked out the door and when I came back you were gone again."
>
> Bev: What does that mean, you were gone again?
>
> Mia: I was asleep again, more or less, I didn't answer him. I think the nurse could have said something, they should have said something. That's what I think.

> Bev: So it's been hard on him.
>
> Mia: How hard it was for him, you don't know. Then afterwards he took the Groat Road and he went for at least a whole hour. The kids, they were so worried he didn't come home. That wasn't like him. He just walked down in Mayfair Park. The kids were waiting for him to come home. . . . he couldn't explain to them or anything. . . . The kids have been around quite a bit, you know, and they will ask questions. But my husband didn't, he didn't know what to ask. He wanted to talk to them so dearly. He just felt completely lost.

The initial transfer between the Cross Cancer Clinic and the University Hospital was a difficult transition for Mia. A trust and a relationship had developed over time and the new ones would have to build slowly.

> When they decided that I should have the surgery they explained everything to me. When I came to the U they didn't even know what it was [an exenteration]. They were a complete lost cause, more or less, but at the Cross they were really good. At the University there was nobody, there was nobody."

Prior to surgery Mia is reported to have said "I don't know how I'll be with all those leaky bags. I would just like to live a few more years." There is a longing for life and also an uncertainty of what life will be like after surgery. The statement might possibly be: "I want to live but can I cope?"

For Mia there are few recollections of the first few days after surgery. "Actually, it was seven days before I really woke up." Later, when reflecting on the hospital experience Mia stated: "Why can't they just leave me alone. I like to go to bed and sleep till I'm better."

Throughout the period of hospitalization there was a struggle for Mia in coming to terms with the aftermath of the surgery. There were days when she questioned whether she should have had the surgery. On those days she wondered if she would be able to manage her ostomies at home, whether she would ever nurse again, whether she should simply go to "an old folks' home." She was ambivalent about her return home.

The Transition Home

When Mia returned home her appearance was so altered that she experienced others who were fearful of her look.

> I looked like a witch, like a ghost. I really did, I really did, you know, and everybody

> when they came, they looked at me and everybody got kind of a little shock, they really did. I think I came close to losing one-third of my weight.

One relative stated: "When I came visiting you, I didn't know what to say. You looked like a ghost to me. I was so frightened. I was so scared to death to do anything." The question might be, is it scared to death or scared of death?

Mia reflected on the difference between her transition home after exenterative surgery and the transition home a year later after a second surgery was performed to restructure the neogavina. "The first time I was so lonely. It was just that nobody came and the second time, I had everybody around. . . . I think probably what it was; they all said I couldn't, wouldn't ever survive." Further she describes the feelings of helplessness and isolation.

> Mia: When I had my first operation, I could do nothing. I couldn't manage a thing and the house was just a shambles. I sat at the kitchen table and I cried - all of a sudden - out of the blue. I don't know where it came from. I just couldn't [voice trails off]. I had nobody who wanted to help me. Oh, how should I say it? I couldn't find anyone for in the house. I couldn't even ask anybody. The second time when I came home, I had three people, you know, who even found the time to help me. The first time I had no one. Why wouldn't they come?
>
> Bev: . . . so it looks like they all kind of stayed back for a while to see whether Mia was going to survive. . . . And the second time, you had already showed them that you were going to survive and you weren't someone to be frightened of, that the cancer had not got the best of you, that you had survived it well.

The exenterative surgery and the subsequent weight loss took a toll on both her body and mind. "I was so weak. It was an effort even to walk. Gerd wanted to show me the garden one Sunday afternoon. I couldn't get back up the three steps, my legs were so [voice trails off]. I got in finally and cried - so much weight loss and I was weak and couldn't eat." Further there was an intense desire to feel at home. "When I came out of hospital, I couldn't eat, my mind was so so. I was getting so lonesome. I'd ask myself, why didn't I go home?" [Germany.].

"I think I had gotten senile a little bit. . . . I couldn't organize things any more." Mia illustrates:

> One day the VON nurse came in. I wanted to talk about my diet with her. I offered her tea and asked if she'd like some cake. I said I had a chocolate cake in the freezer. So I got out the cake, then my daughter called me. I went to her and when I came back I couldn't find the cake any more. . . . It had disappeared. No matter where I looked, I didn't know where I'd put it. Later, I found it in the washing machine - it must have slipped in. If the kids from the farm could have seen that I washed a cake.

> Then I wanted to make tea. First a teaspoon would be missing - then I couldn't find the milk. It was as if I was mentally slow. My mind was always wandering. . . . For about six months I couldn't invite anybody for coffee or tea if I hadn't the girls around.

Further, Mia describes how she encounters life differently, with less confidence.

> Everything is a little more shakey with me. . . . I'm not the same person, I'm always afraid, oh how should I say it? You know, before I could always live, now I live very carefully. Nothing used to bother me. I could attack anything. No matter who came to the house or wanted to visit. . . . Now little things embarrass me. I just can't get myself adjusted as quick.

There were lifestyle changes for other family members. "My kids sure grew up all of a sudden. All of a sudden they came, they could wash, they took responsibility. But I think for a while they were actually very depressed." Mia's husband did not ask many questions or talk with her at length about his feelings but would frequently say "are you okay - are you okay?" For Mia this was a real change in that she had always felt she was:

> . . .a very independent person. . . . He even sensed that he didn't want to bring his friends home from work, you know, because I wasn't as comfortable any more. . . . I was really afraid he'd bring a couple of guys along. One day he did. While they were joking around they had a few jokes that were sexually related. I just went to the bedroom and cried. You know I was sorrowful. Then I couldn't function any more.

On the advice of the medical staff, Mia had been adhering to a bland diet. She had lost weight, was eating very little. Food did not appeal to her. About two months after surgery close friends invited them over.

> He had all this nice black bread, some wine. I couldn't resist. I had two liquers, all this rye bread. I didn't eat very much but I tried everything. The next day I didn't even act sick. . . . I realized it was the first decent meal I'd had. I changed my whole diet around. I threw all my bland diets what I had out. And after when I came home, after that I had a little more courage.

Her advice to others is "Whatever you're accustomed to, whatever you eat before, you should eat it afterwards." Mia was learning to trust her own inner wisdom. "Every person should eat what they like. Go by that little bit. All these little mistakes [shaking her head]."

The surgery and convalescent period had created a change in Mia's financial status. Given Mia's and Gerd's age they had begun to anticipate a lifestyle change in response to Gerd's upcoming retirement, but this change in earning power had been prematurely precipitated by her illness. Financially they are comfortable but "before I had my own money, now I don't."

Nineteen months after surgery Mia reports: "I have energy now. For example, I can carry a whole bunch of bags of groceries in. It's no problem but there is always a milk bottle in there which pushes in your stomach [colostomy]. I have very little back pain. My back is sore but it is different. I have to watch though. If I get upset I get diarrhea so you know it's sort of complicated." Mia manages her ostomies well, having had some help from her daughters when she first returned home. The ostomies have meant more planning, "you always have to think about it in advance."

The Self in the Medical Relationship

Mia has spent most of her adult life involved in the medical community. As a registered nurse she has been the medical care giver. Having been "in good health until now," most of her experience with medical crisis has been from the professional's perspective. With the diagnosis of cancer she suddenly found herself in a much less familiar role. It was now her body, her lifestyle that was being threatened with disease. As patient she felt she no longer had the same type of access to information or interventions. In her position as nurse she had experienced having access to files, opportunity to review and to request diagnostic and treatment results, active participation in patient care and family support and input for treatment planning. As patient her vantage point on these issues was new. She knew what she needed and wanted as a patient. She was also aware of when she experienced good nursing care and those times when it fell short of her expectations, often reflecting on how she might have dealt with her patient differently had she been the nurse. Mia brought both this dichotomy of perspectives and this wholeness of perspectives into her experiencing of the medical relationship.

Mia had been in the habit of having regular medical checkups. Due to death or retirement of her physicians, she had to make a series of physician changes for a few years prior to the diagnosis of cancer. As she speaks of her diagnosis of cancer there is a sense of having been let down by the physician. There is both frustration and anger with the physician and herself. In retrospect she experiences that she misplaced her trust and delayed seeking another opinion due to the information she received from the attending physicians. There was a dichotomy between the information she was receiving from her body and the information given by the physician. There is an inate knowing that is difficult to affirm when there is differing *expert* information. The question might be, who is the expert?

> I went to Dr. X for the last two years; just before I got ill and he actually is a surgeon. I don't think much of him. I really don't. I went to his office in January and I said to him I didn't feel very good and I had spotting. He examined me and I thought he did a Pap smear. Later on when I asked for the results, he said "Oh, we don't need any. We just did it a year ago." So twenty months before I went to the Cross [Cancer Clinic] there was a Pap smear done which was negative. So one wasn't done then and he said everything was okay. Finally I was getting so tired, so run down. I had no pain though but I finally thought I had to do something. So I went to Dr. F. All the nurses go there by the way. He actually told me that it was serious, that I had cancer. Well, he almost started to cry with it.

Dr. F. has become Mia's primary physician. This has become an important medical contact for her. She trusts him and he is the liaison between her and other medical caregivers and provides emotional support to her.

> I had heard of him but I didn't know him. I'm lucky I went to him. So now I always have somebody where I can go and talk. . . . Every few months or so I go there. You know, each time there is something special that comes up. . . . . .Like how to make my last will. Dr. F. helped us a lot with this. I couldn't have gone to Dr. T. [exenterative surgeon] with that, I didn't think so.

For Mia there is recurring sense that the medical process cannot be fully counted on. This periodically emerges. Mia's initial treatment was external beam radiation and radium inserts. In a very high percentage of women like Mia with early stage cervical cancer, this treatment is curative. In Mia's case the cancer was not arrested. She reflects on this.

> The radiation didn't do a thing for me. Nothing. With the radiation, I didn't know anything happened. I just wonder if they had that machine on or off. You know, because I didn't feel anything. I was supposed to have diarrhea and I was supposed to be throwing up or something; no nothing. Then I went back to work and that's why my husband doesn't like that. You know when I went back to work I felt that I was getting somehow tired or rundown or something.

With the recurrance, Mia's trust in Dr. F. was an important factor in her decision to have exenterative surgery. Mia states: "Dr. F. thinks he [Dr. T., exenterative surgeon] is a very skillful surgeon. That's what he told me. But, he thought we might have a personality clash.

But, I must say he is a skillful surgeon and that's why I'm standing here and that's why I was back last spring to have a second surgery."

The liaison that was present between Dr. F. and Dr. T. facilitated a communication process which more fully allowed Mia to trust that her needs could be met. Further, Mia states:

> He [Dr. F.] liked his [Dr. T.] surgery, and he said that is the only way out and you can really trust him. He said to me he is very good but whatever he says discard it all. Come over here, I'll tell you. He has to send a report here. . . . Often when Dr. T. says something, at the time I'm there I have nothing to say any more but when I get home I have a dozen questions. Why didn't I ask that? Why didn't I say this? . . . Actually it's very nice that he sends the report over to Dr. F. and he [Dr. T.] actually sounds like he is actually very interested in me. When I come there, they sound very interested. . . . I'm not sure what you call it but Dr. F. doesn't take any more patients. He's getting old. He just likes to do this. It keeps his practice going more or less. He doesn't do that much anymore. He just treats his old patients. That is what my father always says: "There's always somebody around who wants to help you. When you haven't got anybody, there is always someone coming."

When I phoned Mia to establish a time for a home visit she was very receptive. After getting off the phone though she began to wonder if I was coming to tell her some "bad news". She had been waiting for more than a week for the results of a follow-up assesment. The underlying fear emerges again. "Something may be wrong, is wrong. They're not telling everything." Mia relates an early recollection, a very real event. The story may be a metaphor of the present: others are conferencing, something is wrong and I only have a peep hole view.

> It was 1937 or '38 [in Germany], you know, this time we were living high flying but there was something underneath. Our house, all the people, all our friends, my father, all my uncles they would come on a Sunday. They would go in the back room and they would lock the door. They had their own conference in there. Oh, we were looking through the keyhole there. They always sent us out and there was something going on. They knew something was wrong and they didn't believe in that. Nobody really recognized what was happening or what was there.

For Mia there is an ongoing interweaving of trust and mistrust.

> Sometimes doctors make you feel as though you're asking something about nothing. . . . I made out pretty good here though, you know. I'm still alive. . . . I made it. I'm largely very satisfied with the treatment I got. In the cancer clinic they were really very nice to me. I feel the nurses are very special there. Especially in the beginning when I started. You know, I was so low.

When Mia learns of Dr. T.'s leaving to another medical facility in the United States she experiences a lot of agitation, and again both the trust and mistrust of the medical process. In the last clinic visit with Dr. T., Mia expresses anger, is tearful and again feels a strong desire to read her file to clarify some confusing information she recalls and to check if she has been told everything, all the results. Mia does this with one of the gynecological clinic nurses present to answer questions. I had a sense that for Mia there was a feeling that this visit represented a last chance and the leaving of the person whom she saw as so responsible for her being alive was indeed a very dificult transition. Again she said to me that day "Maybe I shouldn't have had this done here. I should have gone home to Germany." Later, in the summer of 1985, Mia stated: "I'm glad I had it done. I've seen my girls go from 16 to 21. Another time I'd ask more questions. I think I played ignorant. If we could get Dr. T. back here I would apologize to him. I would like him to take me back." Six months later she again reflects;

> I'm not sure I ever want to see him again. You know he's the one who mutilated me and yet if it wasn't for him I might not be alive. It's sort of a love-hate relationship. It keeps going up and down. It keeps changing.

Living with Ostomies

As Mia approached exenterative surgery she knew her decision to go through with it was influenced by a belief that her "daughters were too young to leave." At the same time she wondered how she would "cope with all those leaky bags." After surgery, this apprehension continued throughout her hospitalization and she received a great deal of help from the nursing staff in caring for the ostomies. She wondered if she could ever accept having a colostomy and an ileoconduit. Despite this fear, her need to know "what they looked like" prompted her, two weeks after surgery, to ask her daughter to bring a mirror in so that she might see the surgical sites. The night before Mia's discharge home, one of her worst fears was confirmed. The ileoconduit appliance became disconnected and she "woke up to a totally wet bed." Again she wonders "how will I cope at home?"

On return home she allowed her daughters to assist her with ostomy care. Once her diet concerns had been resolved and she began to regain strength, Mia managed her self care well. There is a marked contrast in the nursing notes that appeared after exenterative surgery and those that appeared one year later when she was readmitted for reconstructive vaginal surgery.

Prior to the first discharge both Mia and the nursing staff had concerns about her ability to cope and deal with the increased self care that the two ostomies required. On the latter admission, the nursing notes state, "looks wonderful, in good spirits, has good self-care." There appears to be a sense of pleasure and relief on the nursing staff's part. They too did not know what to expect. For most of the staff this was the first exenterative patient they had nursed.

Over time there is a sense of Mia's steady progress in caring for, accepting and living with the ostomies.

> I could do things whenever I wanted to and now it's just a little, you know, more difficult. Simple things, before you never thought of it. You can live with it very easy, you know. If you think a little bit, it's no problem at all. Last summer, you know, I went around bicycle riding. You know, I put my bags on my lap so it was no problem. But you always have to think about it in advance. . . . I've gotten used to it now, all the equipment that is where it's linked on, you don't feel it any more. You don't feel it any more, you really don't.

This ability to plan is challenged when after the second operation her bowel patterns change. The change was inconvenient but more than that it focused attention on her bodily functions — not where she wanted her's or other's attention to be.

> Always at suppertime, oh that was so embarrassing, you know. The family comes home, the husband comes home, the kids come home and I go to the bathroom. That was really very, very annoying.

Mia experiences both she and Gerd as growing in their acceptance of and adjustment to the ostomies. They speak about the ostomies and he has seen the stomal sites. As much as Mia experiences they are a part of her, there remains a shielding — perhaps of self; perhaps of Gerd. It's now all part of the planning. "When I'm in the bedroom, I usually keep it covered more or less. I have a towel, then I coverup with that. It's always the easiest thing. I keep a towel around."

In facilitating physical intimacy Mia has made a few creative 'cover-ups'. For example:

> Mia: I have these knit camisoles I brought from Germany thirty years ago. You put them on upside down. Then you have the lace at the bottom and then on top you put a little elastic in. You can put the elastic over your bosom.

> Bev: So it's open in the crotch?
>
> Mia: Yes. It's a deal. You know, I didn't have anything. I think you can buy something now.
>
> Bev: And what did he think of that?
>
> Mia: He laughed his head off.
>
> Bev: He did. So he never gets to touch your tummy?
>
> Mia: He prefers to have it covered. You know if this one [colostomy bag] comes in the road now he just doesn't mind. You know, this old thing, this clown that's awful big. He just puts it aside you know the way he wants it — or often he may stick a towel over it.

Even with a great deal of sharing and openness about the ostomies her sensitivity to her altered body remains.

> When he came home one night he puts his arms around me and says, 'how's the old bag?' He put his hand on me . . . . He meant it as a joke, I wasn't quite sure if he wanted to say something nice, but he says 'you old bag.' I just couldn't take it then.

The Sexual Self

Mia speaks very little about her sexual identity. Mother, homemaker, friend all seem to be roles where more of her overt attention is directed. There is a sense that sexuality is private and therefore is seldom spoken about.

Early in Mia's recovery process from surgery she indicates that indeed she was thinking about her own sexuality and had thoughts about what lay ~~ahead~~ for her with regard to sexual function. Sexual jokes were painful for her to hear. She reminded herself, "I couldn't function any more." Mia's neovagina had stenosed down. She felt a barrier to expressing herself sexually with her husband.

> Like before; he never knows when he should say something. I knew when he was going to, but I couldn't, I just couldn't. You know, there was something between us, and I was so ill as you know. As soon as I was physically well enough even last spring before I had the surgery it was better. As soon as I got clinically well enough then it got better.

With the second operation, Mia's vagina is now functional but she has very little vaginal sensation. Clitoral stimulation can lead to orgasm. Gerd also experiences less stimulation within the vaginal cavity. Something is missing. There is void. It's not like the 'real' thing.

> At first I had a different vagina and that didn't work. I was always tense and now with this, there's another problem. You must not have very many nerves or something. You hardly feel it, In the beginning, yes, it was always pinching somewhere. Also when you have an artificial vagina like me now, it all acts different, you know, there is no more feeling.
>
> He's not as satisfied with all my trying, so it's — it's different. He seems more worried than I that he'll hurt me — my vagina. It doesn't hurt. There is no feeling in there. It's more a hole.

There is a closeness between Mia and her husband and a growing acceptance of the bodily changes that have occurred. There is an affirmation that comes from physical contact.

> Having him close to me, I like that. You know, this. . . . We don't have to have private intercourse any more but, you know, as long as I can, as I can hug him then I'm all right.

Finite Awareness

> The cancer came — totally out of my control and I came completely out of control too. I didn't ask for it.

The struggle with disease begins with the realization that something has occurred that appears to be more in control of you than you are of yourself. Over the months ahead Mia was in a struggle to regain a sense of predictability, to reestablish trust in her body, to reaffirm her roots and to reinvest in life incorporating the many changes that came without invitation. Two years later she states "I'm still alive. I have a little bit of trouble . . . but I made it."

Most of Mia's focus is on living. Periodically her thoughts turn to death, to the knowledge that once before her body went out of control.

> "I can't picture myself dying. I don't feel like dying at all. But sometimes it comes, how long do I have? . . . and you always think, was it all removed? They don't anticipate a recurrance. Well, we would like to live another few years."

Ever present is the anticipation and hope of the future while always mindful of the realities of the recent past. It is not until you lose your health that you think about it. Mia gives an example: "It's like as soon as I had my citizenship [Canadian], I became German again."

Mia's illness focuses her awareness on the strong familial bond she has and the family she left in Germany. There is a sense of standing together alone.

> It's hard for him [Gerd] too, because he doesn't have any relatives here. Nor do I, neither one of us. . . . Our relationship is completely different. I could see that when I came home. The only friend I have here is my husband, my family. . . . You know, when I got married and I was in trouble we had to work out our problems. At home, you could just go home to mama or a sister or brothers. I've never had that. We had to completely — we both had to sort of depends on each other. This is why even the children got a lot closer to me than many others, and they think so too.
>
> How has life changed since the surgery?
>
> You are happy with what you have. Before we were always — you know, we had to have a second house. You have to save and make some more. Now we're satisfied with little and satisfied with my house. Before we wanted it different. It doesn't seem so much to matter. . . . You take it as it comes.
>
> But life is much more pleasant now. We had a stable marriage; We'd fight; I'd speak my mind. Now it's not worth fighting over little things. We don't fight any more.
>
> We shall live our life now. You know you don't get rich anyway. We have our home. We're too old, we're too old to be hurt really.

When Mia learns in the cancer clinic parking lot of the death of one of the women who had had the same surgery and with whom she had visited, "I just had to go backward. I went home again. ~~I couldn't~~ go in." Metaphorically it is this going backwards that provides Mia with safety and strength that allows her to move on, to go forward. And what does she go forward to?

> We're looking to retirement. Both of us. You know he's worked. We didn't have any holidays for the last four years. There was never any time even between jobs. . . . I'd like to see my children finish university and when I go I'd like my children to say, "I had a good mother."

Four years after surgery Mia states:

> I've so much to be thankful for — a stable home, family, daughters doing well, pension, income, and a loving husband. Some day, I want to hold a grandchild. I'm optimistic. Although when I have pain that's a concern. That's the hard part — not sex, not the bags — it's not knowing what could come next. I'm fearful when I hear of Laura [recurrance]. My roots become more and more important, you know, doing things the German way.

B. Laura

Laura is a married woman with a young son and daughter. At the time of exenterative surgery she was twenty-six years old. Just prior to the diagnosis of cancer she had given birth to her second child, a daughter. She had had a history of bleeding in the last trimester of her pregnancy, hemorraged postpartum and continued to bleed for three months before a visual diagnosis was made. She began radiation treatments four months after her daughter's birth. Laura worked part-time as a realtor while her husband Soren worked shift work as a computer programmer. This work pattern allowed one parent to always be at home with the children.

I first met Laura five days prior to exenterative surgery. She came to my office she said "because Dr. T. [surgeon] had requested I see you." She wasn't sure she needed to talk to a psychologist. Laura, along with an older sister [a dentist] had researched the medical literature when she learned of her recurrance of cancer, one year after her initial diagnosis. They concluded that a pelvic exenteration offered the only survival possibility. She then initiated the idea of having an exenteration and asked the cancer clinic in her community to refer her to Edmonton where she had learned this surgery was being performed.

My first impression of Laura was that of a vivacious, confident, energetic and determined young woman. She has dark wavey hair and a dark complexion. She has flashing eyes and an expressive face. She struggles with a "few extra pounds". She was meticulously groomed and presented as a very attractive young woman. She was forthright in her questioning. For example, she had asked the surgeon how good he was at this surgery, or was there someone who is better that she should be contacting in some other centre. She indicated to me she had researched the literature, made a decision and there was now no point in spending time focusing on fears. She stated: "I don't think about it. It's like the cancer is happening to someone else. That's how I cope."

When I met Laura, she and her husband Soren had known each other for six years and had been married five years. During this time she worked as an accountant, then as a realtor. She described [illegible] marriage as a "good one." She felt they were close and supportive of each other. As she discussed the surgical procedure it was clear her focus was on doing what she needed to do in order to survive. At the same time she allowed herself to fleetingly consider her altered body after surgery. She asked questions about the neovagina. Then she made the following statement: "Sex isn't a big thing for us. It's not very frequent, maybe once every three weeks although it's improved in the last two years."

Plans had been made for Soren to take one week off work when Laura had the surgery. He would also take one month off work when she was discharged from hospital. She expressed concern that Soren would say very little when I met with him. She gives an example: "His mom died last fall. He cried one day, then never spoke of it and that's how he is with the cancer." Laura's main concerns as she contemplated the upcoming surgery were the amount of pain there might be and what the outcome of the initial biopsies would be. She wanted to have a chance at survival and this meant the surgeon being able to go through with the total surgery.

When I met with Soren he was very responsive and talkative. On one hand, he'd state he was always an optimist and knew everything would "turn out okay." On the other hand he was fearful of the cancer and the possibility of Laura dying. He spoke of his concerns about their children should this happen — "but for now it's Laura we need to think about."

The Hospital Experience

As noted in Chapter 3, Laura has had many hospitalizations. The following refers to the hospitalizations that occured for both exenterative and vaginal reconstructive surgery. In the year prior to exenterative surgery Laura had had experiences in hospital that left her with a sense of mistrust. Through her discussions and interactions with Dr. T. she began to develop a sense of trust that would continue to build over time. The trust built as the staff spoke about expected occurrences. Very little came as a surprise. Laura clearly saw Dr. T. as in charge of her care.

> One night I started to hemorrage and that scared the dickens out of me. The nurses knew that and they called Dr. T. tout suite and he was there at three o'clock in the morning on a Friday night. That was kind of embarrassing because it wasn't any big deal but I was still scared and I think they felt even if it wasn't a big deal Dr. T.

> would be the only one who would make me feel better. I've been through enough with the gyne residents. I didn't trust them at all. Sometimes I wondered if these people really knew what they were doing because of what had happened to me at the other hospital. As time went along you know it didn't take very long to notice they sure the heck did know what they were doing. Nobody did anything that I felt wasn't right for me. I've never been very concerned coming from the intensive care into the room, only because they told me that you know you're going to feel this way. You're going to be scared. You're going to be concerned whether or not we can take care of you here and all that business and I don't think that was my concern because they had brought that up to me.

Laura's way of coping was to endeavour to keep her emotions to herself. She had a sense that many people [family and medical staff] were very worried about her so she did not want to increase their concerns. She also wanted to be viewed as coping well. The fear of others seeing her lose control kept her in control.

> And I guess throughout the whole thing, what kept me together the most, now this is ridiculous, I didn't want to lose control of my emotions. Through the whole thing that was really important to me and a lot of the reason why that was so important was all the people that were around. I didn't want them to see me go bonkers or do any dumb things like that.

After surgery there was a dichotomy between wanting to appear "strong" and feeling very "fragile." She relates an experience that occured the evening she returned from the intensive care unit.

> The nurse I had was a klutz. She'd drop things, bump into the table, bump into the bed and I was sick to my stomach, like I felt nauseous and every time she'd bump the bed I thought I was going to be sick. And you know she smelled of cigarette smoke and that really bothered me. All the bumping, the smell and then she spilled the water and knocked over the plant. I thought, oh man, like what if she bumps me, I felt really fragile at that time, like I didn't want anybody bumping me.

On reflecting on difficult times while in hospital, Laura decribes the first time her colostomy was changed. She experienced disgust and embarrassment. There was a sense of helplessness when she experienced a deep emotional response while physically she could only be passive. This, too, was Laura's first real encounter with the ostomies — with herself as an ostomate.

> The only other hairy time was the first time that they had to clean the ostomy bag, the nurses . . . that really upset me. Well, first of all she wasn't wearing gloves and that really bothered me and I told her that I would prefer she did but she wouldn't and she said no, I don't need to wear gloves, I've done this before. Later she told me she had never done it before and that they don't wear gloves because they don't want the patients to feel icky. They'd tell me everything those guys, they were great. Anyway

> that really upset me. That was probably one of the most awful moments of my life when they did that bag. Then it all came to me. See, I never thought about the colostomy and the ureostomy, not at all. Like I knew intellectually what it was and all that business and what exactly was going to happen. That first time was hard. I didn't want to have to deal with it and I didn't think I ever would. It really isn't a big deal when you consider all the other business you know. I had to explain to the doctor though, I don't even clean toilets. I can't do that kind of stuff. How the hell am I going to do this? . . . I didn't even watch. I looked once and that was it, then I stuck the pillow over my face and cried my eyes out while she was doing her thing and trying to console me at the same time. It was pretty funny. . . . It's so personal and to have somebody doing it. Of course you have no choice, you got to have somebody else doing it. I felt sorry for that poor nurse that had to do it. That's really God damn close.

Over time the avoidance and dispair leads Laura to a new awareness. She states: "Well, you just know that this is how it's going to be and it's something that I'm just going to be. It's something that I'm just going to have to live with. It's not a big price to pay for being alive."

Prior to surgery, Laura's main concern was pain management. Throughout her recovery this remained a concern. Often pain management was adequate but this varied with the nursing staff assigned to her. There were times when she not only had to fight for an adequate analgesic regime, but also had to educate staff as her own experience with pain was being negated.

> And I had to argue with the nurses about pain medication. I didn't like to have to do that. You know, about Q-4, Q-3 and the doctors had explained to me how that works and that you do not have to wait four hours. You wait for three hours but give less. That was fine with me cause it was the end of those, the third to fourth hour that it was really bothering me and I couldn't understand why, until he explained to me how you know this pain medication works. That it is at its peak for the first three hours and then it really diminishes. Well, I ended up having almost an argument with one of the nurses about it. Which I did not see any need for, I do not understand why I would have to you know, get really adamant about how I felt about that. She said, the pain wasn't supposed to be there. Well, too bad lady, I mean it is there. Like she was giving me all this business about getting addicted to drugs and this garbage. When I feel I do not need it, I will be the first one to tell you because I know that this is a big concern.

After surgery there is a need for the vaginal cavity to be packed. Laura recalls:

> The thing that hurt the worst though — I forgot about this, this was really rotten — is when they take that first packing out and they put the new packing in or whatever they do. That was craziness. It really upset me, the first one. The second wasn't so bad and the third one, you know was okay. But the first time that was terrible. You know it was really incredible, like after that I was actually sick to my stomach, that's how awful it was. I told you about that too and they really should do something about that before, and they didn't for Marge, they only gave her a bit of Demerol before she went in to have that done and I really thought they would change it. You know by the time she got there to do it, cause I told you and Dr. T. about it. You know that wasn't

> really good at all. . . . The vagina that was awful. That was worse than having two kids at one time. Put both those pains together doesn't even compare to that. I don't know why that was so terrible but it really was. Maybe I was imagining it too, because I was really nervous about anything down there. . . . then any time anybody comes near you to look after you after that, you're really hyper.

Laura is now both sensitized to pain in her vaginal area and at the same time feels frustration that her pain has not taught the staff any new interventions. Her first conscious awareness of contact with her vaginal area is that of intense pain.

Due to a deep vein thrombosis Laura's vaginal reconstruction surgery was delayed. She was discharged from hospital, recovering at her parents' home for one month prior to readmission to hospital for the second surgery. There was ambivalence about leaving hospital. The perceived safety and support of the hospital was difficult to leave.

> I was nervous about going home. Well, I wanted to go home, I wanted to get out o.k. and yet I felt that maybe I wasn't quite ready to go. I was thinking about it, you know, for several days like I was worried about my legs, cause I had that clot in my leg. I was really worried about blood clots. Can it go up in my brain and I'm going to keel over dead on the way home — whatever? I wasn't so much worried about managing the colostomy. Just going, you know, that there would be nobody to take care of me. I still had a bit of temperature. When I got home I had fever late at night and stuff like that, and that you know, worried me a bit.

One month later Laura was readmitted to hospital for vaginal reconstruction. She had been managing her ostomies well. The first crisis hit for her when she was assigned a double room. She didn't feel ready to manage her colostomy in the presence of a stranger — another woman — a roommate.

> I wasn't going to be in a private room and that's another time I cried, because I did not want to be in a double room. No, not a chance and I was going to leave. I wasn't going to have this vagina done no way, not if I couldn't have a private room and they said they didn't have any. It ended up that they did, but I would have, I would have left. No way that I would have done that at that time. I don't think I'd do it [respond that way]

Again the fear of pain related to surgery was forefront as Laura anticipated surgery. This second surgery was presented as far less major than the first surgery. With this expectation, Laura became very discouraged when her experience did not match this expectation.

> They kept saying that the second surgery was no big deal. Like this is easy. We've done hundreds of those. No big deal, right. Well, excuse me, but to me it was a big

> deal and it would make me mad that I wasn't . . . the way they thought I should be. . . . In those first two days of the vaginal reconstruction, I know I needed more [analgesics] that I was getting for sure. Especially when I came to. The first time I came to from the first surgery, I did not feel anything, I was fine, I didn't feel pain. . . . Maybe for that reason it is better to do them both at once. Cause that first night after the reconstruction was not any fun at all. That was probably the most painful time except for the removal of the packing.

The recovery process had begun for Laura in her month out of hospital and now the physical assault, the pain and the healing cycle was begun again — and this time from a depleted starting point.

> . . . And I think I got to be a bit of a baby, too, you know, like all this pain? I was sick and tired of it, you know, and any little thing would really bug me, you know they even came in to change the intravenous. Before that, that was nothing. That you know didn't even bother me at all. I never like it OK, because they have to poke around in there and all . . . I don't know, but now I'd get really mad, you know, like Christ, you've been doing this for how many years, do it right! You know, it makes me angry, the pain was starting to bug me. . . . Maybe, as I said, it was because I wasn't emotionally up. I don't know what it was but I wasn't tolerating pain very well at all. . . . I worry about whether or not my tolerance for pain has gone away.

Transition Home

Laura speaks very little about her initial transition from hospital to home. The month between the two surgeries had been spent at her parents' home. After the vaginal reconstruction she was eager to leave hospital and was discharged within two weeks of this second surgery. Soren, Laura's husband, had taken a month off of work to be at home with her and the children. As well, there were other family members who came in to help out. Laura experienced Soren's support and was determined to get back to "normal" as soon as possible. She felt that the exenterative surgery was not as major as she had been led to believe. "It really wasn't as — maybe because everybody put it up to be such a horrendous big deal, and it wasn't anything near what they all said it was going to be. Maybe that was good."

Illustrative of Laura's determination to not be restricted is the following:

> Every time I had a bath, they [the dressings] would constrict, and they were just pulling the hell out of my legs and I couldn't walk after a bath, you know, like for eight or nine hours. So I just took the darn things off. I was mad and what happened was the incision got really really wide. Can you see? [showing scars]. Look at it. It's like almost two inches in spots.

Four months after surgery Laura reflects:

> Yeah, I'm not like I was before. I had blood work done but I still don't have the energy I had before. Maybe it's not so much a physical thing I don't know. I just can't seem to cope with everything the way I did before with the job, and the kids and the house and all that.

She also recalls that she didn't think as clearly when she came home from the hospital. There were times when she lost her trend of thought or responded more slowly. She felt forgetful. Soren also noticed these changes in her mental functioning. "In fact, he insisted on a brain scan wondering if I had a brain tumor."

One year after surgery Laura continued to experience that those around her still have not made the transition from viewing her as a patient, a position that she experiences as invalidating her. She is willing to live with limitations rather than limit living.

> Some of the relatives keep me as an invalid. They go hysterical if I do anything. I can't live like that. One has to do what one can. I need to do these kinds of things. It makes your life feel normal. I have to know I can do things I've always done.

The Self in the Medical Relationship

Laura has had some experiences~~ with the~~ medical profession that left her both fearful and mistrustful. To counteract this Laura was determined to ask questions and state her needs with regard to medical matters. She felt her symptoms had been ignored several times in the past and therefore the diagnosis of cancer was delayed. Of particular significance was the fact that although she bled throughout the last trimester of pregnancy she was not checked for a cervical malignancy. She was allowed to deliver vaginally, only to be visually diagnosed with cervical cancer three months later. From her readings and her discussions later with medical staff she knew that the vaginal delivery exacerbated her condition.

In her first meeting with Dr. T. [surgeon] she began to estabnlish an open relationship with him. She took care of herself and trusted him to take care of her medically. She recalls:

> I was concerned about his competence. I remember that I really wanted to be sure. I knew it was a big surgery and wanted to be sure that I was doing the right thing ~~staying in~~ Edmonton and not going to Vancouver and having it done there or somewhere else. . . . I felt good about Dr. T. and that was important. I don't remember being scared. I think everybody else was really scared.

The "good" feeling she had for the surgeon continued to develop. At stressful times, his presence reassured her. She relates several such times and summarizes:

> Oh, Dr. T. came in and said whatever he said and again it was all fixed, all better, no problems. That's what I mean, he's great. He knows exactly what to say and when to say it.

Laura's style of not wanting to worry others was present in her relationship with Dr. T. Laura wanted to ensure that Dr. T. continued to have a positive attitude about performing exenterative surgery so that this option would continue to be offered to other women. She experienced an ambivalence on the part of the medical community towards such radical surgery being performed for recurrent pelvic malignancy. For her it was important to keep Dr. T. "encouraged". There was a reciprocal nature to the relationship — each taking care of the other.

> I really wanted him to know it was important to me, the work that he was doing. Initially, I didn't even know that the opportunity existed. I just wanted to encourage him to keep going. I know he has his own reasons for keeping going. I didn't want him to feel like it's a big deal. It's you know, don't ever rule this out for anybody. Everybody keeps saying how awful and terrible it is and it really wasn't. . . . and for all these reasons he doesn't do the surgery okay. I didn't want him to see me badly off in case he'd reconsider for somebody else. Maybe you know he'd say: "gee, this is too hard to take and maybe I should be more careful when I do it. Maybe select more." . . . I didn't want him to feel that this was a terrible thing. That it really was a great thing and I didn't want to be low and down, and bitching and complaining when he was there. Although I'm sure I did on occasion when it got the better of me and I did. Even if I didn't feel good I tried. . . . I had to know that he had to know it wasn't terrible. It was really fine.

Both Laura and her husband continued to develop an open and comfortable relationship with Dr. T. and others on the health care team. They continued to acquire the information they needed to deal with each new stage in Laura's changing medical condition. "I want all the facts . . . if you don't understand you just keep asking. They [medical staff] can come down [speak in layperson's terms]."

One of the crises points for Laura was in learning of Dr. T. leaving for another medical centre. During a group session Laura describes her response to this new information:

> It's a total dependency. He's the man with all the answers. We've [exenterative women] <u>all been</u> led to believe because of our history, "this is the last hope gals and this is the man who's going to give it to you." You put everything you've got into one person and you're totally [pause]. He became more important in my life than my

> husband. My life depended on him. To find out he was going to be gone — I was very upset. He knew that.

There is fear that no one else can provide the same quality of care.

> It's just too hard to explain to someone who hasn't done surgery what the heck is going on. They just don't know. Even reading up on procedure, they don't know exactly what he's done. Who knows what kind of follow-up care we're going to need a year from now — five years. . . . I think what's going to happen in two years if he's not here.

Laura continues to require indepth medical treatment for symptom management and ultimately for recurrent disease. Laura and Soren continue to advocate well for themselves and build respectful and reciprocal relationships with physicians and treatment teams. They continue to maintain contact with Dr. T. — particularly as each new medical crisis is encountered.

Laura reflects, along with other members of *the group* on the errors that they perceived had occured in their medical management.

> It frosts me they didn't do something at 18 when I had an abnormal Pap. They said they must have made an error. And later they all said I was silly when I was concerned about the discharge, that it wasn''t offensive and there wasn't any big deal about it. But, they were wrong because it was cervical cancer and that's what the discharge was all about. I mean, I wore a mini pad all the time. . . .But you know, you guys, crumb, maybe it's just not all these people. That's when I calm down and say gee whiz, all these things could happen to somebody else. Maybe it was just me it had to happen to. So many people made so many mistakes. Maybe that's just God's plan. Who knows.

Living with Ostomies

From Laura's initial reaction while in hospital of horror and disgust of her ostomies, she quickly learned to manage them and slowly began to gain some acceptance of them. She believed when she was discharged from hospital that her family would be curious about the ostomies so she consciously chose to show them the ostomy sites.

> I wanted them to see what it was and it wasn't anything horribly terrible, you know. That I'd probably make it. They were probably curious and I thought they may as well see it. Yeh, everybody saw the appliance and all that.

There is a form of reassurance that normal bodily functions continue from altered body sites and that this can be visually verified. It is as though the existence of the ostomies is indicative of Laura's continued existence.

The transition from developing a comfort level with family and friends to a broader public context is difficult. Three months after surgery Laura states:

> I've dealt with all that. Nurses and doctors and family, that's fine okay. If I had to go to somebody's house and had to do that, I'd still be very nervous and this is why I don't. When there's going to be an odour left I'm still not that confident about it okay. So with strangers, no. . . . Publicly, that's my only concern — having to use public bathrooms. I'm concerned about going back to work and being with people. The odor [pause] and I'm concerned about blowing up and the bag getting too full.

Socially the colostomy is the focus of Laura's discomfort. Most of the concern regarding the urostomy is physical in nature. She worries about infection. "I think about that especially at night. When I'm lying on my side it doesn't always drain fully into the bag and sometimes the urine is still up there. . . . I don't like to hook up a night drainage system. I'd feel too much like an invalid."

Sexually, there is an off-limits area of Laura's body, "I don't know if I'm going to get over that. I can't see me getting over the bags business. I really can't see that. I mean what's sensual about my bags, nothing!"

Eight months after initial surgery Laura continues to hope that soon she will be without a colostomy, that a reversal will be possible and the bowel reanastomosis line will have healed. Laura speaks of the colostomy and its presence in relationship to closeness with Soren. Laura and Soren relate how the ostomies affect each of them differently. Laura does not want to be reminded of a perceived non-sensual part of her body. She hopes Soren also forgets about the alterations. For Soren it is important that he communicates a respect for Laura's concerns. The following conversation took place in Laura's hospital room four days after a surgery that has potentially reversed the colostomy.

> Laura: Well, Soren can see it [colostomy] but he can't touch it. Especially at night in bed. . . . Soren knows what to avoid. He knows better because I cringe. Don't I?
>
> Soren: You, yes.
>
> Laura: I wouldn't want him to be looking at them either when we were being sexy.
>
> Bev: So what do you do?

Laura: I pull up my nightie. I stick them under my nightie. That works okay. Right?

Soren: Yes, it doesn't bother me. It's just that I'm concerned how you feel about it. I'm involved. I know how you feel about it.

Laura: I don't think at that time I need to be reminded.

Soren: It's just part of Laura and that's that. It's just one part of her body like her nose and her feet. She's got big feet and she knows that, and she knows I wouldn't touch her feet.

Bev: So having the colostomy reversed is a really important thing?

Laura: Yes, in all different kinds of ways.

Bev: Tell me about some of them.

Laura: Well, just in the sexual part okay. Now he can actually put his arm around me. Over here without having to come all the way up here [demonstrating with hand on abdomen] to make sure he's avoiding it. I thought it was so cute because he never said nothing. The first time we were home and we were sleeping together, he put his arm around me. I mean, your natural move is sort of right along here [motioning]. I mean that's where his arm would have fit perfectly with the way we were laying. He went out of his way to stick his arm right up here. I knew right away why he was doing it, because he didn't want to touch me there. It's just like when I get fat. He never puts his arm around me there where I'm fat because he knows that I've got a tummy and he knows that I'll become immediately, you know, squirmy. 'Don't do that, don't do that', you know. 'Yes, you're crowding me, leave me alone', you know.

Bev: So that really felt that Soren was respecting your needs. It wasn't so much him avoiding or feeling uncomfortable.

Laura: No, I never felt it, no he's being icky and this is turning him off. I've never thought about that. Is it?

Soren: You've asked me that before. At one point you specifically said "Does it bother you when we make love that I have these." I said "It doesn't bother me at all. . . ." It's a small adjustment. I don't find it's a big deal. It's something, like you sort of, I think that really comes from knowing the person that you're married to okay. I know I can joke about the colostomy, okay. I can joke about it and it never even dawned on me that Laura would be upset about it. . . . the two of us, you know, we make light of the fact that she does look nine months pregnant. I have to admit it does look funny. But it's just something that you accept and I know that Laura is upset about this. But I know also that Laura would be upset if, for example, I know that she doesn't like me to touch her, okay, and I do that. That comes from just knowing Laura the way she is.

Laura: When I'm in the bathtub and I need something Soren can come in there you know and get me whatever I need. He can hang around in the bathroom when I've got the bags on and all that. That doesn't bother me. In the daytime I don't care but at night time when we are in bed together, I don't want him touching the bags, because at that time I don't want to feel like I've got those bags. I try to forget about them and I figure if he doesn't touch them then he doesn't remember that they're there either, okay. And then I feel all right. I feel like I used to feel. But if he's touching

> me and then inadvertentely was always touching those bags and they would crinkle. That wou[illegible]poil, everything. It would spoil everything. Maybe in years from now I won't b[illegible]that.

Five months after the reversal of the colostomy Laura describes the difficulty she has had in acquiring bowel control. "I need to go all day then three days nothing. On those days I'm limited. I spend the whole day in the bathroom. On those days I'd like to have a colostomy. It can be up to twenty times a'day." For Laura there is extreme frustration with the control her body periodically has over her rather than she over it. "I get so angry when I have a bad day. It's so disruptive. I get belligerent."

By seven months a rectal fistula is diagnosed and again Laura has a colostomy. Laura relates this to *the group* of other exenterative women. "So I have my colostomy back, girls. I just got it back. You know I couldn't go out for a day. The only warning I had was when it was up against the sphincter. There is only so much muscle control. I exercised but I guess it was not good enough."

Within one month of this Laura was diagnosed with recurrent tumor. Again her focus turned to survival issues.

The Sexual Self

Five months after exenterative surgery and three and a half months after vaginal reconstruction, Laura speaks with me. The ostomies have a great impact on how she feels about her body. She struggles with how she sees herself and how others see her. The questions might be: am I still sexual? Do others experience my sexuality? What can I reasonably expect? What have I lost?

> Laura: Strut, there's no way I'll strut around the room with no clothes on with my two little bags hanging around me. I don't think I'll ever do that, in that way. And because of that and because of the feelings that are behind that, I don't feel about myself the way I did before. I don't feel gorgeous, and sexy and beautiful. Like I wouldn't run around in a short little negligee like I may have done before.
>
> Bev: When you felt gorgeous and sexy and beautiful?
>
> Laura: Yes. . . . You know, I even got a few wolf whistles the other day downtown. . . . That used to bother me but at that time I felt like "hey, that's not too bad."

> Bev: So the gorgeous and sexy part of you only comes out when you're fully clothed.
>
> Laura: That's right. Indeed. Indeed. I don't know, maybe that will go away with time but it sure isn't now. And it's really difficult. I don't know how anybody could honestly feel gorgeous and sexy with these two things hanging down.
>
> Bev: and feelings of closeness?
>
> Laura: That hasn't changed, that can't change. It's probably better than ever in terms of our emotional relationship. It's super. But the sexual part of it isn't what it used to be and it can't be until, well, I'll never feel comfortable with the bags in that sense. But that's okay, I don't care, it doesn't really bug me. I guess it's something I've accepted. I'm not going to feel gorgeous strutting around with these two things flipping and flopping all over. There's no way and that's fine. I don't have to strut around like that.

For Laura, she can't forget the alterations to her body but she hopes Soren can. "I want him to forget about those things. I don't know if he does or not. He says he doesn't even think of them." The rule is; the area of the body with the ostomies is off limits.

> I mean when you're having sex, you want to feel sexy, right? I mean that's a big part of that, being sexy and attractive and desirable and all that business and sort of a lot of that is yourself and a lot of that is how your husband makes you feel. If Soren was touching the appliances, the whole mood and everything, I know it would be spoiled.

Prior to Laura's illness cleanliness was an important factor for being physically intimate with Soren. "I have to know I'm clean before I'm comfortable. . . . and it took a long time for me to tell him why that on some nights he could and other nights he couldn't. It depended on how clean I felt. Dumb, but that's the way it was. That's the way I feel sexier and better when I know everything is spic and span." Given this long standing pattern "feeling sexy" was made even more difficult with ostomy applicances and vaginal healing. Laura states: "right now I don't feel clean about it at all, because of the discharge. . . . So until this discharge straightens out, there is no way things are going to be wonderful."

Laura reports that she hasn't felt like she has wanted to have intercourse.

> Sex isn't on my mind in any big way. Not like before. Not to that extent but Dr. T. keeps asking me when we're going to do it. I gotta report something. Like let's do it and then he'll stop asking me. So I said: "Now is the time, let's get it done and see what it is like and if it's horrible then we'll wait a while." But it wasn't horrible.

Up to this point Laura had avoided all contact with her neovagina. Other than medical procedures she had not ventured to have anything in her vagina to see if it was still an open space (i.e., she had not douched or inserted a tampon). She and Soren embarked on a clinical experiment.

> Yeah, well even when we were thinking about starting intercourse, I was nervous as heck, there's no two ways about it. . . . Touching the vagina and all that business, that was all part of the way we did things before. Well, this time I didn't want him to do nothing. I just wanted him to see if it still fit. It was an experiment. This was the night we were going to try stuff and I thought that's right and that's exactly how we treated it. It was kind of strange. . . . Entering, well that was a long process because we were scared. So we were doing it very slowly. We were just thinking about what was going on. . . . I didn't really feel anything there except on the bottom part where it hurt. . . . It didn't feel anything like it used to feel like. No way, I don't know. It was almost like it used to, to the rectum. Like things were being done backwards.

Eight months after vaginal reconstructive surgery Laura reports "It's still very experimental you know. A lot of talking like yes, how's that? How's that? Can I do this? No, move up." At this time she is in hospital to have the colostomy reversed. There is discussion of how to improve the vaginal function. Presently the vagina is too short and there is pain and pressure near the vaginal entrance on the posterior wall. Laura speaks with Soren as they discuss the pros and cons of further vaginal surgery.

> But you know the length that you need is really not very good. You know it's like nothing at all. It's just a frustration. . . . Well, it's painful okay, it's painful in the sense that it feels that, you're putting incredible pressure on something. Yes, I guess that's about the best way to describe it, you know. There's a particular spot, oh yes. It's quite a definite spot where it really, really hurts. . . . I mean we had to go very slow. There wasn't very much trouble with the opening being too small. It's just that it hurt at the bottom there, right? And I kept telling you to go upwards but that's impossible, you can't do that.

Laura experiences her vagina as inadequate. During "lovemaking" she wishes her husband could move away from her pain. The physicians are considering and presenting different options to possibly improve the vaginal function.

> Yes, Dr. L. coming in tomorrow apparently and him and Dr. T. are supposed to talk today and figure out what they're going to do. Dr. T. I think was suggesting that he take this one out and do skin grafts. Well, he's really going to have to do some fast talking to convince me of that! I went to a lot of trouble to keep this one in, you know, and to have it take — a lot of cleaning, a lot of my time, you know, so I don't. . . . After all I've been through to get this vagina, I think that I would like to at least talk to them about fixing it, you know. See if there is anything they could do, without me having to go through a hell of a lot more.

Perhaps the statement to go through a hell is a metaphor for Laura's experience of her neo-vagina which for her at this time stands out as the most difficult and painful part of the surgery.

Fourteen months after surgery Laura reports a change. Initially sexual contact and intercourse was experimental in nature. Now Laura's energy is increasing. She is aware of a longing to express her sexuality with Soren, a longing to return to the way it was, a longing for a functional vagina.

> The vagina is useless — too short, too painful. I have phantom pain in my leg and I'm not feeling good about that either. I'm longing for it to be the way it was. If my vagina was the way it was, that would be enough. Everything else would fall into place. Alternatives just aren't the same. The longing has been there, only in last month and half. I've never really verbalized that until right now.

For Laura there is a sense that she is letting Soren down. For Soren there is the fear he might be hurting Laura, that she has gone through a great deal of pain to have a vagina for him.

> Laura: When sexual things start to happen that's not the time to say 'stop, let's try this or that.' Soren has worked himself up, then is supposed to get analytical, slow down. It's not fun for anybody
>
> Soren: I'm afraid of hurting or causing pain to Laura. I think Laura is biting the bullet for my satisfaction. The vaginal surgery was the worst pain — worse than the exenteration and it wasn't successful. It probably wasn't worth it.

With Laura identifying her desire for greater sexual expression, Laura and Soren begin to speak about their sexuality with a greater depth than they had been able to in the past. Soren had been careful to not push Laura. Now she was saying, I have concerns, I want more, I know what I've lost. Laura speaks of her discomfort or her *dis-ease*.

> I also feel that so much has happened down there. Is it sexy from Soren's point of view? Is this a sexy part of the body or is this a problem in our lives? Everything is concentrated — this is where the big deal has been going on.

As a way of coping with her uncertainty about her sexual attractiveness to her husband and her ability to function sexually Laura gained weight. Feeling unattractive due to weight gain insulated her from other realities.

> I do feel altered. I don't feel good about my body any more. I was up to the point until yesterday I didn't give a shit about where I was going. Yesterday I had good heart to heart with myself. . . . I'd gained weight — probably done a lot of that on purpose. . . . I know I've purposely gained weight. If I lose weight I'll feel better about myself, then I'll be more receptive to sexual things. . . . I gained weight cause I didn't feel good about my body — to keep Soren at a distance. . . . It was easier to be fat and ugly and not have to deal with it [Soren and sex]. . . . I'm not ready to change my behaviour yet but I'm looking at it. I've got to come to a decision. Enough is

enough, and I'm wanting sexual things to be back.

For two years Laura's body has given her little pleasure. The healthy part of her is now longing for expression. As the healing and renewal continues she makes a commitment to nourish herself rather than continue with the misdirected nourishment of overeating.

Within three weeks of having made this commitment to herself, Laura is again hospitalized with a rectal fistula and a permanent colostomy is done. In order to be present at the first group meeting of the women who have undergone the same exenterative surgery, Laura obtains a hospital day pass. They begin by speaking about their physical symptoms. One group member states: "Actually these vaginas are a write off. They're useless. Mine's disintegrated. How's yours?" Laura responds: "I hope to use mine. When we have used it though I've gotten pain down my legs, down the gracillus muscle. Even douching will send pain down the right leg." Laura then begins to share with *the group* her determination to take charge of her situation and to experiment with new behaviors that may help her to regain the quality of relationship she is longing for.

> Let's put out heads together and figure out a way we can feel better about our bodies — feel comfortable. We may be here for 50 years. We can't be this way for 50 years. . . . I think a lot of the insecurity comes from our own self. We have a low image of ourselves sexually, as women. . . . It's time to start thinking, 'this is going to be my body forever.'

Further she states, "because we can't have vaginal intercourse, it's a big issue. It's the focus of our sexuality."

Laura speaks about the transition from seeing herself as a patient, an ill person to a woman with a changed body.

> What I want to talk about is how you guys are doing with your body image. I'm having more of a problem now with how I look than before. Before I didn't care because I was such a sickie. You're supposed to look like a sickie and bags are okay if you're a sickie, but I'm not sick anymore. Has anyone come to deal with how they look, their sexuality in a positive way? To say, "this is okay?" I'm talking about you and your mirror [the naked self] — you and a see-through nightgown, not in clothes.

Laura tells the others of her experiments, the changed behaviors that she hopes will lead to changed feelings.

> What I've started to do in the last three weeks, I've made myself take my clothes off

> in front of my husband. If I start by doing that, to make it natural to have this stuff hanging down, if I can do that for two or three months to get accustomed to him being accustomed to me with this stuff showing, I think then I'll be more comfortable later when it comes to a sexual thing and bags in way. My husband is good that way. Like when I'm fat, he touches me in places I feel good about myself and stays away from places I don't. So in a few months I'm going to ask him to touch bags. . . . "Go for it, Soren" put them [arms] around me down here and over time even if it's an experiment maybe it will become okay. I'm at that point I've got to do something myself. I don't want him to be scared of touching me with the sense I'm going to be upset if you touch the bag. It's not easy but we have to do it for ourselves. With or without clothes on.

Further, she relates how at times she has rejected being close, sharing hugs, making brief physical contact "probably I fear it could lead to something I don't want to handle." She wonders what this has been like for Soren.

> I'm beginning to say how is this for Soren. I'm the one with all the fears and problems. It's my body that can't accommodate. When you get married, the sex is important. You can't indefinitely cut your husband off from it. This isn't really fair for him. He wants to hug and kiss and I'm automatically thinking he wants to jump into bed. Intercourse! I know that's not what he wants and I don't even give him the chance to do a lot of hugging and kissing. I find all kinds of excuses. I'm sure the poor husbands in this thing are wondering, how long is this going to go on, even though they don't want to tell you that. God forbid she thinks I'm trying to rush her.

Laura summarizes her determination to experience and express her sexuality.

> You know, once you've got health again, are well again, are strong again, and had time to be thankful for surgery — Thank God I'm alive — all that beautiful stuff, it's not enough to be alive. I want a real life. I want to be able to be the way I was before with husband. I want to be able to take my clothes off in front of him. I want to be able to wear my negligee. I'm not sick any more. I should be able to start acting like a real wife.

Finite Awareness

A few months after surgery as Laura reflected on the cancer, she recalled her time immediately prior to exenterative surgery.

> You know I can remember laying awake thinking that if this had been fifty years ago, too bad! You know they wouldn't have been able to stop it or at least I thought they wouldn't and they probably wouldn't have, you know. Radiation wasn't that great at that time, they didn't really know what they were doing. I guess when we discussed the surgery it was just something that I accepted as the only thing to do. Somehow I just stood back from it all. Not pretending it wasn't me. That's not what I did. I just took it as something you had to do, okay. Then the morning of the surgery, I was scared! Scared that I wouldn't come out of the anaesthetic, that I wouldn't see Soren again. What tipped it off, was the priest came. Well, it wasn't even the priest. I wanted the priest but I got a minister. When he did like give you this final blessing business, I

> don't know if you know anything about that, so he did that and that scared me. That just brought it all right out in the open and then I was really terrified. At that point they brought me upstairs and I was still upset. I don't know what Dr. T. said but whatever he said it just did the trick. Then I wasn't scared any more and that was while I was waiting to go into the O.R. . . . and that was my only time of real fear. It was just then and not since that I really am scared. Occasionally the thought will come to mind what if it isn't gone?

Laura further describes a sense of unreality that her life is threatened by the cancer. She fears the known more than the unknown.

> I don't know, it's sort of even now I guess unreal. I haven't really come to terms with it in the sense that I really thought about it. I've just been accepting it. Do you know what I mean, without actually getting super scared about it or any of those kinds of things. Maybe that will come later. Maybe never. I don't know. But when they found the tumor hadn't really gone from the radiation I had already at that point read what would be the next step. So I knew about the exenteration, whatever it's called, that it's the only thing that he could do. My concern was with his competency at that time not with the surgery, which is stupid but that's how it was. Then the only thing that scared me about the surgery is that I'd hemorrhage to death. Can you believe it?

This pattern is familiar to Laura. "Any of the hurdles in my life, I just met them head-on, without breaking down and going cuckoo and crying and screaming and yelling and all that business. I just accept it . . . . Sometimes I worry about making it for five years. I think about that."

Laura perceives her approach as different from her family's.

> They're all very concerned, but I'm not as concerned as they are and I don't worry about it the same way as they do. I just go and I have my checks, never thinking that anything can be wrong. I try and humour them. Sometimes I think that maybe I'm not taking this thing seriously enough and yet, I know that this is serious. But I'm not taking it the same way as they do with these check-ups. Like they're all waiting by the phone for me to call. Like Soren says don't leave the Cross until you call me. Like don't even wait till you get home.

Her husband Soren describes how he copes with the frequent medical checkups. For him it's better to experience relief rather than despair. "I take a pessimistic point of view. Then when it's checked out, any news is better than what you think. The big problem is the cancer. Everything else we can deal with." He encourages Laura to have any or all symptoms checked out. Relief comes when the symptom does not indicate a recurrance of the cancer. Soren continues: "Sometimes she doesn't like to get things checked out because she doesn't want to know. It's easier to say it isn't that bad, I'll be okay. I'm the opposite."

For Laura it is important that she deal with life in a manner that doesn't have her constantly focusing inward. Periodically though her body demands her focus. "I never consciously think I have any limitations, that I'm not like everyone else now. I get so mad, furiously mad, that I have to change plans for my bowels. Some days I don't have the time to spend on myself."

Nine months after surgery Laura is reflecting on the question of returning to part-time work outside her home. She reflects on the significance of having time at home with her children.

> Eventually I will [return to work]. I enjoy what I'm doing at home right now for a little bit longer. I think my kids have been without their Mom for long enough, this year and last year with me being gone all the time. They are really enjoying, you know, being able to count on the fact that I'm there when Daddy's not there — all the time, no exceptions.

Ten months after surgery Laura consciously becomes aware of a shift in her response to her quality of life. She has moved from seeing herself as a "sickie", to a survivor. As a survivor she is wanting more from life than simply being grateful for being alive. "I'm starting to not be quite as grateful for all this. . . . Now it's all the other things I'd like to see. I've had enough time to get used to the idea, 'I'm going to be here for a while' — or it sure looks that way."

Fourteen months after surgery Laura continues to pursue those things that for her increase her quality of life. She states: "Life has to be good or it's not worth living." This belief is the foundation that allows her to live with limitations but pushes the limits of them. It is at this time that Laura learns of a recurrance of a pelvic mass — a recurrance of the cancer.

Once again Laura is confronted with the knowledge that she may not survive the cancer. At the same time she is determined to pursue whatever medical interventions are available to minimize the disease and increase her length of survival.

> I'm not going to get my hopes up [for a cure]. They told me that's not going to be the case with me. . . . I think about my children. I have a daughter who is two years old now. I think, "will she remember she had a mother?" That upsets me when I think about it. I know Christopher will remember. He is five. But I can't remember a damn thing from when I was five. I think though he will be the only one who suffers a lot. For my daughter it will be easier. She'll bounce right back. Time has no meaning for her. A couple of months and she'll be okay. . . . I know I am an influence but I want the memories to be there. A lot depends on Soren. Knowing him he'll soon come to

> terms with it and talk about it. . . . There's no damn good time to die [nervous laughter]. It's never a good time.

At this same time Laura's father has recently been diagnosed with an advanced lung cancer with a prognosis of a short survival time. Laura comments:

> Dad's just been diagnosed three weeks ago with a serious case. He's worked hard. Hey, his life is just starting. He's had a hard life. If he'd lived his life like I'd lived mine, having fun and doing things in between, I wouldn't feel so bad. He's 64 and in his case it doesn't seem right. He's not had fun.

Further Laura says: "I can look at others around me and feel better. I've had my husband, and children, so many things. Sometimes friends talk about issues and I feel, give me a break. I don't give a shit. The issues are so insignificant."

Laura states:

> I've never confronted death. I didn't really believe I was going to die. Even when they told me I didn't believe them. I talked about how they said that to me and how dare they say such stupid things. . . . So just because you have cancer doesn't mean you face death. I don't think I really even thought about me dying even though I had cancer.

Members of *the group* state the fear they have had for their own health since they learned of Laura's recurrance. They had been thinking about the possibility of their dying. Laura responds and understands, for together they are the survivors of exenterative surgery.

> That's what I was afraid of it you guys found out. . . . You want much hope when you have this operation. You're willing to put up with all these inconveniences of bags and such because you have this hope. It's awful when it's taken. Dianne's [patient #3] death didn't bother me and every time you [the group] talked to me about her, I listened but not really. I didn't know her or had spoken to her. It was like watching T.V. and someone else dies. It was meaningless to me. Now I'm sure if it was any one of you here, if something happened, I'd be really really scared and upset.

With each medical crisis Laura chooses to focus on life and options that may offer a further chance to live it. She has many crises — experimental chemotherapy in Houston, Texas, surgical removal of tumor leaving neurological impairment of a leg, a hemipelvectomy leaving her with only one leg, and then two and one half years after the first occurrance a recurrance of tumor in her bowel, liver and diaphragm. Each time Laura chooses whatever options seem left to her. For example, she states: "A one legged wife or mother is better than no one at all and they tell me the surgery isn't as bad as the exenteration." Now with the last recurrance

Laura comments on it.

> I guess I'm no worse off than I was two and a half years ago in Houston. Perhaps it's just spread a little farther. I just hope Dr. M. will be able to have me in his monoclonal antibody study. I'm coming up to see him. He's had some promising results with ovarian cancer. I don't know if he's tried it on cervical cancer yet.

For Laura there is life and with life there is hope — hope for another day and each one is worth fighting for. For Laura there is also a sense that this determination to go on is not always understood. It is the medical community that can provide the options. She needs them to understand; to understand for her and other patients who are not to the point of saying "that's enough".

> If there is any kind of hope with any kind of treatment, I think a patient should be encouraged. I think any patient that is willing to do anything that might possibly increase her chances of survival shouldn't feel like she's abusing the Medicare system. It's subtly conveyed. I think it's my duty as a wife, mother, daughter, and friend to go on as long as I can and without feeling I'm taking resources from those who can be saved. I'll take my life any way I can get it!

C. Marge

Marge is a married woman with two children, a daughter and a son from a previous marriage. At the time of exenterative surgery, Marge was forty-two years old and her children were thirteen and eleven. Marge and her husband, Daryl, had been married six years. Marge worked for an airline company in ground passenger service and Daryl worked in the petroleum industry as a research chemist.

Marge had been diagnosed with a cervical carcinoma six months prior to surgery. When she experienced pain with intercourse she contacted her gynecologist immediately. She then waited five weeks for an appointment. At the appointment a Pap smear confirmed a malignant condition and a cone biopsy was performed followed by radiation treatment, an attempted radium insert and then further external beam radiation. Five months later a biopsy showed persistent disease. She was admitted to hospital to have an examination under anesthetic and a decision was made at this time that she was a possible candidate for exenterative surgery. It was at this time, two weeks prior to surgery that I first met Marge and her husband.

My first impression of Marge was of a very attractive and articulate woman. She is a slender, dark haired, fair-skinned petite woman. She presents also as a woman who attends to her physical presentation — well-groomed and fashionably dressed. Both she and her husband speak with a refined British accent. There was a lot of supportive interaction between her and her husband. There was a sense that they were in this together. They both asked questions, initiated issues, spoke freely about their concerns and collaboratively responded to both a psychosocial and psychosexual history.

As they spoke about their background, they spoke of having emigrated to Canada four years earlier. When they were married in their native England, they had emigrated to Switzerland. They lived there for two years but financially found it very difficult to continue there. Together they decided "to come to Canada and to work together. We didn't know what lay ahead but we just had to do it. I think we're approaching surgery in the same way." For Marge, this had been a long standing coping style. At an earlier time, she was living in Australia and her first marriage was in difficulty. She stated "I knew I had to leave. I packed up myself and my two little ones and left." This leaving took her to South Africa and then finally back to England. Unknown to me at this time but spoken about three weeks later in hospital was Marge's early experience of being raised by her mother who suffered with a chronic mental disorder. Marge had learned early in her life the necessity of taking care of herself.

As Marge and Daryl spoke about the upcoming surgery they felt that it had been explained well to them and they "felt a rapport with Dr. T.". From their perspective this was "the best option and it sounds like one can live a relatively normal life afterwards." For Marge she expressed concern regarding changes in sexuality and wondered what alterations she would have to make in activities she enjoyed outside her home such as skiing, swimming and travelling. She expresed an understanding of the ostomies having specific questions though about "how big will the bag be?" and "where will it be on my abdomen?" Both she and her husband expressed a hope that the colostomy would be temporary. More immediately though Marge had fears about survival but "I was afraid to ask Dr. T. if anyone died in surgery."

When Marge was discharged from hospital and was awaiting exenterative surgery, I was left with an impression that together Marge and Daryl had struggled with difficult times before and they were facing the exenterative surgery experiencing each other's support and hoping for (1) survival, (2) eradication of the cancer, (3) minimal alterations to activity level and sexual function, and (4) reversal of the colostomy as soon as possible after the surgery.

The Hospital Experience

Although I was present in the operating room throughout Marge's exenterative surgery, I was away on vacation for much of her hospital convalescent time, returning about one week before her discharge home. After discharge from hospital Marge referred very infrequently to her hospital experience. Therefore, only a brief presentation can be made of this phase in her exenterative experience. Due to the nature of the study, I did not probe for this specific content material. Rather, she spoke about what was most significant and forefront for her at the time. Marge's approach to life is to be very focused in the present.

Marge was admitted to hospital two days prior to surgery. She verbalized a good understanding of the surgery and was receptive to the preoperative teaching regarding ostomy care. As the surgery time approached, she became increasingly apprehensive about the surgery. The fear of whether she would survive surgery was present for her as well as concerns about the quality of the life she might have after surgery. Daryl was frequently present during this time. He was very supportive and provided good verbal encouragement to Marge.

Throughout Marge's time in hospital she was very responsive to her own feelings and experience at that particular moment in time. She describes this period of time as a continuous "series of ups and downs"; a continuation of the rollercoaster effect experienced by many cancer patients. This is collaborated by the nursing notes. One day would be "a good day", the next would present some setback and Marge would feel discouraged. This pattern continued throughout the hospital experience and even on the return home. Marge stated: "the ups would get longer but the ups don't feel as high as they did before surgery."

Throughout the hospital period pain control was an important consideration in how Marge experienced each day. Marge felt frustrated; "They say let us know when you're having pain, but they stay on the hospital schedule." Further she states "they need to give the patient more control of the pain medication." Like others before her, Marge experiences "excruciating pain" when the vaginal packing is changed. She felt angry that she was "left to experience this pain with little done for it."

One week after exenterative surgery, Marge returned to the operating room for construction of the neovagina. This surgery brings to the forefront the fear "What will be the quality of my sex life after this?" The nurses note Marge wanted more sexual counselling.

After surgery Marge continued to spike a fever. Two examinations under anaesthetic were done during the hospitalization to rule out any pelvic abscess and to establish the status of the neovagina graft. The first such examination was done one week after the neovaginal graft. Later back in her room while several doctors were consulting on her case, she listened to their conversation as they hypothesized on the possible causes of the fever. Upon hearing the word "herpes" she experienced absolute terror. Her experience was of the doctors "whispering to each other" and not speaking directly to her, then leaving her room. During the next thirty-six hours she experienced an acute emotional reaction. Nursing notes chart Marge as having made the following comments. "The doctors are out to get me and find something else wrong with me . . . . I just want to give up. . . . My husband has been so patient with me." Laura [another exenterative patient] came in to say goodbye to Marge, as she [Laura] was going home. Marge states: "I feel abandoned. . . . My children are leaving for England. At least they won't have to see me like this." That afternoon, Marge was having gas pains and crying out. Later that night she vomited over herself and her bed linens. In her discouragement, she states:

> I have to get out of this hospital. They're trying to kill me. . . . I never should have come to Canada. It's my husband's fault. He shouldn't have brought me. I'm going to die right ~~here~~ in Edmonton, Alberta, Canada. The doctors let me suffer at night when I feel all alone. If I don't get out I won't ever get out. Perhaps there is a hospital in the U.S. I could go to where they use heroin.

Early the next morning Marge spoke at length with the surgeon. After this contact she was markedly calmer. Initially, she was upset about "creating a fuss" and later apologetic "over last evening". When I spoke later with Marge about this experience she spoke about how hearing the word herpes had triggered so many fears. Her belief was that herpes was only contracted through sexual contact. She had depended on and valued her husband's support and now feared that he would think she had had extramarital sexual relations and would not believe her that she had not. "He'd been through so much with me and was so patient. How much more can I ask him to take?" When I spoke with Marge about feeling left all alone with the pain and her fear that she would be further harmed if she stayed in the hospital, she spoke at length of her experience of being raised by a paranoid schizophrenic mother and the confusion, fear, aloneness, and sometimes abandonment that was ever present for her as a little girl until her mother's condition responded to medical treatment. One can understand the intensity of the response when Marge already felt emotionally and physically vulnerable, then fear her own support system was threatened. The archaic learnings are embedded in one's psyche.

Marge continued to have "ups and downs" during her hospital stay and communicated her concerns to the medical staff. The persistent fever was further investigated with galium scans. For Marge there was a desire to find the cause and at the same time a fear of "what they would find." There is both hoping that the exenteration will bring about a cure and the awareness that the uncertainty remains.

The Transition Home

Two weeks after Marge was discharged from hospital she returned to the cancer clinic for a routine followup appointment. She and her husband reflected with me on the transition home after surgery. It is not simply the transition back to home. It is the anticipation of *feeling at home* with oneself back in the family context.

> Marge: The back door, the first thing is the steps to the kitchen and I expected to sort of walk up them, and I couldn't get up the steps and that upset me to start with. . . . I stood outside my house and sobbed because I couldn't get back in. . . . . At first coming home from the hospital, it is a walk down the corridor, down the elevator and out. I hadn't moved much until actually leaving the hospital, so by the time I got home I was fairly tired. I suppose when we came in the back gate, down the path and

> walked to the house. I couldn't get up the step without Daryl assisting under my arm and helping me up so that kind of upset me. I thought, oh my gosh, I am a lot weaker than I thought. I felt stronger in the hospital. The first few days at home, I expected to feel better than I did. The first night I didn't sleep well.
>
> Daryl: Yes, you were awake on the hour, every hour and the first night the ileoconduit leaked and we had a wet bed. Of course in hospital a wet bed is no problem, they rush in and change it.
>
> Marge: Yes, you cannot call in a team of nurses to come in and change your bed.
>
> Bev: Plus it involves another person at the same time. Like it wasn't you just being in a wet bed, it was both you and Daryl.
>
> Daryl: And then you would wake up because you were afraid of it happening again. You kept waking up to check if the whole system was working.
>
> Marge: . . . You think that you can go home and immediately feel at home again but [voice trails off].

Daryl had taken time off of work to be with Marge during her first few weeks at home after surgery. They speak about how they are coping with Marge's convalescence. They speak of the fatigue they both experience, the preparations necessary to follow through on the needed post-operative care, and the feelings associated with this new position they both find themselves in. There is a real sense of Daryl's commitment to help his wife and at the same time a sense of helplessless to make a difference. Marge is acutely aware of her need for assitance and at the same time fears being a burden on Daryl, experiencing it as an *in-valid* way of being at home. To feel at home one experiences a sense of comfort with the familiar. For Marge and Daryl much of this experience is new, unfamiliar and certainly not comfortable.

> Marge: The first week at home Daryl was really exhausted. I seemed as if I was very weak. He made all the meals and did everything for me. This second week I'm able to look after myself much more. I don't need as much help.
>
> Daryl: That's right and you see that first week you were running these very high temperatures during the day. . . . I've been on holidays for two weeks. Basically I've been wiped out the past few days so it's nice to get a few hours of extra sleep. I go to bed probably one hour after Marge. I sort of tidy around and finish off and have a bath and relax a little.

There is much co-operation between Marge and Daryl in accomplishing a daily routine that is required in order to meet Marge's physical needs.

> Daryl: You see we have busy mornings. We get up and have some breakfast. Once we've had a good breakfast and then a bath, we do the beds and whatever needs doing.

> You [Marge] have been doing pretty well every day, haven't you?
>
> Marge: Oh yes, and Dr. T. likes me to douche about three or four times a day. You know you got to make up the solution, the saline, the salt water and peroxide solution. That's got to be made up, boiled and cooled before it's used. We find life quite busy until lunch time anyway. The rest of the day is a little bit quieter. . . . Oh yes, and the extra shopping to get fresh fruit in an attempt to get me to eat. . . . I've needed Daryl these two weeks very much. . . .
>
> Daryl: Oh yes, and changing bags and things and all the different skin preparations. The pace and the different bags, we've had to learn all that. I think we're pretty confident with the whole thing now but we still do it together. We still change the bags together because there is a lot to do.

Daryl further describes the fatigue and helplessness he experiences in this intensified care-giver role.

> Oh yes, it's not really the amount of work. It's the amount of work on top of what you've already gone through. And I'll tell you I'd rather work back to back twenty-four hour shifts than do some of the things that we have to do. You know in terms of being physically and mentally fatigued at the end of it because you're working under a strain and you're looking at your wife and she's not responding particularly well, she's got problems, she's running a fever. . . . Oh, the feeling of helplessness is phenomenal. There's nothing you can do that will physically bring that temperature down. . . . There have been times when I've got low and I realize that getting low isn't helping Marge either. . . . What was tough I guess was the amount of care that Marge needed that first week. You know you've come through half a year of trauma really when things haven't worked out. Then all that worry about the operation itself, all the stages that had to be gone through and then hospital visiting was hard because Marge was in a lot of pain and discomfrot and then it sort of eased up. Then suddenly you think now she's coming home and things are going to be better.

There is the anticipation that coming home will normalize things. Perhaps symbolic of the changes is the bedroom, their private space, now a convalescent's room.

> Daryl: We even had to rearrange the bedroom. She began to feel a bit claustrophobic. It was fine when Marge was well . . . . so we arranged it so she could look through the door and widen out the whole thing and you felt much better for that, didn't you?
>
> Marge: [nodding yes] I got home and felt very trapped in by all these walls around me. Also there wasn't much room for getting in and out of bed. When you're agile, getting in and out of bed doesn't matter. When you're not so agile somehow I needed more space so Daryl moved the bed.
>
> Daryl: And then we had to have a table with all the equipment and just a phenomenal amount of bottles and packages and different bags and things. It's all there. It's all got to be in the bedroom.
>
> Marge: It really did upset me at first to see all that equipment, everything, when you laid it all out on that big table. But it comes easy laid out on the table. Whatever you want you can reach, rather than putting it in the cupboard and having to search for it.

> Eventually we can change it to a cupboard.

For Marge and Daryl they are acutely aware of the changes the illness and surgery have brought to their lives but for Marge's children life appears to continue on with little apparent interruption in their routine.

> Marge: They haven't asked anything, they know I have two bags. Neither of them have asked about them or asked to see them or displayed any curiosity. Basically I think they don't want to know. They don't want to see anything.
>
> Daryl: Life's going on as normal basically, isn't it? There hasn't been any behavioral changes in them. In fact, I thought they might have helped a bit more with their mother not being too well, but no, it's the same.
>
> Marge: If they prefer not to know I'm just as happy to leave it as well. With a bit of luck I will get rid of one bag, which will be nice.

Marge had lost a significant amount of weight going from a presurgery weight of 120 pounds to 90 pounds. This was her literal loss but for Marge she was indeed experiencing a loss of her self.

> When I saw how thin and emaciated I was, yes that upset me but more than that it upset me having to lean so much on Daryl. I felt almost like an invalid when I first got home — having to lean and depend so much on someone else — even to lift you in and out of a bath.

The Self In the Medical Relationship

From a position of feeling an "open rapport" with the surgeon and seeing the exenterative surgery as "the best option". Marge has reflected on her surgery and her experience of the decisions she has made and she has a new persepective on the nature of the relationship between herself and the medical staff.

She finds herself reflecting on the "what ifs", seeing in hindsight what alternatives might have been followed. She has a sense of being experimented on, a betrayal of her trust, that "they know what they are doing".

> If I had gone to surgery after the first lot of radiation I do feel that there might have been a lot better chance of the bowel and of the vagina working. They now say they would not go to the second course of radiation, the extended radiation, if the first course of radiation did not work. They would go straight to surgery. So I feel sort of betrayed that they did not find that out on someone else.

On reflection Marge indicates that more discussion would have been helpful in making more informed decisions. In retrospect she knows the questions she should have asked but feels this information should have been forthcoming from the "experts" — the medical team. She recognizes that of the information she received, she may have filtered out some of those things that she wasn't as receptive to hearing.

> Marge: I also, as you know, felt very betrayed by Dr. T. that he told me that this colostomy would only be temporary and then it was not temporary and I have a lot of bad feelings about that. My recollection is that he said it would be temporary. He may have put some area of doubt in my mind that I did not hear at the time because [voice trails off].
>
> Bev: Which is also understandable. You did not want to have a colostomy for the rest of your life.
>
> Marge: Yes, the way I understood it is perhaps I'll end up with only one ostomy. It did not seem so bad.

Further Marge explains:

> It seems to me they act without really explaining to you the down side of anything. . . . It made me feel that they thought I was just so dumb. They do not want to tell me anything. That is just about what I felt at the end of it all. As though, well, she will not be able to understand so we will not tell her. I think it must be what it boils down to. They think people cannot understand so they decide what they think is best for you without giving you any choice in the matter. Or they do what Dr. T. does and that is he decides what he feels is best. So he tells you, 'this is what is best, don't worry about that over there. That will probably never happen.'

For Marge the down side is two ostomies, and a non-functional neo-vagina that left her with a deformity and scarring of her thighs due to the muscle graft that was used to create the neo-vagina. She states: "I seem to have lost out all around. But I think that is the way it works out sometimes." Marge explains how she experienced the decision making process regarding the exenterative surgery.

> I think, though, that they should give people the choice. They should not just do what they think is best, all the time. Although I suppose it is a huge responsibility that they are carrying. If he had said to me, "we think we can save the bowel for you but if we do this vaginal procedure it may in some way put at risk the bowel", I am sure, I think, I would have said, because I was so keen just to have one colostomy, do not do the vagina then. Concentrate on saving the bowel for me. I feel betrayed because I have ended up with two colostomies and also the surgery to the vagina I felt was much more experimental than was ever really explained to me. Another doctor said they are now waiting six months before they do the vagina construction. I think if I had been allowed to wait those six months I may or may not have been in a better situation to say to someone, 'How big are these thighs going to be?' I never asked that. Nobody

> told me the scars were going to be 15 inches long and I do not remember them telling me about the deformity of the legs. I did not understand how bad the legs were going to look afterwards and that things like playing tennis and this sort of thing were going to be gone because my legs are not now as strong as they were. Really, if someone had said these are what the scars are going to be, that is how long they are going to be. They are going to be fairly thick. You are going to have bulges at the top of your leg. It may mean that if you are a person who spends a lot of time on the beach or if you like to go swimming at swimming pools, it may mean that you are not going to be able to do that as much. You will not want to do it as much. It may affect you with skiing. If you are a person who goes to aerobics, you may not be able to go to those sort of classes any more. . . . Often, they say afterwards, "Oh, well, that did not work." Well, this is all those things that I did not tell you about and what you find out on your own. But that is your business and that is your private life. Like the tennis, aerobics, and the beach and all those sort of things, they are your own private life and the doctor is not probably the least bit interested in ~~how they~~ are now. But you still have to think for yourself. . . . I think a lot of medical people say it is not our responsibility, it is not our business. We have kept you alive and you go away and exist the best way you can and be grateful we have kept you alive. You know this seems to be the way he [the surgeon] feels, and the way they operate. And maybe one cannot expect any more than that. . . . But, on the other hand, we can see that he is working very hard to do what he feels is best, what he feels has the best surgical possibility of working.

Marge is clear in stating there was a need for more information for her to experience both an attitude and a process that facilitated her being a central part of the decision making team. She contrasts this earlier experience to a later one when she was needing to decide with the surgeon about either having a permanent colostomy done or having further repairs done to the rectal fistula that was not healing. Marge experienced this latter choice as her decision. A question might be are there skills to be acquired in being a patient especially as one moves from an acute episode to a chronic illness?

> He told me about the vagina operation what he wanted me to know and that was, we can do this, and this is what we are going to do. He did not tell me anything he did not want me to know because that would have clouded the issue on my deciding whether to have it. He gave me a choice, do you want to have it or not, having only told me one side of the whole thing. But when it came to November and he could not close the colostomy after all, I think he was very honest with me. He said "Well, we can do this for you. These are the risks involved. This is what you will be faced with and you will have a tube down your nose and the tube into the neck. You will probably stay, whatever it was, three or four weeks", or whatever estimate he gave me. He laid it all on the line and then it was my choice. I felt this is up to me to make the choice. I have not actually had any bad feelings about it. . . . I was really involved and he was really honest about all the aspects and I was able to weight it all up.

Throughout the first year after exenterative surgery there were recurring concerns — periodic fevers, vaginal discharge, some leg and back pain. This meant regular contact with the surgeon. When Marge learned that he would be leaving the cancer clinic and relocating to another city there was both fear and anger and acknowledgement of his skill in dealing with her medical concerns. She states:

> You've gone a long way and through a lot with this guy — a lot of scary things you know nothing about. Suddenly he's leaving. Course he's leaving for all of us at the point where he's got us through it.

There is hope that the medical concerns are in the past, that she will not need someone like him in an ongoing way. At the same time he is seen as the person responsible for offering life — providing an option as illness persisted. At the same time he was also the man who altered her body — altered it in ways that had a deep impact on her own sexuality. Together they had been through a great deal. He had offered a lot and taken a lot. Perhaps the intensity of this relationship is poignantly illustrated by Marge's statement: "I felt like a discarded mistress. How can you walk out on me?"

Living with Ostomies

Much of the initial ostomy care was done conjointly by Marge and her husband, Daryl. Together they had a shared knowledge of the physiological aspects of living with two ostomies. [illegible] the early convalescent time at home they spoke of the ostomy care as a "we" activity. Daryl stated: "we're pretty confident with the whole thing now but we still change the bags together." Daryl's early involvement with the ostomies allowed them a large degree of openness in speaking about concerns related to the ostomies.

Marge soon moves to complete self-care. Within two months Marge has returned to working part-time in airline ground passenger service. She works a few shifts a month. She eagerly anticipates having her colostomy reversed. Within three months of the initial surgery she learns that due to radiation damage to her lower bowel she will not be able to have a reversal done and that the permanent colostomy will the done. As discussed earlier this is a great disappointment for her. Marge sees the colostomy as the part of the aftermath of surgery most difficult to accept. She clearly states that if she'd had a choice between a functional vagina and functional bowel and rectum, she would have opted for a functional bowel and rectum and for no vagina.

Three months after surgery Marge is working two or three shifts a week. She describes her experience of being back at work, and caring for her ostomies. Initially she lives with constant fear of a leakage or of embarrassment from uncontrolled bowel sounds. It's with real determination that Marge faces this fear and carries out her work activities.

> Marge: It's really difficult. There's so many times when you're in a part of the airport where there's no washroom and you've got people with you and you're responsible for these people. Sometimes they're in wheelchairs and you can't just leave them. Yesterday I was training on a new luggage belt. We had some luggage going around and I had some luggage going around on the fragile belt as well and C.P. wanted our luggage off that belt. This bag filled up again and I was afraid it was leaking but I had to get that luggage off because C.P. had a flight coming in and I was all tied up and I thought if I don't get to the washroom soon . . . .I was afraid the bag was going to burst because it did on me once before. I was still in hospital. I was terribly embarrassed about the whole thing. It was my own fault. I didn't go right away. I was talking. It burst right outside. I was afraid yesterday that was going to happen and a person would be in such a mess.
>
> Bev: So you live in a kind of fear.
>
> Marge: Yes, and also going to the public washroom at the airport. For us to use the public washrooms. It's not easy. You've got so many bottles and people looking at you filling this bottle and wondering what you're doing. To not get anything on your uniform is also tricky, a straight skirt and fairly tight and I was worried I would get something on it. It's really better to take the skirt off, I think, but you know what they're like, little cubicles. And, then of course everyone is sitting and you're kneeling on the floor — and you're kneeling down — oh gosh! Also the floors are cold and so hard of course and there's no chair to sit by so you can do your bag. There you are kneeling down on that stone cold floor. You get up with dirty knees and I thought, oh! And I had to go three times in one four hour shift and I thought, I'm working again tomorrow. Probably it'll be a lot easier. Sometimes it will be good and sometimes it's not so good but I really found yesterday a strain. . . . But there's no choice really. It's a lot harder, I've realized, than staying at home. I realize that now but I feel that, if I quit my job now, I'll probably never go back.

The fear and determination persist side by side as Marge continues in her job. One year later she reports:

> My bags are an ongoing nightmare. At meetings I sit in absolute terror because I have no control over the noise of the colostomy. I wish someone would rant and rave or switch on a radio. That is a worry. I sit there paralyzed! Or, there is a lineup at the ticket counter and the bag fills. It's poking through my uniform — just a big bulge. I know I've got to go and empty it. I started to get so nervous. Finally, I say: "one moment please" and carry something over the bag. I dash out and empty it in a hurry. I'm a stinking mess. Sometimes I say: 'why are you doing this? Just quit.'. . . I guess I must get enough out of it and enjoy it. I wouldn't enjoy being at home. So far there

has been nothing so terrible I couldn't cope.

In order to relax at night, Marge continues to "hook into a night drainage system. I wouldn't work if I had to wake up every few hours to check the urine." As Marge speaks of the ostomies you clearly sense that more than the diseased tissue has been taken away from her.

> Another thing that is very disruptive about these ostomies is it is not that enjoyable to be in bed any more. I do not think people realize how comfortable it is to get into bed and just sink into sleep in any position you like until it is taken away from you. I always slept on my stomach or quite often turned onto my stomach in the night. I cannot do that any more. I cannot sleep on my stomach because of the drainage tube and if I try and flip over the whole thing flips apart or it gets all tangled up and backs up so I have trained myself to sleep on my back or just to turn onto the one side, and although it is not too terrible it is not the same.

Marge continues to speak of further losses:

> Often we used to stay in bed in the mornings and maybe in the mornings have some toast and coffee in bed just together. But I do not like to do that any more. I am attached to this machine and when I get up [pause]. Anyway I have to get up and the bowel bag has very often worked at night so I have to go right away and empty and deal with that and empty my urine bag, the overnight bag and this sort of thing. We have also lost that particular closeness that we used to have in the mornings. I found that quite a loss as well. Although it seems a very small part it still seems important. You do not realize just how important these things are until they are suddenly gone.

There is a continued hope that somehow it may be possible to reverse the colostomy. "I still sort of have hopes occasionally that some sort of miracle might happen and that fistula will close and they would be able to rejoin my bowel. That is why I stopped him when he wanted to remove the rectum." Further Marge expresses acceptance and acknowledges her ability to cope with her ostomies. Unspoken is the implication that she does think about them at night during intimate sexual times. "Well, the bags are there. The problems are not insurmountable but they definitely inhibit every area of you life just about. But you can forget about them actually. I do not think that I think about them during the day very much."

As Marge speaks within *the group* about the ostomies, one woman comments that several friends have told her they would never know she had the bags. Marge replies:

> People say that all the time. It doesn't help me at all. So what. I know with clothes on I look okay. You can't wear clothes all your life and protect yourself. . . . You know I even went to a doctor the other day and he said to me he'd never examined someone with two stomas. You feel like such a terrible oddity. Something almost untouchable. My God, the poor doctor. I'm going to shock this poor guy.

Socially, Marge found she was regaining her confidence. At one point she recognized she "was able to make it through an evening until I decide I want to go home, rather than until my body decides I have to go home." The balance of control often feels precarious. "It's not so much that you're having problem, it's worrying you might."

The Sexual Self

Early in the recovery phase at home, Marge began thinking of herself as only partially a woman. She felt that in the long term if the vagina did not last that the caring thing to do was to separate from Daryl so that he would be "free to go to another relationship with a full woman." She began defining her marriage in terms of the sexual relationship. She saw her husband as a good man who always did the right thing and she wondered whether he was in the marriage now because he felt an obligation. She could not conceive that he would want to be in the marriage if they could not have a full sexual relationship the way they had had before. She does not want sympathy and obligation. She finds the idea, that her husband is attracted to her, unbelievable. In her independent style she sees precipitating a separation as the logical progression.

Two weeks later, three months after surgery the following statements were made in a discussion between Marge, Daryl and myself. They describe how both of them have lost confidence. The old repertoire of behaviors is at times not possible. Some new ways of relating to each other are demanded by the situation. Daryl clearly acknowledges the changes that have occurred and speaks with admiration of Marge and what he perceives her to have gone through.

> Marge: My vagina is non-functional. And it's still uncomfortable, it still swells up and there is a feeling of pressure in there and its discharging and I get pain down there as well, but the doctor thought that was a good sign, he said those are healing pains.
>
> Bev: A lot of tissue is trying to connect. So how are the two of you managing sexually, in terms of expressing that part of your relationship?
>
> Marge: Well, during the last few weeks we're starting to feel a little bit more like being closer.
>
> Daryl: One I guess subdues the need anyway because there is a larger need. You know the sexual action need is very much lower in importance than the need for Marge to

recover. We're getting used to having a quality of life. We try to support each other in that. The actual need for physical sex is very much subdued, but I don't have a problem with that. I don't think you have a problem with it because the alternatives are so uncomfortable, aren't they? So you know I'm not having any problems at all in that sense. . . . at the moment they are a lot less important than getting Marge back to normal quality of life because there has to be quality of life. Survival is not enough, is it?

Marge: No.

Bev: I'm going to be the middle person for a moment and put forward some hunches I have about that. I'm sure, Marge, you're really questioning what is my attractiveness, my femininity and how has that been affected by the surgery.

Marge: Well, it's been affected tremendously. . . . I don't feel attractive at all. I feel mutilated, deformed. I feel like a bit of a freak.

Bev: So therefore you would find it hard to understand why Daryl would find you attractive and want to be close with you.

Marge: Oh, yes, definitely. I mean now at the hospital when I go, if someone walks in while I'm unndressing I get very upset. When I used to have a normal figure it wouldn't worry me but now I don't like anybody to see me, two huge things attached to me and lumps on top of my legs. So I don't feel in the least bit attractive or feminine except for sometimes.

Bev: So what's it like when Daryl does cuddle you and want to be near with you?

Marge: Well, that's a pleasant feeling but. . .

Bev: Does Daryl know that?

Daryl: Oh yes.

Marge: Yes, I've let him know that it does feel nice but I think I've lost some [pause]. I don't think it will come back.

Bev: You don't think that will ever come back.

Marge: Not the way I used to feel, feminine and sexy.

Bev: I'm hearing some of what you lost is that belief system. The important part of our sexuality is how we think about it.

Marge: I think after all I've been through you become bi-sexual shall we say. Not feminine and I haven't transgressed to masculine but you know it's maybe it's no man's land.

Bev: If I held a mirror up in front of you now I see you presenting yourself as very feminine, I see those things and those beliefs about yourself are still very much there.

Marge: It does make me feel better to keep up appearances. I must say, if I don't put any effort into my appearance at all then it makes me more depressed. I find it's really good for me to put an effort into my appearance. I feel better and happier. I discovered that but you know for the sexy side [pause]. . . At this point if the vagina is healed and it's no longer discharging or giving any pain it still seems hard for me to conceptualize how I would feel very sexual or how Daryl would find me attractive with two bags on my tummy.

Daryl: We don't dwell on it too much, it's still early and Marge is still Marge to me, not the fact that she has two bags or that she's lost something in her thighs is really not that important but I can understand why Marge feels it is so very important. Really, Marge's feelings are most important at the moment and slowly we're building up self-confidence again in that you'll go out and meet your friends, and go out and meet the public which two months ago you didn't want to do.

Marge: Right, I supppose I didn't.

Daryl: But it is a very gradual process and if one tries to rush it too much it can do more harm than good.

Bev: You're saying Marge is the same Marge to me and physically there have been changes but that doesn't change the meaning of who Marge is to me.

Daryl: No, there's very major changes and you know how you feel about accepting it.

Marge: I don't think I'm the same person at all.

Daryl: I don't think either of us can be the same person after all you're been through. . . . What I try to do is give Marge reassurance all the time. No matter what anybody says Marge is the one who came through this. I was close to it but I didn't actually go through it. . . . Marge needs the reassurance that says, "Hey, there is a quality of life that we're shooting for and some enjoyment will come back into life." Maybe not exactly the same sort of enjoyment as before but something can be worked out. But of course so close to it, it is very difficult to accept that and necessarily believe in it because where is the evidence. All you have got is the immediate memory of the suffering and the inconvenience and the feeling that, gee what a life when every day you have to change two bags and go off to the hospital for an appointment, and. . . [Marge cuts in]

Marge: I feel different to everyone else. Like a couple of friends of ours had some pornographic movies and wanted to know if we wanted to come over and watch them. I said, "Oh, my God, the last thing I can bear to watch is pornographic movie." I was never that interested before let alone ehow. I just couldn't bear to watch.

Daryl: We went to see the movie *The Best Little Whorehouse in Texas* and we had some real concerns before we went that it was going to titillate, upset the balance we had established for ourselves. Was it going to lead to a degree of frustration? We went and it was highly enjoyable.

Bev: And part of it is, it's done, you went to the movie and you had the experience and it was fun. It's each one of those events that builds a little more confidence.

Daryl: And I guess my concern is that we take it one step at a time and not get into a situation where we take five steps or all at once which gives a real problem, which really breaks down a lot of the progress that's been made.

Nine months after surgery, Marge has a chronic vaginal discharge and pain in the vagina and pubic bone. A decision is made to remove the remaining vaginal graft and debride the area. Within a few weeks Marge reports that she feels like a "reborn woman," free of pain. She declined any further grafting and felt pleased that there was still a space above the vaginal opening. She continued to douche and clean this area. Marge describes the deformity to her upper thighs due to using the muscle for the vaginal graft as the most upsetting aspect. "I'm so thin it looks awful and the flesh at the top is constantly rubbing and the vagina didn't work out anyway." Further she stated: "I didn't feel nearly so angry though when Laura described the pain she had when they attempted intercourse. Sometimes you think you're the only one." Marge believes the following information would be useful for other women who are preparing themselves for the aftermath of reconstructive vaginal surgery.

> I still have discharge. I would love to know when it is going to stop. . . . If I was talking to anyone who was having the operation I would say 'be prepared to wear a pad for at least nine months because you probably will. Nine months, one year, two years, who knows. Be prepared for six months of real ache and pains so that you cannot bear the thought of anyone going near your vagina, not even touching it.' This was it with going for these examinations. I mean, I thought I was never going to stop hurting and aching there.

One year after exenterative surgery Marge reports that she and Daryl "experimented with vaginal penetration."

> Marge: A few nights ago we did try and it did feel extremely good. Daryl felt that it really felt good as well. He was able to go in probably not more than an inch or maybe a couple of inches and then it got painful for me. . . . But it seems as if perhaps if we keep trying that something is going to be possible. Certainly it is not what it used to be but it was something. There is some sort of a cavity in there. Whether it would eventually actually be deep enough I do not know. . . . I really have relaxed quite a lot because the whole area now has stopped hurting. . . . We felt good about it. Although it was only a little something it was quite a big step to even get that far. I never would have thought that I would have come this far to even try ever again. And the amazing part was that it felt quite good and sort of familiar in a way. I know it has been well over a year, probably 18 months. Yes, it has been 18 months since the radiation and I think it boosted Daryl's morale as well. . . . So it was a fairly big step and I felt that there is a little bit of hope there and that things might become a little better. But I think Dr. T. feels that the area should be opened up surgically. It is just with this feeling of being so let down about my legs, when he talks about doing anything to me my reaction is you know, keep your hands off me. Goodness knows what you will do or what you will talk me into having done [fearing turning control back to the surgeon].

Further Marge tells me:

> Marge: I still have not managed to actually reach a climax yet over the period of a year now. It has been exactly a year now, the end of June that I had the operation.
>
> Bev: When you say I have not felt orgasmic since the surgery, I can believe that because there is part of you that is just sort of experimenting with how far it feels comfortable. We know when our head is just sort of observing every movement it is really hard to just lose ourself into a physiological response.
>
> Marge: This has happened, losing myself in sex. Most of the time I was very relaxed and most of the time I reached a climax.

Marge describes a dichotomy between her desire for sexual closeness and her current feelings of unattractiveness. Prior to surgery Marge readily experienced a sense of attractiveness. She was an equal player in the sexual messages sent between a man and woman. Now:

> You find yourself repulsive and I find myself absolutely repulsive most of the time. . . . People only find me attractive because they do not know me. They do not know that I have two bags. . . . You know, Daryl still seems to find me attractive.
>
> Bev: Do you believe that? Do you find that hard to believe?
>
> Marge: I find that almost impossible to believe really. . . . I really do not believe it actually. I do not say that to Daryl but I really do not believe it. You know, I do believe that he still does have some love and deep feelings for me, otherwise he would not have done everything he has done and shared this with me. He is so worried about me and has been supportive in everything.
>
> Bev: So you believe the loving but it is hard to believe the physical attraction to you.
>
> Marge: Very much and in a way sometimes I think that if he were to meet someone else and want to be with someone else and fall in love with someone else it would be a tremendous relief for me because I feel I have this responsibility on my shoulders of him not being able to lead as good a life as he could have with someone else. I have mentioned this to you before.
>
> Bev: Does that mean a good sex life? Is that what the good life means?
>
> Marge: ~~Yes, a~~ good sex life. And also someone who feels good about themselves. Yes, we have had all those things. And we have had sort of, there was a time when we could have a real, should I say, real sexy evening with just the two of us. Put on something slinky and just have fun together and that sort of thing. Well, that is gone. You cannot be sexy and slinky with two colostomies. It is just not there. It is probably just a question of attitude I guess, although these things are physically there. You know. They make sounds and stuff running into both. Certainly always running into one. The other one is not always working. So you are not just imagining it. . . . I think that it is only in regards to sex that the biggest problem comes. . . . I think it has totally destroyed my own sexuality. I do not think that there is any way of ever getting that back. I do not think, like say if Daryl did find someone else, I do not think that I would ever get involved with another man. I think that phase has gone, that era [era

> of men finding me desirable — even fantasies are taken]. A lot of women do not in fact have lives that evolve around men so I do not think it would be a tremendous loss for me. I do not know if it will ever go that far but I think it might in years to come.

There are days when Marge describes herself as, "I'm in it and I take it out on the kids and Daryl." Daryl confides: "I think I can sometimes help her by being a target for her anger. I feel helpless as I can't do anything physically."

Men continue to acknowledge Marge's attractiveness but for Marge, even flirting doesn't seem legitimate any more.

> Flirting, it would have been a boost to my morale before. But now I think don't talk to me like that. I guess because I feel I am not even a woman any more. It depresses me. I always want to rush off when anyone says anything like that. Like don't talk to me because I am not a whole person. It's as if I'm masquerading as a real woman, but I am not. I ~~do not~~ know if any other women feel like that or just me.

A few months later as Marge speaks with the others in *the group* she states:

> Well, we're different now. There is this nucleus, the world and then there is deformed people, freaks, us around the outside and you can't get back in. There is no way back in. . . . We dress up. We go out. That's all camouflage. We're all very attractive women camouflaged.

Later Marge reflects on her progress. She focuses on how she experiences her life now without setting expectations for the future.

> I guess you might say, you have come a long way, baby. I have certainly come a long way in the last six or eight months anyway just building slowly up on little things. You know, one day at a time. Things have been getting a little bit better and a little bit better but I feel now maybe it has reached a plateau. This is as good as it is going to get.

Finite Awareness

As Marge and Daryl made their initial adjustments to the exenterative surgery, their descriptions of this process frequently referred to a normal reasonable life. For example,

> Marge: You're left wondering am I ever going to be able to enjoy life again, sort of thing, with a normal ~~sort of~~ life within bounds.

> Daryl: There has only been a month of reasonable life with the changes, because the operation was in June. July was spent in hospital or at home in a very weakened condition, essentially an invalid and then you started to get up and around. . . . You can't fly around to the normal sequence of events like you could before. Marge can't rush now. She's got to take time out to do things. Life has to go at a more relaxed pace with more room for unexpected changes.

They have hope in an increasing quality of life as healing occurs on various levels, physically, psychically, and socially. The recurrence of difficulties is often discouraging as they hope for an improved future. Marge states: "Nothing is so bad except when it keeps on happening and happening and happening. You can go and have something done and say 'right, well, that's it, I'm finished with it,' but then again and again there's problems." A few months after surgery Daryl describes a diminished vibrancy in how they experience life. "I think the situation now is that the highs are nowhere near as high and the lows are just as low. So the average is sort of shifted down." There is this struggle between the normalcy of life I/she/we had before the surgery now and the concern can life/I/she/we be or become normal with the changes brought about by exenterative surgery. At one level Marge expects she will never feel "normal" again. At the same time both she and Daryl strive for what they describe as a "reasonable quality of life — survival is not enough."

Early in Marge's recovery she made contact with another of the exenterative patients. This was an important contact as she struggled with her own issues — someone who literally understood what she was experiencing.

> I don't know whether it's comradeship or suffering together, that kind of thing. You know we were both going through similar things. But it did help me. I just feel uplifted by talking to her.

As soon as Marge was able she returned to part-time work. For her this was immensely important in re-establishing a reasonable lifestyle. She states: "I'd be lost without it and I just feel if I do quit it, I probably won't pick up the thread again, I'd just sort of stay home." Daryl recognizes the importance of Marge's return to the work force. As he sees her fatigue his own fears of her reverting to an unhealthy state come to the forefront. Marge reflects on this:

> I am feeling fine and he says, "oh yes, you were a skeleton I had to carry around everywhere." He remembers me as a skeleton. I think perhaps that image is in his mind and when he sees me working a lot and doing a lot he worries about me. . . I also think though he's glad I'm not dependent on him now.

One year after surgery Marge reflects on the year. The underlying theme is I would not knowingly put myself through this.

To sum it up I would say it has been like living in a dark valley that I have not been

> able to get out of. That [illegible] basically it but even now I feel as if I am still in it to some extent, not down to the bottom where it has seemed at times as though there was nothing for me any more. My head is up, I can see some light and I am starting to get a little bit more out of life. But over the last six months — year, however long it has been, I have felt as though life does not hold anything for me — as though there is nothing for me. There is no enjoyment for me. There is the mechanical getting up and doing things and going to bed but no fun. No real enjoyment. . . . You would not think that two colostomies, basically, should be that devastating but really it has been. It is as though, what is the point of just carrying on like this. These last two or three months I have begun to feel that I can enjoy life. I can look forward to doing things again. But I think if I had it all to do over again I do not think I would do it. I would not go for the surgery. . . . Perhaps just allow myself to die. But it is easy to say looking back, not when you are at that crisis point. I feel certain now that if the cancer comes back anywhere else [pause] Dr. T. examined me and he feels I have very lumpy breasts and I am supposed to keep an eye on these lumps just to be sure that they do not develop into anything. I feel that if there was anything like that I would not try and go through any more. I would not say, so okay, take my breasts now and start all over again. And I think that if I was back at the point where I was before I would not go through it all.

Further Marge states:

> So just in general I feel I cannot get as much out of life. I cannot feel as good about myself. . . . It seems to have worn off now that I am so different from other people, that I am not as good as other people and that I am not a whole person any more. And that feeling has sort of gone a bit just lately.

As Marge reflects on the surgery and the changes it has made in her life she adamantly states the need for more consultation in her making an informed decision. Having gone through this major crisis she is very aware of her need to be central in making decisions about her own life. She is the survivor, she knows the aftermath. One is no longer naive of the consequences — there is no longer innocent trust.

> They did feel in the first place that the statistics were fairly high of the radiation being successful but when you go through all that has happened to me you feel very betrayed by the medical profession and I feel really badly betrayed. . . . There are things that you lose and although each individual one might not seem all that important you put all these things together and you realize it is a fairly big chunk of your life that is gone through an operation you did not realize. Now, if it is explained to you that this is going to be the effects of this operation and you decide to go ahead and have it anyway — when you feel you cannot go to the beach or swimming or skiing, or whatever sports you do — well you decided, you know, it was your decision. I do not feel that I was given the choice or the opportunity of making that decision. I feel positive that I would have said, hey, wait a minute now. These things are very important to me and being able to play a bit of squash and tennis with my husband and go swimming, and do some of aerobics with the girls, these things are really important to me. . . . They really need to say, "you are faced with this terrible decision and we will talk it through with you". You can tell them what you are involved with and what is important to you to help you make a decision about these big operations that you have to go through. . . . They should have more facilities there

> and they should give more help and guidance. Instead of just being there to cut you up and send you off on your way. That is the way it seems to me. But, maybe it would not have helped. Maybe it would not have made much difference anyway. But anyways I really feel betrayed. I feel you walk in there and you are so innocent. You just do not know. What has come true is that I am still alive. You know this is what they hoped for. But!

One of the positives that Marge has experienced emerging from her medical crises is a growing depth of relationship with her husband.

> This whole experience has brought us very very close together and made us appreciate each other more. Certainly I have learned to appreciate him much more. It did bring a closeness of the two of us together, like we are in this together. This is the way Daryl always felt about it and I felt a lot of the times. Sometimes we have felt like it's the rest of the world against us when there was one disappointment after another.

Marge has always enjoyed her career. It now also provides an important external focus. "Sometimes I think I'd commit suicide if I didn't work." Further she states:

> I really enjoy it. When I am at home I have too much time to think and I start to feel sorry for myself. I work by choice. Financial necessity at times but also by choice. I find it much more satisfying to go out and do a job and be paid. I do not have time to concentrate on feeling sorry for myself so it's better for me. I mean, how do others stop themselves from feeling sorry for themselves who have been through what I've been through."

Marge has thought about the possibility of her own death due to the cancer.

> "Don't talk to me about dying." I felt that the first time when they said if you don't have this exenteration you're going to die in about six months. I think though I confronted death when Dianne [former exenterative patient] died and about that time my pain was getting more persistent and then with Laura having a recurrence. . . . You know though there is no good time to die.

How has this confrontation with her own death affected Marge? "I do things more because I'm well enough to do them now. . . . I travel because I'm going when I'm well enough. I may not be here a year after." Further "None of us are giving up and dying. We're just saying this is the attitude we're approaching it with — do what you can while you're well enough to do it."

Marge experiences some impatience with others as she encounters "the petty things people spend time on. . . . Probably the traumatic experience we've [exenterative patient group] been through leaves us with the feeling — "hell, it's not worth it."

With regard to her two children, Marge states:

> What I'm trying to do now with my children is make them more independent — make their own decisions. Like, I may not be here so you'll have to learn to do that. Learn not to turn to anyone — to turn to yourselves, not run to me. Act as if I'm not there.

D. Pam

Pam is a married woman, forty-three years old at the time of exenterative surgery. She and her husband have two grown children and two grandchildren. Pam has spent most of her married life working within the home and volunteering in the community.

Pam describes her marriage as stable. Her husband has had a variety of jobs in the areas of building construction and insurance sales and frequently was self-employed. He's been a good provider for the family and has had difficulty accepting those times he has been unemployed temporarily. For the past two years he has worked for a courier service. One area of concern for Pam is her husband's "drinking problem."

Prior to surgery Pam described herself as optimistic, energetic and liking to do things for others. Her presurgery leisure activities included bicycling, swimming, camping, bowling, and volunteer work.

My first meeting with Pam occurred a few days prior to surgery. She was already in hospital and awaiting surgery. My first impression of Pam was of a pleasant, open woman. Her face showed the signs of many years of living with illness. As soon as she began to speak though, the lines melted away and she spoke in a trusting and disclosing manner. As we spoke she indicated that she had had many medical crisis points in the past and approached this one with an attitude of trust and hopefulness. She had trust in both the medical advice she had received and in their skill and competency to do the surgery. I had a sense that she was telling me and herself, "I've survived, sometimes against the odds, in the past. They have always taken good medical care of me and I am again hopeful that there will be a good outcome." For Pam there seemed to have been little questioning about whether or not to have the surgery. Pam's main concern was how her husband, Doug, was feeling about the surgery and how he would respond to her body changes. She was anxious that I speak with him but also was concerned that he would not say much. I had the sense that she was hopeful that "someone else" could facilitate their talking about difficult issues. I met with them together the following day, reviewing their understanding of the surgery and inviting them to speak about their concerns and where possible answer their questions. Pam felt very encouraged, saying "I can't believe it. I don't think I've heard him open up like that before." For Doug there was more reservation about the surgery and its outcome. He was supportive of Pam and verbalized that he had seen the decision as her's to make.

The Hospital Experience

Pam's first recollection is awakening in the Intensive Care Unit after surgery. She knew that there was a possibility that she would not be able to have the surgery if the recurrent tumour had begun to spread either to the lymphatic system or to the pelvic side wall. Without the surgery she knew her chances of survival were slim. She had been dealing with the idea of her own death. "When I did wake up and tried to see the time or ask the time and found that I had been in the operating room that long, that was a load off my mind." The length of time let her know the surgeons had been able to continue past the biopsy stage. A burden had been lifted. In the Intensive Care Unit there was a feeling of respect and safety. "Nothing came as a surprise. In ICU, everything that they told me, where they filled you in, it was right!"

As Pam was recovering, the fears kept formulating. The pain medications seemed to intensify the struggle. Later she stated:

> I think that you should just try and put everything else out of your mind and think about yourself. Go into the operation with a clear mind. A lot of silly dreams came into mind once I got on that morphine. I was dreaming about things that were sort of linked with things, and it just made it worse, blown up. I made it bigger and bigger. The medication sort of exaggerated everything.

For Pam there is a need to speak of her experience; to make sense of it; to pass on her learnings to others who may follow on a similar journey. Through the recovery period she experienced much confusion and a loss of time sequencing.

> I appreciated the nurse that suggested I start writing out a diary; even if you have a good friend that would come up and write down a few lines for you each day, so that I can sort of go back and see what really happened. Maybe I can help somebody else too and I can maybe just run over something like that.

There are many setbacks in the recovery process.

> Somewhere you think you are just really getting going and then some little thing would come along. Like the other day, for instance, when the tube in my uterus [some misunderstanding of surgical outcome] had slipped out of place and that was a little painful. I was sort of looking forward to getting out of bed the next day and getting up and it put it off. I waited and probably enjoyed it just as much. You've got to put off a few things to enjoy a few things too.

The surgery is presented as a very major procedure with extensive recovery. Along with this image was the fear of having a great deal of pain.

> I find it wasn't nearly as bad as I thought it was going to be. I expected it to be a lot more painful than what it was. I was so well looked after, not given a chance to get into any real pain. It means a lot.

While in hospital, rest is important. Not only is there exhaustion from the actual physical assault to the body but also the necessary constant care is exhausting. The support and care of family and friends is impotant but can be overwhelming. There is little energy left to take charge of this situation. Both family and staff are needed to take over a protective function. This statement was made sixteen days after surgery:

> First thing, I would definitely stress it to your family not to have visitors. Cut it down to your immediate family. Of course, that does not help either if you have a big family. I think that a family should arrange that before the operation has even begun. Your hours of rest are most important. That is the way that I feel and I have found that out myself by overdoing it and I didn't even overdo it that much either. You definitely need your rest because they have given you so much attention and care that you do not rest that much when you are in hospital the first two weeks. It's tapering off a bit now. Before it was, every time you turned around someone else was coming through the door. "Oh no, not again. When is it ever going to stop?" . . . I appreciated it when I was sleeping and they didn't allow anyone in the room.

Pam has been dealing with cancer for many years and is again facing a crisis point. She alludes to the awareness that her death lies ahead. This is presented almost as one more reprieve as though someone has decided it is not yet her *death turn*.

> Pam: There are lots of days when I have had tears in my eyes lying here, thinking about different things.

> Bev: If those tears could speak, what would they say?

> Pam: Thank God I am alive.
>
> Bev: The tears are related to that knowledge that you might have died,
>
> Pam: Yes. I thought about that a lot, because I told you I am pretty lucky. I figured it is going to be my turn some time, but thank God that I am still alive and so I have a chance to be with my family and know that they are still here.

Perhaps the art of being a patient is simply that, "The only thing I can do in hospital is relax and be very patient with things."

After hospitalization Pam's husband, Doug, asked her a very probing question. "What do you think I felt like while you were in the hospital?" During a subsequent hospitalization of Pam's, when he was having difficulty with her confusion related to an electrolyte imbalance, the following conversation occurred between myself and Pam's husband.

> Doug: I know I should be more considerate than I am but as I said, I am a terrible one to go visit somebody in hospital. I care and I'm doing my best. She thinks I'm making fun of her but I'm just trying to keep her on track. I guess that's what she told the doctor and why he reamed me out.
>
> Bev: And, I would like to keep in touch because I think this is a really stressful time for you, like you sit on the outside with Pam going through a lot, suffering, being confused. You want to help but you do not know how to do that and people have expectations of you. Then you say "hey, hold it, I'm not sure that's me."
>
> Doug: Ya. Well, this is it. She is not going to have another one as far as I am concerned.

Transition Home

As Pam anticipated the transition from hospital back to her home she focused on her colostomy and vaginal reconstruction. For her going home was going back to the marriage, to her husband. Moving from patient to wife. There was a hope that she could rid herself of or hide the colostomy. The major question is how acceptable will I be to my husband?

> I guess some of the circumstances that are involved with this operation, like the colostomy, I am gradually accepting, but it is hard. But now I have gotten to the point where I think in three months it will be off and I will feel a lot better and if it is not by then, I can accept and get along with it. . . . I am thinking of how I am going to cope with it or hide it or something right now, which is probably very easy to do, but at the moment it seems like it is about the size of a football and it is going to be hard to get rid of it.

There is a need to appear attractive in spite of the colostomy. One has the sense that there is a game to be played. As in a quarterback sneak, there is the illusion the ball has been passed off and the hope is the game will continue without the opposition knowing where the ball is until you have either scored or made some appreciable forward motion.

There is the fear that if she is not as attractive as before her husband may look elsewhere. The question appears to be how changed, how altered am I?

> I mean, I certainly am not any beautiful woman, but you still like to keep your appearances up. It is all in what you learn and how you do it. It means a lot to a woman, especially when you have been married for 28 years and you want your husband to still look at you and not somebody else. It means a lot. . . . This is something that I am going to have to find out when I get home and when we are alone and see how he is feeling towards something like this.

There is an awareness of the need to also support her husband in this adjustment. His response is not predictable but there is a belief that the vagina will be of more interest. Pam does not refer to her vagina specifically, instead referring to the plastic surgery. Is my vagina plastic or real?

> He hasn't really asked to see it and I thought well I am not going to push it on him because he is a very curious person and I think that when he is ready, he will ask. I still don't know him, I cannot actually say I know him after 28 years, I get to know him day by day. . . . I know he is going to be curious, not only about this, but about the plastic surgery that has been done. And that, I think will probably come before the colostomy. That is the way I feel about it, that he will want to see that before.

After a period of time at home, some of the fears have been realized. There is some feeling of isolation regarding the ostomies. There is a longing to share thoughts, feelings and concerns openly with her husband, to have some open acknowledgement of her changed appearance and altered function; a coming together and seeing each other.

> Well, I don't think it's been as bad as I thought it would be. I've been able to accept it pretty good. It's been hard, I know that, really hard. With Doug it's been the hardest. If he could accept it — which he still hasn't done, I don't think. He still doesn't realize what I've gone through. I think he does in his own way. That's been the hardest part of all trying to get together with him and talk about it more. He just seems to want to seem to bury his head and not want to do that yet. Otherwise it doesn't bother me as far as having the colostomy and ileoconduit. I've always been a person who could accept a lot of things like that.

One year after surgery Pam continues to feel "a lot of pressure around my rectum." This is relieved somewhat by standing and moving about and by focusing on other activities. "I'm a bundle of energy. I've got to be going constantly."

The Self in the Medical Relationship

Pam has had a ten year experience with her cancer. This has meant radiotherapy, surgery, and chemotherapy all prior to the last recurrance that led to the exenterative surgery. "I read my last report from the Saskatoon clinic. It said 'Nothing more we can do for this 37 year old woman, maybe you can.' That's how they were. I was written off."

This was seven years prior to the exenteration. She had gone from no hope, to new options, to having survived against the odds. "Dr. B. calls me his miracle." She speaks of her trust and confidence in the medical care she has received since her move and this pervades the stance she takes to each new crisis. "I've got so much good care here, personal attention, not a different doctor every time. When I was having more and more pressure I was seen within one day and not put off." When there was a decision to offer exenterative sugery "Dr. T. picked up so fast and explained my whole 10 year file to the residents. That encouraged me a lot and kept me going." Her sense of being seen and treated as an individual is important and she develops a positive relationship with her physicians.

There is an appreciation for even the opportunity to wait. The waiting seems to be an affirmation of being, of being alive.

> You have to accept the fact that you are here, so you have to be patient. Now I have learned to be very patient. Going to the cancer clinic I think taught me that. They were good and I didn't mind waiting. I knew that it was going to accomplish something in the end and it did not bother me to wait over there. I would go over there now and I will wait. It makes me mad to hear patients complain because I think, oh my gosh, you are complaining about waiting when you might be dead today if you weren't waiting, so if that is your attitude why bother even being here because there are lots of other people that would be willing to be in your place. Stop and think of the people who do not live in Alberta or Canada, getting the care here that they do not in other places.

There has been a changing development in the way in which Pam involves herself in her medical care. She is learning to advocate for herself. She acknowledges not only her symptoms but also the gravity of her illness. She has taken a new position on the health care team.

> I know now to say something about it. I was a person who didn't. I'd just go along and suffer with it. Now I know better, if something is bothering me I get it out right away and tell him. If I hadn't said anything about this, I'd still be sitting here with it, or [nervous laugh] maybe be in my grave [gallows laughter]. It just seemed as if I never had enough time at the clinic to talk to the doctors so I booked an appointment

at his office downtown and that's when he found the tumour.

For Pam there is always the awareness of others who are also ill, who need the doctor's attention. The struggle is ever present between having her own needs met and not infringing on others needs.

> I know they'll take the time but I always feel like they're so busy. You just hate to take all their time up to discuss things. Yet I know every doctor I talk to will listen. They've been really good so I think if anything else pops up it's not going to go too far.

Experiencing an openness to talk with members of the health care team has been an important factor for Pam in coping with prolonged medical concerns. "You, the doctors, the nurses, having someone to talk to has been my biggest help. A person has to talk to someone, then you feel better."

About 14 months after exenterative surgery there is an awareness by Pam and the other women who have had this surgery that *their* surgeon may be leaving and establishing a practice in the southern United States. As the group discussion proceeds and each expresses her concern regarding the *leaving*, Pam states:

> There is always somebody there to replace him. Sure you've got to think positive sure he's leaving. There's going to be someone else who'll pick up from him. It's hard to change — he knows the case — but I've had so many doctors. Maybe that's why I can look at it that way. They've all been good doctors. Some should have explained better. I can blame myself for that too, though. I should have asked rather than take their word for everything.

Underlying Pam's trust that has developed with herself and the health care team, is the question — how did this happen? "That's why I really stress to my daughter 'Don't wait a year for a Pap test. Go every six months!'. I had it every year and somehow it got missed."

Living with Ostomies

Prior to leaving the hospital Pam had concerns, not about managing her ostomies, but the impact they would have on her husband and their relationship. On her return home Pam's husband suggested she sleep in another bedroom until she had fully recuperated. He was "fearful he might bump me or hurt something." At night Pam "hooks into a night drainage system" so that she does not have to worry about awakening to empty the urine. Three years post surgery this routine continues and Pam expresses both an awareness of a need for a redecision and some avoidance of making a change, "I know I'll have to make the first move back into the same bedroom but he has a waterbed now and I don't like to sleep on one."

Eight months after surgery: "Oh, he's seen them, yes, but not really, just to look at them, that's it. Just look and look away, but never really asking me questions about them."

One month later Pam entered hospital to have surgery to possibly reverse the colostomy. This did not prove to be successful and due to complications Pam was hospitalized again for approximately three months. Pam's husband stated: "everything has gone sour since and I do not think they accomplished a damn thing. . . . She's not going to have another operation as far as I'm concerned." Pam understood how difficult it was for her husband to see her in hospital, in pain and then slowly recuperating. At the same time she believed that without the colostomy he would find it easier to be physically close with her and less concerned with hurting her or "bumping it." I said to my husband, "I know you didn't like me going in but I was doing it for you. I wanted to improve myself to see if I could get rid of that colostomy." There is a belief that she is not as acceptable as she would like to be. A question that might be asked is "who keeps whom at a distance?"

One year after exenterative surgery Pam has no difficulty with ostomy care. She speaks openly of her surgery with close friends. She regards her ostomies as *foreign* not yet assimilated into her body culture. Their function is sometimes unpredictable and she cannot will them under her control.

> I'm a little self conscious of the bags still. I feel like people notice but I've asked my daughter and different people and they say "Oh, we don't hardly notice it at all" — till I start tooting [laugh] you know you can't control that. It starts acting up when I'm out in company. It's embarrassing but they realize. Most of our friends know what I've been through, what I've got. . . . I think anybody is like that [little self-conscious] with something that's foreign to your body and that shows to some extent.

Pam's sense of humour and practicality are evident throughout her adjustment. "The fact is it's convenient sometimes. I call it my portable bathroom. I don't have to stand in line now." With Pam there is a sense of wanting to live with the ostomies without having to take them constantly into account.

> The other day the bag had split open a bit and I just caught it on time. I could just feel it coming out. But otherwise I have never had any real trouble with it at all. And I'm very careless cause I should carry an extra bag all the time, and I don't and I keep thinking jeepers what if something happened and I haven't got any supplies. I have to get a little bag just to carry. You never know, like the other day, but it hasn't happened before.

Pam has returned to most of her post surgery leisure activities: walking, bicycling, camping, and card playing, but "swimming, I don't want to go swimming any more."

Two and a half years after surgery the area of greatest concern is still the inability for her and her husband to speak openly about the colostomy. Pam then interprets this silence and incorporates this interpretation into her evolving self-image. "I've got a colostomy. He knows it's there but he just doesn't want to talk about it. Maybe eventually he'll come out of it. . . . He jokes about it the odd time but never really asks." She speaks with hope that there will be a change. His open acknowledgement is important in her adjustment to her altered body function.

The Sexual Self

Recognition of the presurgical relationship climate puts current concerns into perspective.

> We used to be able to talk until he got into this drinking. Gradually it got worse and worse over the years. I think how he feels cut off from sex. We've always disagreed about that. He always says sex comes first. I always say love comes first. We always argue about that.

At eight months post surgery Pam's second statement in a conversation was "Well, things are good at home, not sexually, but otherwise they are good." While feeling she had recuperated well and her quality of living was acceptable the area of sexuality was still very forefront for her. When I asked whether the changed sexual patterns had created much stress between her and her husband, she replied:

> When he gets drinking it's brought up but otherwise it's, you know, it's not every time. I'm a hard person to live with but we get along. We're not fighting all the time.

> When he's drinking I just ignore it. . . . His drinking has gotten a lot less now. We've got a lot of worries on our mind but it's not nearly as bad. . . . I think it's going to take a lot of time between the two of us, he's talking more and is close to me in the last little while. Even when he's been drinking, he has, you know, kissed me and that. I've helped him a lot and things like that but I hope that the abuse [verbal] is going to be an improvement for the better.

Periodically the sexual contact will culminate in her husband ejaculating outside her vagina. "It makes me feel a little bit better that he doesn't completely ignore me, but I know, I definitely know that these two bags do bother him."

For Pam there is both a longing for and a fear of vaginal intercourse. There is a fear of pain, a fear of failure, and the fear of rejection. There continued to be discharge from the vaginal graft. For the first year a dilator was used daily to maintain the viability of the vagina. Pam's husband would also be involved periodically in inserting the dilator. Some bleeding occurred with the use of the dilator.

> I think that kind of scares him too because I start to bleed. I think he figures that maybe he's going to do something wrong and maybe possibly that is me too. I, in a way I want to have sexual contact with him but deep in my mind I feel like something is going to happen. It sort of scares you, you know. I think a lot of it is my fault too, maybe if I made more advances towards him maybe. I'm probably waiting for him which really isn't fair because I should be. . . . [voice trails off]

At one year post-exenteration and after a recent unsuccessful attempt to close a vaginal-rectal ~~fistula and~~ reverse the colostomy, Pam ~~states~~ "I'm wondering what is going on for me. I have constant pressure and pain in my rectum, vagina and lower back. If I'm standing I'm okay. Worse now than before, there is constant pressure." There is the uncertainty, the nagging fear of recurrance. One side of the vaginal graft has sluffed off. "We've tried penetration and that's impossible. I just can't take that. . . .A couple of times it's been fine, we've had oral sex. I haven't even been using dilators. I didn't know if I was healed."

As time goes on the sexual expression continues. There continues to be adjustments to the ways in which Pam feels altered. "I don't undress in front on him. I get a nightgown on. Half the time I didn't wear one before." Patterns have changed. She speaks of feeling as though there is a non-existent zone in her body. "Doug avoids that part of me as though it wasn't there." This zone, her abdomen, is the part of her body that through necessity she must attend to regularly while at the same time her husband avoids it both in a verbal and tactile way.

There is the underlying fear that there may be another loss to yet encounter. This often emerges when Pam begins to focus on her altered body image and their changed sexual patterns. In a group meeting one woman stated: "When you have such a poor body image you have all those doubts about your husband. Even if you have no right. You feel so crummy about yourself — how could anyone find you attractive?" Pam's response was:

> I went through that first time with cancer. Everything happened, the children left home, we moved, I had my change of life, and I wondered who else will leave, maybe Doug. Even now I think Doug would sometimes like to walk out on me. I think the family holds him.

There is a continuing sense of a holding back on being held and a wanting to be wanted.

> Often I want to be cuddled or loved a little bit. I wonder why my husband isn't doing this. You want it. . . . I'm not the greatest person to be the first person to approach it. I should. I want to be approached by Doug — I feel neglected. We sleep in separate beds. . . . I should be the one to initiate, to say "I want to sleep with you tonight." Something in there stops me.

Finite Awareness

> Gee, there is one person that did not make it, am I going to be the next one but you have to keep living anyway. I am going to live from day to day, enjoy myself and not going to sit here and worry about it and miss today or tomorrow.

Pam was in hospital, two weeks post-exenterative surgery at the time of this statement. By this time she has dealt with having had cancer for over ten years. There are "a few breaks in between and then something else pops up. . . . I've had so many operations I just sort of accept them."

One year after surgery Pam has further developed this philosophy of living in the present. She has begun to assign more priority to self care. She enjoys and appreciates time with family. There is an attitude that each day is a gift.

> I'm day to day now. I'm better off. I don't think what's going to happen tomorrow. I don't plan anything. If I'm enjoying that day I enjoy it. . . . I'm pretty good at keeping my spirits up. I have odd days when I feel down. I just go out and take a walk

> to work it out — keep going. My daughter has been really good for helping me. Bringing my granddaughter over can build my spirits up.

As time progresses this then continues to be present; an acute awareness of today and an awareness that tomorrow is unpredictable. "I think I say I better do this in case I'm not here tomorrow." Further:

> I'm put here on earth to be here a certain time and when my time comes I'll be gone. In the meantime I keep asking for more things. I'm not a religious person but God's given me this time — almost eleven years I might not have had. It's faith and positive thinking. I keep saying I've got to live a little longer. I've got to see this done and this done. It's kept me going. I try to live day by day. Lots of time I push myself to do things. It is paying off — Doug is not the same person he was two years ago.

One of the other women in the group asked her if she thinks that is because of her changed attitude.

> Yes. I speak up to him more — tell him how I feel: I get it out of my system. I've started putting myself first, then I think of others. I have always put someone else ahead, trying to please people. I found I'm better off to please myself than to please others. That is paying off with husband and family. . . . I avoid arguments now. I walk away. They are a waste of time.

A rethinking and a remobilization of resources occurs each time there is a medical crisis for one of *the group*. For Pam there is a belief that she is in a winnable battle and her past experience supports her belief. "I just felt I was going to beat it. . . . I made it last time, I'll make it again." One member of *the group* has a recurrance and the awareness of death, death without a name, comes to the forefront. "I've thought about *IT* more this week. Like I've been doing little things I've put off for a long time. I could go to the clinic tomorrow and be told the same thing."

At three years Pam still has chronic pain. For her there is always the question "Is the pain related to a recurrance of the cancer?" Sometimes the pain could become the total focus if allowed to.

> I wanted them to do more tests on me, my pain. They said: "No, we've done enough for now." The pain continues though. I live day to day. I keep active and I read. Neither the hypnosis or acupuncture worked for pain control. . . . You know though I'd go through the same as Laura — simply to live.

As Pam speaks at different times and in different circumstances this theme recurs. "I'm just thankful to be alive, that they've been able to do something." And life goes on, "I'm working on my granddaughters to remember me."

V. A THEMATIC DISCUSSION

This research is an exploration of the lived-experience of four women, Mia, Laura, Marge and Pam, who have undergone pelvic exenterative surgery. The present chapter continues the interpretive process. Common themes that emerged from the conversations that occurred between and among the women and myself, will be presented. These themes are not discrete. There is an interplay between and among them and it is my contention that this overlap and interaction is consistent with the complexity of human experience. This chapter is a synthesis of the interactions between myself and these four women. As interpreter it is my task to look for and present the commonalities in meanings, situations and bodily experiences as depicted by the women of this study and to communicate them to you, the reader. To paraphrase Bergsma et al. (1982, p. xxii); in the final analysis, communication between you and me will result if the ideas expressed resonate with experience.

Before focusing on the common themes that emerged in this study it seems relevant to give some attention to the recurring patterns, of the individual women, which influenced their responses to the experience. I refer to this life pattern as personal posture. My understandings of the commonalities across the women's experience will comprise the balance of the chapter.

A. Personal Posture

The notion of thematic dimensions to one's life is not a new one (Adler, 1963; Berne, 1972). We may speak of this as "personal style," "her signature of life-events," or simply "isn't that just like her." Each of the women in this study had her own unique style which I will now illustrate.

Mia: "I should have gone home."

Home is Germany. Germany for Mia is a feeling of the familiar, of safety, of being loved and cared for, of being a growing child, the youngest child in the family and having a father she could depend on. These early recollections also include her mother dying, and political tensions that find Germany at war. There is simultaneously security and insecurity.

As Mia speaks of her experiences with exenterative surgery this theme recurs. Much of her energy has gone into providing secure environments for others. Her home, making a home, providing a home are an important focus for her. Professionally she has spent her adult life in a caregiving role. In her own medical crises there is an ongoing sense of the security-insecurity dichotomy. Mia's focus is often on her family and being sure they are cared for. "My family didn't know what to do. The nurses should teach the family." She finds security in the crises, in a trusting relationship with her primary physician. At those times when she feels mistrust in the medical experience she can count on him to be her liaison with others, to interpret the events and support her in her concerns. As her physical status improves with no sign of recurrent disease she often verbalizes the pervading sense of an insecure future. Often expressions of security are immediately followed by expressions of fear. "I've so much to be thankful for. . . . I'm optimistic. Although when I have pain that's a concern. The hard part . . . is not knowing what could come next." As Mia is thankful for survival and fearful of recurrance she finds herself "doing things the German way" and finds comfort in moving closer to her roots.

Laura: "I'll take my life anyway I can get it."

Laura's exenterative story is woven with a sense of active and proactive involvement. She does not passively encounter this experience. From researching the surgery and finding someone to do it, to the symbolism of wanting to wear her Polish Solidarity button into surgery, to "experimenting" with intercourse, to seeking out treatment alternatives when each "last chance" was no longer effective, Laura's style is to go after life. She lives with limitations but lives to the limits. As she simultaneously anticipates both her own and her father's death from cancer she reveals "if he'd lived his life like I'd lived mine, having fun and doing things in between I wouldn't feel so bad."

Marge: "It upset me having to lean and depend so much on someone else"

Early in life Marge learned to take care of herself. "I never knew what state I'd find Mom in when I came home from school." She has learned to count on herself. This belief is an important part of her current functioning. She allows herself to be dependent only while absolutely necessary, quickly moving to self-care and independent functioning. She returns to work within three months of exenterative surgery and rapidly resumes social contacts and begins to re-engage in inter-continental travel. The crisis for Marge is that the self she has always counted on is no longer present to her. She struggles with a new self. She experiences a lack of vigour and experiences a significant loss of physical and sexual attractiveness. She interprets this as no longer being a "whole woman". In her independent style she believes she should send her husband away so that he can lead a "full life". She believes she would then not feel the burden of no longer being able to offer him the life they had had together. "I sometimes think he stays because he is a good man."

Pam: "I'd just go along and suffer with it."

Tolerant might best describe Pam's recurrent style. As she tolerates many crisis points in her life she does so with an underlying trust that "things will be okay." She has learned to accept difficulties and disappointments. She has dealt with her recurrent cancer for more than fourteen years. Often she would like to speak out more and ask [not demand] that her needs be met. Historically in her marriage she has longed for more open communication with her husband but also has avoided conflict, appreciating other qualities in him. She has tolerated his drinking patterns. Since the exenterative surgery she is more acutely aware of her pattern of tolerating and not verbalizing her needs. She made efforts to actively change the pattern and saw some positive changes in her marital relationship. When her physical symptoms increase (nausea, disorientation, or chronic pain) and her energy goes into coping with them, her resolve to speak out and to advocate for herself is lost and the "suffering with it" predominates.

B. Decision: A Critical Moment in the Exenterative Experience

Each woman in her own way stated her decision to have exenterative surgery in the following manner: "I just had to do it. It was a survival choice." The decision is voiced as a life or death choice. Mia agreed to surgery based on her trust in her gynecologist's opinion. She recalls him stating: "that is the only way out and you can really trust him . . . he's very good." With a differing approach to the decision for exenterative surgery, Laura researched the treatment options for recurrent cervical cancer. She concluded that this surgery offered her only survival possibility. The decision was made: now to find someone to perform it. Marge had moved from having her cancer diagnosed to considering exenterative surgery in just six months. Each intervention had been unsuccessful in eradicating the tumor. Her decision was based on wanting "to get rid of the cancer" and she stated: "it's the best option and it sounds like one can live a relatively normal life afterwards." Her focus was on life after surgery and her fear of even surviving the surgical event went unexpressed as she and her husband spoke with the surgeon. Pam's decision was based on faith that the medical profession would have another alternative that would treat her recurrent disease. Her decision is perhaps best summarized in her statement: "I've survived, sometimes against the odds, in the past. They've always taken good medical care of me and I am again hopeful that there will be a good outcome."

The major decision is viewed by the women almost as a non-decision. They spent little time deliberating the pros and cons. The only alternative they attended to was one that offered them hope of a cure. Indeed they were making a significant decision. They entered into the decision-making process frightened and discouraged with their recurrent or persistant disease. All the women had some degree of ambivalence towards their past medical management. They again reinvested their trust in the medical caregivers who presented the exenterative option.

Later, several of the women interpreted the information they heard as "without the operation you will probably die. With the operation you may be cured. In the process you may have two ostomies and if you choose we would like to do a vaginal reconstruction. After three to six months you should be able to resume many of your previous activities."

It is not until sometime after surgery, six months to a year, when they were beginning to trust that they were surviving, when they were saying to themselves "I'm still here", that they began to reflect on their decision differently. Their focus turned from survival concerns to concerns about their quality of life. It was at this juncture that they began to say "I should have asked." "I should have been told." "I wish I'd known." "I'd like to have had the choice between certain aspects of the surgery." "I did not realize how important some things were." "I did not know how much I'd lose." They were now verbalizing a need for more information and were able to be specific about the nature of the information they believe they needed. In their own way, they each address the issue of informed consent and bring into focus the nature of an enlightened choice.

C. Being Patient

The word patient comes from the Latin root *pati - to suffer*. In the illness process often the women saw patient as what they were rather than how they must act. It was as if the noun form had taken on the full meaning of the word. At particular times in the exenterative experience being "a patient" subsumed all of the other roles in the women's lives. Particular behaviors and expectations are ascribed to this role. While being a patient it may be acceptable to be dependent, to be egocentric in focus, to have low energy, to sleep longer and more frequently, to contribute less in social interactions, to do less self or other care, or to have altered body functions. Pam recalls her hospital experience: "The only thing I can do is relax and be very patient with things." There is a context wherein these behaviors and ways of relating to self and others are viewed by the women as functional and congruent to their experience. The dependency is experienced as legitimate. The fatigue is overwhelming. There is an expectation that for a limited time period the body will look and feel "different".

Impatience sets in when the expectations and contexts change. For instance in leaving hospital the expectation was leaving being "a patient". Marge recalls: "I stood outside my house and sobbed. I couldn't get back in. . . . By the time I got home I was . . . tired. . . . I felt stronger in hospital. . . . At home I expected to feel better than I did." Laura reflects on the changed context and changed meaning for her. She says: "At home, I don't like to hook up to a night drainage system, I feel too much like an invalid."

For the women there is also impatience with others. Attempts to show caring and concern may be experienced as invalidating — as maintaining the "patient" role. Laura's comments poignantly illustrate this. "Some of the relatives keep me as an invalid. They go hysterical if I do anything. I can't live like that. One has to do what one can. I need to do those kinds of things. It makes your life feel normal. I have to know I can do things I've always done."

D. Communication: Speaking with Another

Throughout the exenterative experience each of the women stress the importance of good information exchange. It requires an open reciprocal attitude to listening, speaking, and hearing. Speaking with others was a significant theme. Communication did not always occur. I heard the women saying: "Sometimes I spoke but they didn't listen, sometimes I was afraid to speak, sometimes I wasn't ready to hear, sometimes they spoke and I listened or I spoke and they heard, sometimes we just talked together and sometimes we didn't have to speak." These phrases brought into focus those times when indeed there was communication and those times when attempts to communicate failed.

"I spoke but they didn't listen"

Each of the women early in the illness process voiced concerns about physical symptoms that alerted them to their state of dis-ease. For example, Mia's chronic fatigue alerted her to a need for a complete physical examination. She requested a Pap test only to be told it was not necessary and not to worry. Similarly, Laura's recurrent inquiries about her chronic vaginal discharge met with statements "it's not offensive" and "there is no problem". There was a disconfirmation of the information their own bodies gave them, an invitation to not listen to themselves. The *experts* were not validating their concerns. Later, after the diagnosis of cancer, these experiences made it difficult to initially trust professional information and judgement. They felt a sense of betrayal in the trust they placed in the professional. The dichotomy between self knowledge and professional knowledge had been formed. Only as the credibility of the health care professional was perceived by the women, were they willing to re-establish a trusting relationship that allowed a sharing of information. A similar scenario happened each time the information they gave about themselves was negated by a health care professional. Laura recalls: "I had to argue with nurses about pain medication. . . . She said the pain wasn't supposed to be there. Well, too bad lady, I mean it is there."

"I was afraid to speak"

To speak, to reveal what is on one's mind might invite a response that one is not prepared to hear. Marge states: "I was afraid to ask Dr. T. if anyone died in surgery." Soren, Laura's husband, tells me: "Sometimes she doesn't like to get things checked out because she doesn't want to know." The same process occurs in the women's private relationships. Pam speaks of wanting to move back into the same bed and bedroom with her husband. She acknowledges: "I should be the one to initiate, to say 'I want to sleep with you tonight.' Something stops me." Illness escalates a sense of vulnerability. The risks of speaking openly may be too great. In illness, they may find themselves entering into relationships in an impaired state and experiencing a need to protect a fragile balance.

"I wasn't ready to hear"

The information may be given but it may not be received. Some information may be blocked until one is able to process it. For example, Marge speaks about her distress with having two permanent ostomies. She states: "My recollection is that he said it would be temporary. He may have put some doubt in my mind that I did not hear at the time because [voice trails off]." The motivation for not hearing is not articulated but points to the need to repeat significant information and to check for understanding. For the women so much of the exenterative information they received was not only entirely novel but they were struggling with the knowledge of recurrent malignant disease and at the same time imagining the impact of the surgery that was being contemplated. Perhaps Marge's statement provides a summary when she says: "You walk in there so innocent."

"They spoke and I listened"

When information is heard and it accurately portrays the women's experience it provides safety and offers the women the opportunity to feel more in control of the events that are happening around and to them. Information is also important for interpreting body signals which so often cause fear and uncertainty. Accurate predictions strengthen her trust in her own body as it progresses along *normal* lines and it also increases the trust in the professionals who predicted the effects. Laura illustrates this when she says:

> I've never been very concerned coming from intensive care to the room, only because they told me that you know you're going to feel this way. You're going to be scared. You're going to be concerned whether or not we can take care of you here. . . . I don't think that was my concern because they had brought it up to me.

Pam's comment further illustrates this when she says: "Nothing came as a surprise. In ICU everything they told me, when they filled you in, it was right."

"I spoke and they heard"

To voice concerns and experience that they were heard was important to each of the women. They each could readily identify the relationships where this occurred. In their health care relationships this was a significant criterion for them in judging the quality of the care they received. Mia's statement illustrates this. Whenever she had a concern she returned to her referring gynecologist because "each time something special comes up. . . . I always have somebody where I can go and talk." There is a need to talk. Pam states it this way: "Having someone to talk to has been my biggest help. A person has to talk to someone, then you feel better." It is not only the opportunity to ventilate. It also includes experiencing that your words precipitate action — have impact in the exchange. In contrast to Laura's experience of telling the nurse about her pain, Laura relates an incident where she felt heard. "One night I started to hemorrhage and that scared the dickens out of me. The nurses knew that and they called Dr. T. toute suite. . . . They knew he was the only one [I'd trust]." In the illness situation there are numerous times the women felt completely helpless and needed to depend on others not only for their care but also for their survival. Bergsma et al. (1982) address the significance of the interplay between dependency and information exchange. They suggest that the distance between the degree of knowledge and the degree of dependency is the amount of power that can be brought to bear on the relationship. This equation addresses the nature of mutually satisfying communication.

"We talked together and sometimes we didn't have to speak"

Occasionally there were times when the women perceived there was a high degree of mutual understanding. When this occurred with the health care professionals, the women experienced a sense of partnership in their health care. Marge recalls one such exchange. "He laid it all on the line and then it was my choice. . . . I was really involved and he was really honest about all the aspects and I was able to weight it all up." Often the shared understanding occurred when there was trust in the relationship and a shared history. Laura recalls the first time after surgery that she and her husband attempted coitus. "It's still very experimental you know. A lot of talking. Like: "Yes. How's that? Can I do this? No, move up." Marge's account of speaking with another woman who had had exenterative surgery underlines this sense of shared understanding. "I don't know whether it's comradeship or suffering together. . . . You know we were both going through similar things. . . . I just feel uplifted by talking to her."

E. Increased Body Consciousness

Massive amounts of body tissue are removed in exenterative surgery. The surgery alters the women's body both physically and visually. Due to this, the women of this study experienced profound changes in both bodily function and body image — neither body nor bodily function is familiar — both seem to demand attention.

The Objectified Body

The crises of illness may precipitate a crisis in one's self identity. Earlier in the dissertation I spoke of the need to provide health care that addressed the body-mind-spirit unity of persons. Through illness, the women of this study encountered a personal crisis that was experienced as a disintegration of the body-self as a unified whole. They did not know this body. *It* responded differently. *It* functioned differently. *It* looked different. *It* repelled them. Their self-concept no longer was congruent with *it* or *it* was incongruent with their self-concept. The body and body-image no longer fit the self and the self-image. The congruent body self-image that had been "passively present" in their consciousness was now central in their consciousness due to the radical changes made by the surgery. (Bergsma et al., 1982) It was as though the self observed "the body." It was no longer "my body." The body became objectified in an attempt to come to a new formulation of self.

Early in the illness process Laura illustrates the beginning separation as she says: "It's like the cancer is happening to someone else. That's how I cope." Shortly after surgery as Laura sees her colostomy for the first time she observes her body and withdraws. "I looked, then stuck the pillow over my face and cried my eyes out," leaving the body to the nurse "to do her thing. . . . I didn't want to deal with it and I didn't think I ever would. " The struggle to integrate her altered body into a new concept of self had begun. Similarly the struggle was there for each of the women: the struggle between observing and caring for the body and of rejecting and required attending to the body.

My Body/My Friend — My Body/My Enemy

As friend, the body is frequently peripheral to one's awareness. The body and self are one. Once a trusted ally, in illness it becomes an untrustworthy enemy. No longer able to identify with it and feel admiration for it, one may experience living in constant fear and loathing of one's own body. One's body is no longer a familiar home and it is experienced as an unsafe place to dwell. For the women, they had become an unwilling host for the cancer in their body. In his *Psychology of the Sickbed*, van den Berg (1966) also refers to this process. He suggests: "the body becomes a stranger, and a strange ruler invades his quarters and makes them uninhabitable. An evil reigns over this body and weaves its way into its tissues, organs, with sores and swellings. The body becomes a betrayal." (p. 45)

Laura describes fearing her body. "I felt nervous about going home. I wanted to go home but . . . there would be no one to take care of me. . . . I'd had a fever. . . . I'd had a clot in my leg. I was really worried . . . can it go to my brain and I'm going to keel over dead on the way home."

Months after surgery Marge relates the following: "My bags are an absolute nightmare. At meetings I sit in absolute terror because I have no control over the noise of the colostomy. . . . I sit there paralyzed."

Sexual intimacy for each of the women had been prior to illness a significant and ~~pleasurable~~ part of their relationship with their husbands. Three of the four women experienced pain and chronic discharge from their neo-vaginas. Intercourse was no longer a spontaneous expression of closeness. Attempts were painful and as one said: "Be prepared for six months of real aches and pains so that you cannot bear the thought of anyone going near your vagina, not even touching it." With two ostomies and difficulties with their neo-vaginas they experienced their own bodies being barriers rather than vehicles to intimacy.

The Hidden Body

"I never undress in front of my husband now."

"I do, down to my panties."

"I always keep a towel handy to cover myself."

"I get a nightgown on. Half the time before I didn't wear one."

In their most intimate relationship, each woman experiences a need to cover her altered body. There is hope that "if it's out of sight it's out of mind." As Laura relates: "I try to forget about them [ostomies] and I figure if he doesn't touch them then he doesn't remember that they're there either and then I feel all right. I feel like I used to feel."

It is not only the naked intimate body that gets hidden, this is the same body that participates socially. Mia relates: "When they told sexual jokes I had to leave. I couldn't function any more." Marge recalls: "We were invited to go with a bunch of other people to a condo in the mountains - hot tubs and the whole bit. I couldn't go and be that close." Pam states: "I ask my friends and they tell me they couldn't tell I have a colostomy." Summarizing this, Marge states: "We dress up. We go out. That's all camouflage. We're all very attractive women camouflaged."

Illustrative though of the individual responses to similar events is the following:

> Marge: Flirting, it would boost my morale before. Now . . . it depresses me. I always want to rush off. Like don't talk like that, I'm not a whole person. It's as if I'm masquerading as a real woman, but I'm not [a real woman].
>
> Laura: You know, I even got a few wolf whistles the other day downtown. . . . That used to bother me but at the time I felt, hey, that's not too bad.

Tired of hiding her body, Laura reveals to the group her plan to confront her fears and challenges them to find a way to do the same for themselves. These are some exerpts from the conversation. "Has anyone come to deal with how they look, their sexuality in a positive way. . . . I'm talking about you and your mirror . . . not in clothes. . . . I want a real life. I want to be able to be the way I was before with my husband. . . . I want to be able to take my clothes off. . . . It's not easy but we have to do it for ourselves. . . . I should be able to start acting like a real wife." She then proceeds to tell them of the desensitization process she has planned to conquer her fear of her naked sensual self.

F. Mutilation — Destruction

In the struggle to gain a new body-image the women experienced their bodies as so altered that they experienced mutilation. Mutilation is what had occured to their bodies and until such time as a re-integration of the self and the body concept was achieved, it was destruction or fear of destruction of the self that occured. These are Marge's words: "This surgery destroys relationships because it has destroyed me." Earlier in the discussion I refer to the objectified body — the split between body and self. A progression in the adaptation to bodily assault is the reintegration of body and self. The self may become defined by the body, particularly if prior to illness the individual placed a high priority on physical attributes or functions. It is as though "I am my body and there is horror in what I've become." For others, there is a struggling acceptance. "This is my body but who am I?" For others, even in the face of fatal disease, body annihilation, it may not produce the destruction of self but rather affirm her own indomitability.

These are some of the women's words:

> "I find myself repulsive most of the time. . . . People only find me attractive because they do not know me."

> "I think it has totally destroyed my own sexuality. I do not think there is any way of getting it back."

> "Well, we're different now. There is this nucleus, the world and then there is deformed people, freaks, us around the outside. You can't get back in. There is no way back in."

> "When you have such a poor body image you have all those doubts about your husband. Even if you have no right. You feel so crummy about yourself — how could anyone find you attractive?"

> "I do feel altered. I don't feel good about my body any more. I was, up to the point until yesterday, I didn't give a shit about where I was going. Yesterday I had a good heart to heart talk with myself. . . . I gained weight cause I didn't feel good about my body, to keep him at a distance. . . . I'm not ready to change my behavior yet but I'm

looking at it. Enough is enough and I'm wanting sexual things to be back."

"You know he's the one who mutilated me and yet if it weren't for him I might not be alive. It's a sort of love-hate relationship [with surgeon and self]."

G. Loss

The most recurrent theme that emerged from the conversation with the women of the study was that of loss. The women experienced loss in the social, psychological and physical realms of their lives. Marge's words allude to the all encompassing nature of loss associated with exenterative surgery. "They aren't always that big of thing but when you add them all up, you've really lost a lot." The women speak of loss of" mobility, control, independence, confidence, trust, self-image, sexuality, body parts, bodily functions, relationship, role, energy, predictability and morale. This theme pervades all of the other themes of the exenterative experience. It is as though the women in having pelvic exenterative surgery have given up a quality of life for an unpredictable future. Cassel (1982) in his commentary on the nature of suffering indicates that losses associated with illness can invade every aspect of the individual. He states:

> Suffering is experienced by persons, not merely bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. (p. 639)
>
> All the aspects of personhood — the lived past, the family's lived past, culture and society, roles, the instrumental dimension, associations and relationships, the body, the unconscious mind, the political being, the secret life, the perceived future, and the transcendent dimension — are susceptible to damage and loss. (p. 643)

Perhaps the most obvious concrete loss to the women of this study is the loss of body tissue — some which is diseased and some which is healthy. The healthy part is sacrified in the hope of insuring that *the cancer* has been taken from the body. Earlier in the dissertation the women's words describe graphically the losses associated with this tissue loss and altered body function. Later in the exenterative experience the women had to deal with their responses to the loss of the man who had removed their organs and structurally had altered their bodies, and who had offered a possible cure. He had not only deeply penetrated their bodies but was now central to their sense of hope and security. For some he had become their partner in this crisis.

The severing of the relationship by the surgeon's relocation to another city was experienced as another painful loss. The women's words indicate how extensively they had woven him into their lives. The loss elicited more than fear of continuity of medical care.

> "He's the one who's been inside my body."

> "It's a total dependency. . . . You put everything you've got into one person. . . . He became more important in my life than my husband. My life depended on him."

> "I felt like a discarded mistress. How can you walk out on me?"

Only Pam, whose survival had been challenged many times prior to exenterative surgery was able to say: "It's hard to change but there is always someone there to replace him."

Central to the theme of loss is the experienced loss of sexuality. As part of our North American culture, the women place an emphasis on performance. Sexuality is a complex experience of self but it becomes redefined in terms of sexual function. The ostomies and the loss of the vaginal function with unsuccessful reconstructive surgery left the women focused on their limitations rather than their possibilities. Laura's statement is: "I feel so much has happened down there. Is this a sexy part of the body or is this a problem in our lives. Everything is concentrated. This is where the big deal is going on." Then she says: "If my vagina was the way it was, that would be enough. Everything would fall into place. Alternatives just aren't the same. . . . I'm longing for it to be the way it was."

There is a loss of predictability. Normal is viewed as "the way it was before." The body has gone out of control before. It grew a cancer. The words could be: "when will it happen again? What else will happen without me having any control? My body has betrayed me, so have the doctors in whom I trusted to identify medical problems early in my illness. Now everything has changed. I now have to think about what I'm going to do and how I can accomplish it. I no longer move about as freely or with as much confidence or energy. I wonder about the future. It's hard to plan. I get discouraged when I think about it. Will I ever feel like a 'real' woman again?" For the women, Mia, Laura, Marge and Pam, it is not simply coping with innumerable losses, it is acknowledging and grieving what has been. They suffer the losses and in part move on.

H. Re-arrangement of Life Priorities

Pam, Mia, Marge and Laura each speak of the re-ordering and priorizing in their life that has occurred since exenterative surgery. They have chosen not to participate in particular interactions, are often more focused in the present, and are more deliberate about their use of time.

Trivializing the Trivia

Mia states: "Life is much more pleasant now. . . . Now it's not worth fighting over little things." Pam's words affirm this when she says: "I avoid argumnents now. I walk away." Sometimes the women feel impatience when they find themselves in the midst of what is experienced as trivial. One reflects: "the petty things people spend time on . . . leaves us with the feeling — hell, it's not worth it." Another recalls: "some of the issues my friends talk about, I think, give me a break. I don't give a shit."

An Enhanced Sense of Living in the Immediate Present

Perhaps it's a feeling of urgency, perhaps it's uncertainty about the future, or perhaps it's simply appreciation of the moment but whatever the motivation, each of the women express a philosophy of life that says: "Don't delay. Do it now." They speak about a shift that has occurred during their illness. These are some of the ways the women have expressed this.

> "None of us are giving up and dying. We're just saying this is the attitude we're approaching it with. Do what you can while you're well enough to do it."
>
> "I'm day to day now. I don't think what is going to happen tomorrow. I don't plan anything. If I'm enjoying that day — I enjoy it."
>
> "I enjoy what I'm doing at home right now. . . . I think my kids have been without their mom long enough."
>
> "I travel because I'm going when I'm well enough."
>
> "You are happy with what you have. . . . Before we wanted it different. It doesn't seem so much to matter. . . . You take it as it comes."
>
> "I just enjoy being with my granddaughters."

> "Between the chemo we do things. We go to the park for a cookout or to the beach and on the days I'm not well enough the kids come and color on my bed or read or come into bed and we watch TV together. They just love to cuddle, so we do lots of that."

The women each identify a significant external focus for them. For Marge it is the work whereas for Laura it is to be at home for her children. Each of the women though consciously choose where they want to focus their energy and attention. They discuss their concern that without something meaningful "out there," they would focus too much on themselves, feel sorry for themselves and that was not how they wanted to use their time. As Pam says: "life's too short."

I. Survival

The choice to have exenterative surgery came out of a profound desire and will to survive. The losses are encountered, tolerated, and eventually accepted all with a focus on a perceived future. Hope dwells in this dimension of existence.

Early in the initial thematic discussion I refer to the perceived non-choice in undergoing exenterative surgery. To survive supercedes all other considerations. Perhaps Pam's statement "Thank God, I'm still alive" underlines this.

There are times in the illness process when each of the women questions the quality of their survival, like Marge's statement: "I'm not sure I'd knowingly go through it again." Or Laura's statement: "Once you've had enough time to be thankful for surgery — Thank God I'm alive — all that beautiful stuff; it's not enough to be alive. I want a real life." Each time, though, that their survival is threatened they choose to take whatever measures are necessary to continue living. Laura dramatically illustrates this with continuing to choose what might be considered drastic interventions. Mia, Marge and Pam observe her process, admire her determination and courage, fear the uncertainty in their own future, but in Pam's words: "I'd do the same as Laura, just to survive."

J. Transcendence

Each of the women acknowledges the reality of death in their own life. Sometimes the death awareness is more forefront than others. A new ache or pain, "bad news" — recurrence of cancer in their own or a friend's body, a special time she "wants to last forever", someone asking about next summer's plans are only a few of the triggers that begin the thinking about "life after my death". Each wants her life to have made a difference to the lives and world around them. They look to what is often referred to as the transcendent dimension in life; that quality of being greater or more enduring than an individual's life. It locates each of us in a far larger landscape. We might refer to this as symbolic immortality. Lifton (1979) states that it involves the knowledge of death and "reflects a compelling and universal inner quest for continuous symbolic relationship to what has gone before and what will continue after our finite individual lives." (p. 17) The symbolism may take a variety of forms. It may be expressed through transmission of cultural values and traditions; through biological connectedness to the generations that follow, children and grandchildren; or through creative works, those things that we do that others will remember us for. Each of the women in the study contemplates the meaning this has for her. They each express a desire for a timeless dimension to their life, a connectedness to what has been and what will come after their death.

To pass on her "German ways", to nurture her children so that they would come to know and appreciate the traditions of her homeland is important to Mia. This focus intensified after her exenterative surgery. It was as though there is an acknowledgement that the opportunities were not limitless. She wants her children to remember her as a "good mother" and hopes she will have the opportunity one day to know grandchildren.

Marge expresses a desire to have her children learn to act as if she were not there. In the event of her death she wants to know her children can function independently; that aspect of her life that she so dearly clings to. She wants her children to understand that in life you must "learn not to turn to anyone — to turn to yourself."

Both Laura and Pam state a belief that their lives are part of a larger plan — God's plan. Laura comments on her cancer: "Maybe it was just me it had to happen to. . . . Maybe that's just God's plan." Pam states: "God's given me this time, almost eleven years I might not have had. . . . I've just got to see this done and this done."

Memories of their grandmother is what she's working on, as Pam spends time being with and doing things with her granddaughters. Laura senses the influence she is having and has had on her children. She too wants her children to have memories of their mother. Two years after surgery and now with the recurrent disease Laura states: "I think about my children. I have a daughter who is two years old now. I think, will she remember she had a mother?" Each additional day provides the opportunity for more memories and "each one is worth fighting for."

K. Reflections on the Themes

As interpreter of the four women's experience of living with exenterative surgery, I have endeavored to present the commonalities in meanings, situations and bodily experiences that were revealed to me by the women. Their experiences may be viewed as unique to the phenomenon of exenterative surgery due to the specific challenges that the illness in combination with the surgery present to the women. Alternatively, though, they are not unique. The themes (structures) that emerged also speak to and confirm the underlying structures that others, particularly the existentialists, address as they focus on concerns that are rooted in an individual's existence, concerns that often come to the forefront during times of personal crises. Yalom (1980) addresses this perspective when he states:

> If we can brush away or "bracket" the everyday world, if we reflect deeply on our "situation" in the world, upon our existence, our boundaries, our possibilities, if we arrive at the ground that underlies all other ground, we invariably confront the givens of existence, the "deep structures" . . . . "ultimate concerns." This process of reflection is often catalyzed by certain urgent experiences. These "boundary" or "border" situations, as they are often referred to, include such experiences as a confrontation with one's own death, some major irreversible decision, or the collapse of some fundamental meaning-providing schema. (p. 8)

It is not surprising that the exenterative experience touches on other parallel experiences. The surgery may present an uncommon crisis but each of the women encounters it with her own historical background, her immediate needs and concerns and her perceived future; all of which are rooted in a broader cultural context. Their experience is part of the human condition.

There are parallels between the understandings arrived at in this research and the theoretical perspectives in existential-phenomenological psychology. To explore these parallels I will turn firstly to the underlying principle of existential-phenomenology — *Man and his world are never separate. They are in constant dialogue.* This is often referred to as embodied-being-in-the-world. Following this, I will endeavour to illustrate the way in which the women's experiences address the "deep structures" that are referred to in the existential literature. In order to do this I have chosen to highlight the writings of two men who base their research and practice on existential-phenomenological concepts. They are: Irvin Yalom (1978) whose writings focus on the application of these concepts to the practice of psychotherapy, and Robert J. Lifton (1974, 1976, 1979) who has extensively studied survivors of crises (holocausts) and employs existential insights to understand the human struggle with the awareness of death in life.

The Embodied-Being-in-the-World

Moss (1978) in his article "Brain, body, and world: perspective on body-image" states:

> For existential phenomenological psychology, the question of *who am I?* is inseparable from the question *what kind of world do I live in?* To be at home with myself is to be at home with my personal world. To be ill at ease with myself is to be ill at ease with this or that region of my personal world. The continuous, essential unity of the individual, his body, and his world is the basis for the concept of man as *embodied-being-in-the-world.* In this total structure no part can be understood in isolation from others. (p. 92)

Throughout the women's descriptions of their experience one can sense the intimate interconnectedness of the body, the self, and the social world. The personal world has traditionally been divided by phenomenologists (May, 1958) into the *Umwelt* (How I am my body in space), the *Eigenwelt* (how I am myself in time), and the *Mitwelt* (how I am embedded in interpersonal agreements). (Keen, 1978) If we are to come to an understanding of the women of this study, who each of them is for herself and others, we must explore what is the meaningful organization of her personal world.

Perhaps Marge's statement: "This surgery destroys relationships because it destroys you," most graphically illustrates the interconnectedness of the *Umwelt*, *Eigenwelt*, and *Mitwelt*. It was not *the* body that had been altered. For Marge it was *my* body. *I* am mutilated. *I* cannot relate to others this way. Initially there was a depersonalization of the body. Procedures were done to *it*~~.~~ Briefly this allowed the self-concept and the social world to remain intact. The body may have been disowned as *not me*. Her world had been organized around having a functional vagina, urethra and rectum. It is as though she was now denied access to her familiar world. The alteration in the body must now be reintegrated into the personal world that the body now inhabits. A period of reorganization follows as each aspect of her personal world adjusts to the alterations. And so it is for each of the women. We can begin with statements about any one aspect of the phenomenological world and understand the women's experience only as we account for the other aspects. There is both a circular and reciprocal relationship between an individual and her world.

Deep Structures

Yalom (1978) refers to the deep structure of human existence as "ultimate concerns"; the dread that underlies our existence. He describes four ultimate existential concerns: death, freedom, isolation and meaninglessness. It is confrontation with each of these facts of life that precipitates conflict for the individual. Death concern is the tension between the awareness of the inevitability of death and the wish to continue to exist. Freedom is the absence of external structures. Freedom in the absolute sense is a void, leaving the individual to be the author of his or her own world. Existential tension arises as one becomes aware of the sense of groundlessness with its inherent opportunities of choice and responsibility and the desire for ground and structure. Isolation refers not only to interpersonal and intrapersonal isolation but also to the fundamental isolation that comes with the awareness that one enters existence alone and eventually leaves it alone. The conflict is therefore the tension between awareness of this ultimate isolation and one's desire for contact, relationship and community; a wish to be part of a larger whole. The fourth existential concern arises out of the tension between meaning and meaninglessness. Whether one believes in a preordained design or not, each of us must find our own meanings in life.

Each of the four "ultimate concerns" appears to have bipolar themes: death-life, groundlessness-ground, isolation-relationship, meaninglessness-meaning. I have come to realize that seemingly bipolar themes, far from being linear antagonistic dichotomies, are circular themes — merging, even overlapping in levels of understanding.

I invite you to reflect again on the women's lived-experience with pelvic exenterative surgery. For the women, these "ultimate concerns" were woven through their descriptions of their experiences. It is not my intention to reanalyse the women's descriptive narratives but simply to briefly explore each of the concerns, illustrating it with the women's words. Your own reflections may also highlight other illustrative passages from the women's experience.

Death. Ever present in the exenterative experience is the tension between the awareness of death and the desire to continue in life. There may be particular "urgent experiences" when each of the women are confronted with their impending death (i.e., recurrence of disease, a hemorrhage, another's death, renal failure). Often, though, the awareness of death is less direct and its effects more subtle. When death anxiety builds, each finds her own way to deal with it. She may be told of the possibility of death only to deny it. These are Laura's words: "Even when they told me, I didn't believe them. How dare they say such stupid things" or "I pretend it's happening to someone else." Sometimes though the death awareness moves closer. "Dianne's death didn't bother me. . . . I didn't know her. . . . It was like watching TV and someone dies. If it was anyone of you, I'd be really scared and upset." Laura has allowed the *other* to become part of her self, her *mitwelt*. Before she could depersonalize death, now she was contemplating death coming to someone she knew, someone who was a part of her world. Others find alternative ways to place distance between themselves and death. For Mia it is becoming more and more "German," doing things the old way. She states: "I'd ask myself, why didn't I go home." It is a retreating into the familiar that eases the tension of the unknown future or the inevitable future. Repeatedly the women experience a partial death. A portion of them dies (biologically or socially) and the remaining self observes and grieves. They live with the fear of further losses (deaths) while not only protecting what remains but also while participating in creating newness (life) in their personal world. The most poignant illustration of their desire for life is the decision itself, to have pelvic exenterative surgery. There, life and death strive for ascendency. After surgery one can observe the focus on life, the desire for continuity, in the goals the women set for themselves; those things that are yet to be done (before death) — attending graduations, travelling to Australia, seeing grandchildren, having children be old enough to remember. Yet, through it all there is the reality of death. They exist simultaneously, exerting their influence on each woman.

Freedom. Inherent in the concept of freedom is the notion of the individual's freedom to create one's own life, a freedom to desire, to choose, to act and to make personal changes. Illness may precipitate a profound sense of helplessness and discouragement. The "ground" is new and unknown. Often the challenge for the women of this study was to find ways of increasing their own sense of power and control. As Marge states: "You walk in there, so naive." They learned to ask questions, to demand more information, to request time with their physicians, and to see their own medical charts. Pam recognizes the need for this when she says: "I should have asked rather than take their word for everything." Laura further illustrates this when she says: "If you don't understand, you keep on asking. They can come down to your level." It is impossible to make real choices until there is some ground on which to base them. The most significant choice in this experience is the decision to have surgery. The women experienced it as a non-decision due to the perceived immediacy of death. Perhaps the question that most raises the dread of groundlessness is: "Why is this happening to me?" There is no answer but psychologically there is a need to attempt to solve the question. This perhaps is the positive role of blaming. It is more tolerable that this terrible thing has happened because of something that has been done, than to be at the mercy of chance. Eventually the question becomes "How am I to live with what has happened?" There is a recognition that the "why" is unanswerable and that there are now choices to be made as life proceeds. There are times throughout the exenterative experience when the women recognize their choices but are not yet prepared to take responsibility for what their actions could precipitate. Pam's words illustrate this when she states: "I feel neglected. . . . I should be the one to initiate, to say "I want to sleep with you tonight! Something in there stops me." Change is beginning when one recognizes there is a decision that can be made. As Laura states: "It was easier to be fat and ugly and not have to deal with it.[husband and sex]. . . . I'm not ready to change my behavior yet but I'm looking at it. I've got to come to a decision. Enough is enough." Thus, the struggle continues between the freedom to choose and the awareness that with choice comes responsibility. Sometimes to will oneself to act is difficult.

Isolation. Interpersonal isolation is generally experienced as loneliness and is the isolation from other individuals. Intrapersonal isolation occurs when one partitions off parts of oneself (i.e., disowning a body part, stifling one's feelings or desires, burying one's potential). "There is an even more basic isolation that belongs to existence — an isolation that persists despite the most gratifying engagement with other individuals and despite consummate self-knowledge and integration." (Yalom, 1978, p. 355) Confrontation with death and freedom will undoubtedly trigger the experience of this ultimate isolation. They bring with them the awareness that no one can die for us and that ~~ultimately~~ we choose our own posture to life. Often it is difficult to verbalize this sense of existential isolation. It becomes known to us through our relationships or in our inability to feel "whole" within ourselves — when we no longer feel "at home" in our being. Marge's words hint at it when she says "I stood outside my house and sobbed because I couldn't get back in." She teaches her children: "learn not to turn to anyone — turn to yourself." Her learnings may come out of a desire to guard against further pain and betrayal or they may come out of her own life experiences of aloneness. No relationships can eliminate isolation. They may co-exist. Bugental (1965) states that a human being's basic interpersonal task is to be at once "a-part-*of*" and "a-part-*from*" (p. 308). As I reflected on interpersonal isolation as it was experienced by the women of this study, Marge's words graphically illustrated the dynamic interplay between isolation and affiliation. "There is this nucleus, the world, and then there is deformed people, freaks, us around the outside." There is both isolation from "the world" and affiliation with "us around the outside." Each of the women speaks of her own sense of isolation and her longing for relationship. The perceived quality of the relationship with their marital partner is a significant factor in their pelvic exenterative experience. Sometimes the isolation anxiety that emerged as they felt alienated from their own body could be reduced as others not only acknowledged but made physical contact with them and the "non-existent zone" of their body. The challenge of relationship is to "learn to relate to another without giving way to the desire to slip out of isolation by becoming part of that other. But one must also learn to relate to another without reducing the other to a tool, a defense against isolation." (Yalom, 1978, p. 362). The confrontation with their own biological finiteness, the pervading sense that ultimately they were alone in this crisis, the constant challenge to re-evaluate their priorities, and the desire to continue to be in relationship with others are all part of the women's experience.

Meaninglessness. Jung (cited in Jaffe, 1970) commented, "Meaning makes a great many things endurable — perhaps everything." (p. 146) How does one have meaning in life? Do we ascribe meaning to things and experiences? Can we seek meaning? Do we discover meaning? Alternatively perhaps life has no meaning (Sartre, 1956). Frankl (1963) would claim that meaning is essential for life. Yalom (1978) states "one who possesses a sense of meaning experiences life as having some purpose or function to be fulfilled, some overriding goal or goals to which to apply oneself." (p. 423) The women's participation in this study grew out of their desire that others could benefit and learn from their sharing of their experience. Pam states: "Maybe I can help someone else too." Each woman establishes what is meaningful for her; working, being with children or grandchildren, being a "good mother". What is meaningful shifts as the women's lives are altered by the surgery. Mia illustrates this when she says: "You are happy with what you have. Before we were always [a thoughtful pause] you know we had to have a second house. You have to save and make some more. . . . we wanted it different. It doesn't seem so much to matter. You take it as it comes." Some shifts are not easily made. The surgery may have brought about losses in bodily function or interactional patterns that were experienced as central to a meaningful life. Laura states: "If my vagina was the way it was, that would be enough. Everything else would fall into place." Or Marge speaks of separating from her husband so he is "free to go to another relationship with a full woman." Frankl (1963) speaks of three meaning systems (1) creative — what one accomplishes or gives to the world in terms of one's creations; (2) experiential — what one takes from the world in terms of encounters and experiences; and (3) attitudinal — one's stand toward suffering, toward a fate that one cannot change. One can sense the importance of being creative in Laura's words. "Some relatives keep me as an invalid. . . . One has to do what one can. . . . I have to know I can do things I've always done." Her words also speak to the meaningfulness of individual encounters. "On the days I'm not well enough the kids come into bed. . . . They just love to cuddle, so we do lots of that." And again her words resonate as she shares her belief about what she must do. "I think it is my duty as a wife, mother, daughter and friend to go on as long as I can. I'll take my life any way I can get it!" And so it is for each woman, it is the meaning that is there in the events of her life that gives her a life "story" rather than merely a life chronology. It is her autobiography — her signature on life.

Surviving the Crises

The experiences of four women, Mia, Laura, Marge and Pam are the basis of this study. They are the ones out of a group of eight women who are continuing to live with the impact of pelvic exenterative surgery. They are survivors. Lifton (1976) describes a survivor as "one who has come into contact with death in some bodily or psychic fashion and has himself remained alive." (p. 114) Lifton (1976) has focused much of his professional career on the study of the survivors of what he terms "extreme historical situations involving violence and massive death" (i.e., the bombing of Hiroshima and the Vietnam war). (p. 26) He further states that "man's task is to develop concepts, imagery and symbols adequate to give a sense of significance to his experience" (Lifton et al., 1976, p. 52). This inner imagery is seen as important in shaping a person's evolving vision of self and the world. They are inner guiding pictures that are constantly changing throughout the life cycle. Lifton proposes an evolving dynamic model of life-death imagery organized around three sets of opposites: (1) connection-separation, (2) movement-stasis, and (3) integrity-disintegration. Life images have aspects of connectedness, movement and integrity. Death images are associated with separation, stasis and disintegration. These images respond to changes in one's personal world. Lifton et al. (1974) state:

> If the conditions of a person's life suddenly change, death imagery may intensify. At a a number of times in the life cycle, there are "critical points" — major transitions that occasion a flare-up of death imagery. When the changes have to do simultaneously with one's own body and with the social world in which one lives, then one may easily lose confidence in the belief that anything is definite or reliable . . . . There seems to be neither a comfortable world nor a known self (Lifton et al., 1974, p. 52).

At these times of crises as the death images seem forefront, we also quest for forms of integrity, movement and connection that affirm life in the face of death.

Survivors are confronted with the psychological task of accepting their loss and continuing to live. The grief persists until new images and feelings take shape that allow the loss to be accepted and a new formulation of self and the world to be achieved. How closely life and death lie in our being. In allowing the "death" to be complete there is the opportunity for renewal. Perhaps the most universal religious symbolism is that of death and rebirth. The image of rebirth, finding life anew, is inseparable from hope. The continuity of life is an evolving series of deaths and rebirths.

As the women of this study speak of their experiences with pelvic exenteration they speak of their pain, their struggles, their fears in ways that parallel Lifton's notion of death imagery. You hear their experience of being separated, of being cut off from their known self and world. Mia recalls: "I was so lonely. It was just that nobody came. . . . I think what it was — they all said I couldn't, wouldn't ever survive." In another realm Laura's words also illustrate her lived-experience of separateness from the self she knows and longs for: "Strut, there is no way I'll strut around the room with no clothes on or with my two little bags hanging around me. I don't think I'll ever do that, in that way. . . . I don't feel about myself the way I did before." The women describe their feeling of being restricted in their movement — a sense of stasis. These are Marge's words: "It upset me having to lean so much on Daryl. . .having to lean and depend so much on someone else." Pam states: "I don't have the energy I used to." Laura illustrates how one can forget about limitation only to have your body remind you." I never consciously think I have any limitations, that I'm not like everyone else now, I get so mad, furiously mad, that I have to change plans for my bowels." Perhaps the most profound sense of death imagery comes when one experiences that not only has her known world disintegrated but that there is a biological disintegration occurring. These are Mia's words: "The cancer came — totally out of my control and I came completely out of control too. I didn't ask for it."

Even while the women's words reveal their experience of death and the imagery associated with it, they also speak of their hope, their anticipation of a future and their enjoyment and appreciation of their now. As mentioned earlier, the challenge is to integrate the losses into one's experience so that a new formulation of self and the world is arrived at. The death imagery can have a re-creative function. As healing (physically or psychologically) occurs the connectedness, movement and integrity of life imagery become more frequent. The women, while feeling disconnected from the "normal" world, have a sense of community with others who have had similar experiences. Mia reflects this when she says: "I found them really good at the ostomy association." Marge recalls: "I don't know whether its comradeship or suffering together; that kind of thing. You know we were both going through similar things. But it did help me. I just felt uplifted by talking to her." Each of the women describe in their own way a connectedness that has developed with their husband or family through this crisis. These are Marge's words: "The whole experience has brought us very close together and made us appreciate each other more. Certainly I've learned to appreciate him much more. . . . Like we're in this together." Pam states: "We argue less, . . . It's paying off. Doug's not the same person he was two years ago." As energy returns the women begin to turn to activities that are important to them, feeling less restricted by their bodies. Marge states: "I'm getting so that now I can go to a party and stay until I decide to go rather than when my body decides." Even when her body restricts her, Laura's words illustrate how she focuses on life and movement. "Even though I'm not feeling great, we go to the park or to the lake. I like to go for picnics with the children. We take a lounge and I can lie there. We're there together." The focus on life has become more finely tuned. Priorities are established and "petty things" are not worth taking time for. Pam states: "If I'm enjoying that day — I enjoy it! . . . I've had eleven years I might not have had. Its faith and positive [illegible]king." Mia reflects: "I've so much to be thankful for — a stable home, family, daughters doing well, pension, income, and a loving husband. Someday, I want to hold a grandchild."

The images of life and death entwine. Laura speaks: "There's no good-time to die. . . . I look at others though and I feel better. I have my husband and my children." The challenge then is to affirm life images after having been in contact with death; to become more than *just* a survivor. It is not only to *remain* alive, it is to *feel* alive. Lifton (1976) states: "Ultimately, genuine transformation requires we 'experience' our annihilation in order to prevent it, that we confront and conceptualize both our immediate crises and our long range possibilities for renewal." (p. 149) We may come to recognize that every significant step in human experience involves some inner sense of death — dying to the *old* in order to embrace the *new*.

In a dark time
The eye begins to see.
Roethke (1982)

EPILOGUE: REFLECTIONS FROM THIS SIDE OF THE RESEARCH

Like the classical Greek actor called upon at the conclusion of the drama to speak directly to the audience, I too will speak briefly, not to conclude the drama (for most surely it continues), but to reflect on the process that allowed me to explore the meaning of pelvic exenterative surgery in four women's lives. It is a gripping drama that did not allow me to sit comfortably in the audience and observe it. There was power in the horror and there was power in the hope. I felt drawn to participate. The research grew out of the question, "what is life like for a woman who chooses to have pelvic exenterative surgery?" I wanted to grow in understanding of her experience. The question pointed to a methodology that would allow the women's experience to guide the research. Thus, I chose a phenomenological approach as my questions were *what* and *how*, not *why*. "*What* is the experience?" "*What* are the meanings?" "*How* do women live with it?" The writing of this dissertation, a communication of the women's experience with cancer and exenterative surgery did not come easily. I was on new ground. My academic preparation had been to do empirical research. Now, to communicate my understandings rather than to report the results, was my intent. In this study, the reading and re-reading, writing and re-writing immersed me in the women's experience over and over again. The methodology demanded my involvement.

Early in the research process I had the opportunity to be in attendance throughout one of the women's surgery. I had never been "awake" in an operating room before. I watched as the surgeon placed his hands on her abdomen prior to her being surgically draped for the operation. I have no idea what was occurring within him. He appeared meditative and his touch seemed almost like a consecreation before *he* opened *her*. Initially during the surgery I could stay physically present in the room only if I depersonalized the process. Standing directly by her head, I stopped myself from looking alternately at *her* face and then *her* body. I simply observed what was occurring to *the* body. As the surgery progressed I found myself asking inwardly. "How much can be removed before the self is lost?" (This question would shout again in my being when Laura's cancer recurred and she would have her right leg and a portion of her pelvis removed.) I stood in awe as organs and tissues were removed — understanding that they were now diseased but also being aware of the miracle of the intricacies of the body — the miracle of life. It was important to me that each of us in the operating room might be honoring the preciousness of what, in order to offer the possibility of continued life, was beingtaken away. In a matter of hours what had taken years to develop and reach maturity was gone. I found myself speculating on the dwelling place of the human spirit, for to my untrained eye, the portion of the body that was now exposed looked little different from other animal bodies when they were opened and eviscerated. It is four years later now; some of these observations and questions still haunt me.

As I reflect on my involvement with these women my hope is that this research honors their courage and their despair; their strength and their fragility, their hope and their fear, all of which they revealed and entrusted to me. The research has uncovered many aspects of the women's experience and yet what is essential to the experience may still remain hidden. What has been learned? What is it like for a woman to have exenterative surgery? The questions point to the open-endedness of the research — the layers of understanding to be explored. So in a sense the questioning is not finished. It cannot be finished. Questions spring from the understanding.

The research emerged out of the question — "What is it like for a woman who chooses to have pelvic exenterative surgery?" The word that now penetrates, as I hear that question within me, is "chooses". Chooses implies a decision has been made. The decision to have exenterative surgery is far more complex than what the rational decision making process encompasses. ~~The threat of~~ death may negate the possibility of choice. The research has highlighted the questions — "What is informed consent?" and "How do we assist these women in making an enlightened choice?" I believe that an enlightened choice involves having information about the nature of the treatment proposed, information about alternatives, presentation of the risks and benefits associated with both, and an opportunity to speak about life style patterns and values so that the consequences of the choices can be explored. Above all it requires an attitude on behalf of the medical personnel that there are *joint* decisions to be made. The process requires a dialogue. It requires committing time to be present to the women, offering support, hearing questions, repeating information and respecting individual patterns.

Another question that arises is one of meaning. For me it is not only the existential question: "What is the meaning of life?" But more, the question is: "What is meaningful life?" and it points to a willingness to hear the individual's interpretation. I also think: "What of those women who choose not to have surgery? What is their quality of life?"

As I reflect on the research, I must also ask, "What is good adjustment to the surgery?" Often the emphasis is on coping, not on grieving. What is normal in grief often goes contrary to what we think of as good adjustment. Grief often makes others uncomfortable. I am aware I view life as a gift that is meant to be enjoyed not simply endured. Grieving is a way beyond endurance, back into the enjoyment of life. Grieving is pivotal in the healing process. It is the deep recognition of the loss that opens the possibility for renewal.

Significant in each woman's adjustment to the surgery are her partner's responses to both the illness and the impact of the bodily alterations. His support is critical as she attempts to reconstruct her concept of herself and her world. An important question may be, "What is the lived-experience of men whose partners undergo pelvic exenterative surgery?" I hear Pam saying: "I wish our husbands could get together with you as a group and talk about how they are feeling. I don't know whether they would do it but I sure think it would help."

My intent is not to reflect on all the events of the research process nor all the implications or questions that arise from it. I have highlighted some aspects that speak to my being-in-the-world as the research evolved. It has been a challenging, emotional and rewarding process. I have been enriched by the women's gift of opening their experience to me. I offer it to you — to explore your understandings, to create your meanings and to influence your actions.

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APPENDIX A

CONSENT TO PARTICIPATE

in a research study concerned with understanding the life experience of women who have undergone a pelvic exenteration for treatment of persistent pelvic cancer.

This research study, conducted by Beverley Edwards of the University of Alberta, Faculty of Graduate Studies, Department of Educational Psychology has been explained to me. I agree to participate in the study. I agree to be interviewed and to describe my lived experience with pelvic exenterative surgery. I understand that some interviews will be recorded on audio tape. I also recognize that previous conversations prior to the dating of this document have occurred with the researcher. I agree that this information may be included in the description of this life experience. In ~~exchange, I~~ understand that I will receive feedback about the study outcome when it is completed.

I further understand that:

Any questions I have about the study will be answered by Beverley Edwards.

All information is confidential and my identity will not be revealed.

My participation is voluntary and I can discontinue my participation in this study at any time.

On the basis of the above statement, I ______________________________ agree to participate in the above study.

SIGNED ______________________ DATE: ______________________

WITNESSED ______________________ DATE: ______________________