1999

Living with chronic illness: Subjective contributions toward a patient-centered ethic of care with Crohn's disease as the focus.

John James, McCann
University of Windsor

Follow this and additional works at: https://scholar.uwindsor.ca/etd

Recommended Citation
McCann, John James, "Living with chronic illness: Subjective contributions toward a patient-centered ethic of care with Crohn's disease as the focus." (1999). Electronic Theses and Dissertations. 2627.
https://scholar.uwindsor.ca/etd/2627

This online database contains the full-text of PhD dissertations and Masters' theses of University of Windsor students from 1954 forward. These documents are made available for personal study and research purposes only, in accordance with the Canadian Copyright Act and the Creative Commons license—CC BY-NC-ND (Attribution, Non-Commercial, No Derivative Works). Under this license, works must always be attributed to the copyright holder (original author), cannot be used for any commercial purposes, and may not be altered. Any other use would require the permission of the copyright holder. Students may inquire about withdrawing their dissertation and/or thesis from this database. For additional inquiries, please contact the repository administrator via email (scholarship@uwindsor.ca) or by telephone at 519-253-3000ext. 3208.
INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

Bell & Howell Information and Learning
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
800-521-0600

UMI®
LIVING WITH CHRONIC ILLNESS: SUBJECTIVE CONTRIBUTIONS TOWARD A
PATIENT-CENTERED ETHIC OF CARE WITH CROHN'S DISEASE AS THE FOCUS

by

John J. McCann

A Thesis submitted to the College of Graduate Studies and Research through the
Department of Religious Studies in Partial Fulfilment of the Requirements of the Degree
of Master of Arts at the University of Windsor

Windsor, Ontario, Canada

1999

© 1999 John J. McCann
The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L’auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L’auteur conserve la propriété du droit d’auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-52606-2
ABSTRACT

Contemporary Western medicine tends to define illness only in terms of the disease process operative within the sick person. As a result, the existing ethos of care within the health care system and specifically within the medical profession is primarily oriented toward the biological and pathophysiological implications of disease.

Employing a phenomenological approach, this thesis explores the perspective of illness as a synergy of disease as well as the lived experience of being ill. Within this context the ethic of care that guides contemporary medicine will be evaluated. The biomedical model of illness is shown to be inadequate in light of a patient-centered understanding of chronic illness.

The methodology used was developed by Sandra Kirby and Kate McKenna in their book Experience, Research, Social Change: Methods from the Margins. This methodology begins with a concern that is rooted in experience, it also recognizes the integral role of the researcher's experience and familiarity with the research question. It is also based on the commitment to advancing knowledge through a process of exploration grounded in the experience of people who have usually been treated as the objects of research. This methodology is especially useful for this study which supports the thesis that the existing ethic of care that characterizes the medical community in its approach to people who live with chronic illness is one that by its focus on the pathophysiology of the diseased body treats the body-in-illness as object.

The primary research was qualitative in nature and involved interviewing eight human subjects using an unstructured interview style. Thematic threads evolved from their reflections on living with Crohn's Disease, the meaning of illness, the meaning of care, and
their relationships with physicians.

The conclusions of the research leads to the development of an alternative patient-centered model of care, one that includes a broader definition of illness not only as clinically definable disease states but also as lived experience. The patient-centered ethic of care is understood not in terms of attending to people as fragmented organ systems but as embodied unities seeking wholeness in mind, body, and spirit.

***
DEDICATION

Simply put, the journey of this project would not have been possible without the unwavering support of my dear wife and life companion Margaret. I am also thankful to my daughters Heather and Hannah for their instruction on living.

I am grateful to my parents, Matilda and Hugh McCann, for their courage in choosing to seek a better life for their children in this great country. Their vision and early sacrifices helped pave the way in providing me with the opportunities to develop my academic potential.
ACKNOWLEDGEMENTS

My sincere gratitude to my thesis director, Dr. Maureen Muldoon. Throughout the seemingly never-ending process of writing and finishing this thesis I have been graciously humbled by her persistent patience and unwavering compassion. Her guidance and gentleness through the moments of my own self-doubt will be remembered long after the completion of this project. I am fortunate to be able to call her my friend, thank you Maureen.

I am also grateful to Dr. Norman King and Dr. Sharon McMahon for their support and patience in assisting me in the completion of my thesis.

Finally, I deem it important to acknowledge the sufferers of Crohn’s Disease and other chronic illnesses. Their stories are the gateway to the healing ethic.
# TABLE OF CONTENTS

ABSTRACT iii  
DEDICATION v  
ACKNOWLEDGEMENTS vi  

INTRODUCTION 1  
Thesis Outline 2  

CHAPTER 1: THE MEANING OF ILLNESS - A REVIEW OF THE LITERATURE 6  
What is Crohn’s Disease? 6  

ILLNESS MEANINGS  
A. The Biomedical Model of Illness 9  
The Origins of the Biomedical Model 11  
B. The Need for a More Patient-Centered Model of Illness 12  
The Physician’s Conceptualization of Illness 14  
The Patient’s Conceptualization of Illness 17  
Embodiment and the Illness Experience 20  

SUFFERING 24  
The Patient-Centered Meaning of Suffering 24  

CHAPTER 2: THE MEANING OF CARE - A REVIEW OF THE LITERATURE 32  
The Clinical Encounter and the Physician-Patient Relationship 32  
Acutity, Chronicity, and the Ends of Medicine 36  
Chronic Illness and Chronic Disease 40  
Care and Chronic Illness 40  

MODELS OF CARE 43  
A. The Cultural Model 43  
B. The Humanistic Model 46  
C. The Feminist Model 50  
D. The Patient-Centered Model 52  

Empathy and the Use of Narratives 53  

Empathy and the Use of Narratives vii
CHAPTER 3: METHODOLOGY OF THE PRIMARY RESEARCH

Research Methodology 58
Interview Format 63
The Use of the Narrative 64

CHAPTER 4: CONTENT AND ANALYSIS OF THE INTERVIEWS 67

ILLNESS STORY
A. Everyday Living 67
B. Control 69
C. Pharmacological Effects 70
D. Family Issues 74
E. Psycho-Social Suffering 77

THE CARE RELATIONSHIP 81

Negative Experiences
A. Narrative Credibility 84
B. Clinical Competence 84
C. Omnipotence 86
D. Doctors in Training 87
E. Bedside Manner 89

Positive Experiences
A. Active Listening 91
B. Personal Presence 92
C. Honesty, Compassion, and Empathy 93
D. A Holistic Approach 94

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS 96

Recommendations for Future Research 97
The Socialization of Physicians 97
Nursing Theory and Practice 98
Financial Resources and Bedside Care 98

APPENDIX “A” Consent Form for Research Participants 100
APPENDIX “B” Interview Protocol 102
BIBLIOGRAPHY 103
VITA AUCTORIS viii
INTRODUCTION

The impetus for doing this study has come out of my own experience of living with Crohn's Disease and also through my involvement with the Crohn's and Colitis Foundation of Canada (CCFC). As a CCFC volunteer I have served as President of the Windsor Chapter and most recently as a member of the National Board of Directors. These experiences have provided me with the privilege of speaking at length with many people who live with Crohn's Disease. I have become aware of many of the issues concerning those who live with chronic illness in general, and Crohn's Disease in particular.

One of the most common themes that I have encountered in these informal conversations is a sense of frustration and dissatisfaction with the medical community, specifically physicians.

The source of this frustration seems to focus on the perceived ethic of care that permeated the course of treatment they received from their doctor, an ethic that seems oriented solely on the organic dysfunction of their disease to the neglect of the overall lived experience of chronic illness. Having experienced this frustration myself, I became interested in exploring the issues further in the hope of articulating a more patient-centered ethic of care. It is my opinion that the need to explore the meaning of care is of profound importance for those who suffer from a chronic illness such as Crohn's Disease. The long term, incurable characteristic that sets this and other chronic illness apart from acute illness begs for an ethic of care that is comprehensive of the many ways in which people are affected by the lived experience of the illness beyond the pathophysiology caused by the disease. This is the background against which this study is set, and out of which the goals
of the study are formulated. The goals of this study are as follows:

1. To study the meaning of illness from the perspective of physician and patient. The historical evolution of the biomedical model of illness will be discussed in order to gain an appreciation of the guiding principles that guide clinical medicine.

2. To explore and identify the themes and the ethic of care that guides the course of contemporary medicine with reference to chronic illness.

3. To examine the life stories of people who live with Crohn's Disease. It is anticipated that responses to suffering and living with chronic illness will advance the development of a more patient-centered ethic of care, one that will embody a more comprehensive understanding of the meanings of illness. This may be shared with professional caregivers to enhance their intuitiveness in delivering empathic care.

**Thesis Outline**

The first chapter will be presented as an overview and a review of the literature pertaining to the meaning of illness including the meaning of chronic illness in general terms, and the meaning of Crohn's Disease more particularly, as a chronic illness. The literature will be examined for issues and consensus pertaining to the meaning of illness. The prevalent concepts associated with illness will be examined within a broader construct
of "illness as lived experience."¹ The meaning of illness as lived experience will be the foundation upon which a more patient-centered ethic of care will be constructed.

The second chapter is written as a survey of the literature on the meaning of care. It is hypothesized that the existing generalizable ethos of care within the health care system and specifically within the medical profession, is primarily oriented toward the biological and pathophysiological implications of disease. The characteristics of this bio-medical model of care will be shown and compared to other models of care such as one that defines care in terms of attending to people as holistic entities seeking to embody wholeness in mind, body and spirit.

In the third chapter, the qualitative research methodology will be outlined. The methodology that has been selected is qualitative in nature and was developed by Sandra Kirby and Kate McKenna in their book Experience, Research, Social Change: Methods from the Margins. The justification and a detailed explanation of the methodology used in this study as well as the protocol employed in carrying out the interviews will be described.

In the fourth chapter, the content and analysis of information gathered from the primary research will be presented. Data analysis was done for hermeneutic evidence and thematic development under two main categories: (A) Illness Story and (B) The Care Relationship. Discussed under the heading of Illness Story will be the themes: everyday living, control, pharmacological effects, social suffering, family issues, and emotional and psychological effects: discussed under the general heading of the Care Relationship will be the themes: negative interactions and positive interactions. These themes evolved out

of the content analysis of the recorded interviews.

The fifth, and concluding chapter, will present the interpretation of results from the primary research in chapter three. The concepts and constructs outlined in earlier chapters will be reviewed. In conclusion, a summary of the subjects' suggestions for changes in the way they are cared for will be described. These suggestions will serve as a basis for a responsive, ethic of care that is more patient-centered in its representation of the lived experience of chronic illness.
Living with chronic illness is not simply a physical affair:...it is our ontology, a condition of our being in the world.¹

CHAPTER 1

THE MEANING OF ILLNESS - A REVIEW OF THE LITERATURE

The purpose of the first chapter is to present the scholarly work on the meaning of illness. To accomplish this, it is necessary to begin with an overview and discussion because it is from the respective interpretations of the meanings of illness of patients and physicians that a shared understanding of illness can be developed. Exploration of the phenomenon of illness will be conducted to construct a patient-centered ethic of care.

Within this chapter the literature concerning the meaning of illness will be reviewed and evaluated. The review and analysis of the literature will be presented within the context of: (a) models of illness, (b) physicians' and patients' respective conceptualizations of illness, (c) embodiment, (d) suffering, and (e) the physician-patient relationship.

The prevalent conceptualization of illness as a clinically defined disease state will then be critiqued in light of a broader construal of illness as lived experience.

What is Crohn's Disease?

Named after the doctor who first described it in 1932, Crohn's Disease is one of two chronic gastrointestinal disorders that fall under the category of Inflammatory Bowel Disease (IBD). Crohn's Disease can effect any part of the gastrointestinal tract from the mouth to the anus although the area most commonly involved is the last part of the ileum (small intestine) where it connects with the colon (large intestine). Crohn's Disease is identified by the inflammation or thickening of the intestinal wall.
Crohn's Disease is characterized by alternating periods of remission and exacerbation. When active, the disease causes spasms of severe abdominal pain, diarrhea, fever, weight loss, nausea, arthritis, chronic fatigue, anemia, vomiting, and malnutrition, as well as problems affecting other parts of the body, such as the eyes, liver, skin and joints. At present, there is no known cause or cure for this disease.²

As this thesis develops, the above description of Crohn's Disease, with its origin in a biomedical model, will be shown to be too limited and narrow. In its place will emerge a more subjective and patient-centered understanding of Crohn's Disease in terms of its effects on the individual, one that extends beyond mere alterations in biological structure or functioning.

Further, search of the literature will be conducted particularly for evidence that the medical practitioner's historic responses to disease and acute, episodic afflictions of short duration does not offer an adequate way of understanding or responding to the personal, social, and ethical challenges posed by chronic illness and disability.³ Citations will be searched out to demonstrate the presence of a different conception of the personalized perspectives of medicine in the face of chronic illness: beyond that, a comprehensive and holistic understanding of the human and social meaning of chronic illness will be explored.

Until quite recently, it was difficult to justify doing research on a vague and nonspecific issue such as chronic illness. Instead, scholars were encouraged to study

²For more information on the pathophysiology of Crohn's Disease see P. Steiner, P.A. Banks and D.H. Present, People Not Patients: A Source Book For Living With Inflammatory Bowel Disease, (New York: The Crohn's and Colitis Foundation of America, 1991).

aspects of particular diseases, the idea being to understand each disease as a distinct entity. However, subsequent research has shown that sufferers of chronic illness seem to have more in common than was previously thought possible.\textsuperscript{4} It is the experiential nature of chronic illness that has not been accounted for in previous scholarship.

Arthur Kleinman in \textit{The Illness Narratives} says that the study of the experience of chronic illness has something fundamental to teach us about the human condition:

Nothing so concentrates experience and clarifies the central conditions of living as serious illness. The study of the process by which meaning is created in illness brings us into the everyday reality of individuals like ourselves, who must deal with the exigent life circumstances created by suffering, disability, difficult loss, and the threat of death. Yes, chronic illness teaches us about death; the process of mourning for losses is as central to growing old as it is to healing.\textsuperscript{5}

Studying the meaning of illness, specifically a chronic illness such as Crohn's Disease, has to do with the very essence of being human. Kleinman adds, "illness has meaning; and to understand how it obtains meaning is to understand something fundamental about illness, about care, and perhaps about life generally."\textsuperscript{6}


\textsuperscript{6}Kleinman, \textit{The Illness Narratives}, xiv.
Illness Meanings

A. The Biomedical Model of Illness

In Western scientific medicine, the prevailing conceptual model of illness is the Biomedical Model. Molecular biology is its basic scientific discipline and it assumes disease to be fully accounted for by deviations from the norm of measurable biological variables. In this case, physiological processes become translated into objective, quantified data and disease is constituted as an entity defined via medical categories. According to this scientific account, illness is identified solely as a pathoanatomical fact and as a result it leaves no room within its framework for the social, psychological, spiritual, and behavioral dimensions of illness.

In her book The Meaning of Illness, Kay Toombs, philosopher and a person living with Multiple Sclerosis, writes that the biomedical model conceptualizes illness as a disease state whereby illness is thematized in terms of theoretical, scientific constructs and the patient's experience is wholly subsumed under the causal categories of natural scientific explanation.

The biomedical paradigm has certain strengths that have made it an attractive model.

---


9Engel, "The Need for a New Medical Model: A Challenge for Biomedicine," 129.

for medical practitioners. One of these strengths is that it imparts systematic unity and rigorous coherence to medical practice. If illness and health are exclusively biologically based then the conceptual framework that guides the treatment of disease and the restoration of health can exhibit the intelligibility and clarity of highly developed systematic theory. An illness model based on the natural sciences possesses an appealing exactitude and precision in conceptualization that allows for a predictive power that is of great benefit to the practice of medicine both in the diagnosis and treatment of disease.

However the unity and exactitude of the biomedical model is flawed when one considers the plethora of illness symptoms that elude identification within the parameters of the natural sciences. Engel points out that these components of human distress have too often been ignored or denigrated as irrelevant in medicine. Engel describes the problems with the biomedical model this way:

It assumes disease to be fully accounted for by deviations from the norm of measurable biological (Somatic) variables. It leaves no room within its framework for the social, psychological, and behavioral dimensions of illness. The biomedical model not only requires that disease be dealt with as an entity independent of social behaviour, it also demands that behavioral aberrations be explained on the basis of disordered somatic (biochemical) processes.

Engel's model emphasizes the reciprocal influence of personhood on biologic function and biologic function on personhood. It is an alternative paradigm that utilizes general systems

---


theory in place of classical reductionism.\textsuperscript{13} Here, the patient is conceptualized as a
conglomerate of interconnected systems both at the micro level (tissues, cells, molecules)
and at the macro level (dyads, families, communities, nations). In his own criticism of the
biomedical model Kleinman states:

It (the biomedical model) turns the gaze of the clinician, along with the
attention of patient, away from decoding the salient meanings of illness, which
interferes with recognition of disturbing but potentially treatable problems in
the patient's life world. The biomedical system replaces this allegedly "soft",
therefore devalued, psychosocial concern with meanings with the scientifically
"hard" therefore overvalued, technical quest for the control of symptoms. This
pernicious value transformation is a serious failing of modern medicine: it
disables the healer and disempowers the chronically ill.\textsuperscript{14}

\textbf{The Origins of the Biomedical Model}

The origins of the biomedical model can be traced back to the 15th and 16th
centuries when the Christian Church began to permit the dissection of the human body.\textsuperscript{15}
The Church, however, did not grant corresponding concessions of scientific investigation
into the human mind and behaviour, for these activities it was believed, had more to do with
religion and the soul. At the same time, the basic principle of the science of the day, as
enunciated by Galileo, Newton, and Descartes, resulted in an investigative methodology
that sought to isolate causal chains or units. From this view it was assumed that the whole
could be understood by reconstituting the parts. Further, Cartesian dualism made it possible

\textsuperscript{13}James E. Rosenberg & Bernard Towers, "The Practice of Empathy as a Prerequisite

\textsuperscript{14}Kleinman, \textit{The Illness Narratives}, 9.

\textsuperscript{15}Engel, "The Need for a New Medical model: A Challenge for Biomedicine," 131.
for science to escape the control of the church by assigning the noncorporeal, spiritual realm to the church, leaving the physical world as the domain of science. In that religious age, "person", synonymous with "mind" was necessarily off limits to science. As Medicine evolved as a science, the assignment of personhood to the realm of the mind became increasingly problematic because it was not easily identifiable in objective, quantifiable terms, therefore the emphasis on the person in Medicine diminished.

The genesis of this new scientific worldview together with the mind-body dualism that was firmly established under the authority of the Church set the foundation upon which the classical scientific approach would build the notion of the body as a machine and of disease as the consequence of the breakdown of the machine.

Thus, the biomedical model has its roots, not only in a mind-body dualism, the doctrine that separates the psycho-spiritual from the somatic but also in scientific reductionism, the view that all illnesses are ultimately derived from primary quantitative scientific principles.

B. The Need for a More Patient-Centered Model of Illness

S. Kay Toombs argues that the prevailing biomedical model of disease, which tends to focus exclusively on the dysfunction of the biological organism and the pathophysiology of the diseased state, is an incomplete model for illness. Based on her study of

---


*18* Engel, "The Need for a New Medical Model: A Challenge for Biomedicine," 129.
phenomenology she suggests that an adequate account of illness must include not only a construal of illness in terms of clinically definable disease states but also an understanding of illness-as-lived.\textsuperscript{19} In this regard, illness may be understood as a particular way of being in the world as it manifests itself in social isolation, frustration with dependency, intrafamilial stresses, economic pressures, and incongruencies in body image and the concept of self. She writes that:

\begin{quote}
Illness is a state of disharmony, disequilibrium, dis-ability, dis-ease, all of which incorporate a loss of the familiar world, a loss of wholeness. Illness represents an altered state, the taken-for-grantedness of everyday life is disrupted, not only in the sense that routine activities and involvements are disturbed but additionally in the sense that the usual experience of time and space undergoes a significant change. The unavoidable preoccupation with pain, sickness or incapacity, grounds one in the present moment. The future is suddenly disabled, rendered impotent and inaccessible.\textsuperscript{20}
\end{quote}

The chronically ill individual may well find these manifestations of illness far more problematic than the somatic indications of the disease itself.

A patient-centered model of illness, one that recognizes the multifaceted nature of human life and is inclusive of all relevant biopsychosocial elements, is needed to advance beyond the limitations of the biomedical model. Disease must be understood to include the embodiment of the symbolic network linking body, self, and society. Where the biomedical model defines Crohn's Disease as inflammation of the bowel or lining of the gastrointestinal tract; the biopsychosocial model interprets this disease as a dynamic dialectic between

\textsuperscript{19}Toombs, \textit{The Meaning of Illness}, xvi.

\textsuperscript{20}Toombs, \textit{The Meaning of Illness}, 96.
digestive tract disorder, psychological and emotional states and environmental situations.

The Physician's Conceptualization of Illness

The focus of the physician is guided by a worldview that is characteristic of the profession and is due in large part to the socialization process that occurs over the course of the physician's scientific training. This scientific worldview provides a means of interpreting reality. Doctors leave medical school believing that symptoms are clues to disease, evidence of a "natural" process, a physical entity to be discovered or uncovered.  

Howard Spiro claims that during their medical education, physicians in training are first taught about science and then they are taught about detachment. In medical school, he says, "they learn detachment...the increased emphasis on molecular biology to the exclusion of the humanities encourages students to focus not on patients, but on diseases."

Kleinman, also a physician, writes that one of the most important lessons he learned from his patients was that there is a marked difference between the patient's experience of illness and the doctor's attention to disease. He claims that his medical training had systematically educated him about the latter and blinded him to the former. Kleinman claims that "the everyday priority structure of medical training and of health care delivery, with its radically materialistic pursuit of the biological mechanism of disease, precludes such inquiry

---


into the meaning of illness."^{23}

Doctors are trained to reconfigure the patient's illness problems as narrow technical issues, disease problems. Kleinman says that "the patient's health problems are interpreted within a particular nomenclature and taxonomy, a disease nosology, that creates a new diagnostic entity, an "it" - the disease."^{24} Physiological processes become translated into objective, quantified data and disease is constituted as an entity defined by means of medical categories.

In an attempt to explain how physician and patient experience illness differently, Toombs applies the phenomenological principles of Edmund Husserl in distinguishing between the natural attitude and the naturalistic attitude. The natural attitude, indicative of the patient's perspective, involves the immediate pre-theoretical experiencing of the world in everyday life. In other words, illness attains its meaning from the lived experience of the individual who is ill. The naturalistic attitude involves an essential abstraction from immediate experiencing in favour of a theoretical, scientific account of the causal structure of such experiencing. In conceptualizing the patient's illness in terms of objective, scientific constructs, the physician remains within the naturalistic attitude. The naturalistic attitude articulates disease as a scientific abstraction autonomous from the immediate experience of the patient.^{25}

This distinction between natural and naturalistic attitudes is particularly important in


^{24}Kleinman, The Illness Narratives, 15.

^{25}Toombs, The Meaning of Illness, 15.
understanding the gap that exists in the physician-patient relationship where the lived experience of illness and the scientific account of such experience clash in a direct way when compared to the phenomena of illness.\textsuperscript{26}

This conceptual distinction between physician and patient can be illustrated within the context of \textit{temporality}. The patient experiences his or her illness in its immediacy in terms of the ongoing flow of lived, subjective time. Abdominal pain is not experienced as a series of time units along a time line but rather as a continuum of discomfort in which "past and future pains coalesce into a stagnating present."\textsuperscript{27} The physician on the other hand uses the objective time scale to measure the physical events and biological processes which define the patient's illness as a disease state. The use of analgesics for the control of pain, which are generally administered on a fixed multi-hour interval, is an example of this objective time schedule guiding the course of treatment. The difficulty with the utility of this objective time scale is that individuals exhibit a wide variation in pain thresholds and differing responses to pain medications in terms of the temporal longevity of the medication's effectiveness. It should be noted that recent advances in the delivery of intravenous pain relief medications now respond more efficiently to the unique needs of the individual patient. Using smaller calibrated doses and a patient controlled delivery mechanism the individual can access pain relief on a more immediate and needs-specific basis.

\textsuperscript{26}Toombs, \textit{The Meaning of Illness}, xv.

\textsuperscript{27}Toombs, \textit{The Meaning of Illness}, 15.
The Patient's Conceptualization of Illness

Toombs cites the work of Jean Paul Sartre\textsuperscript{28}, who in his analysis of pain and illness identifies four distinct levels of constitution of the meaning of illness: prereflective sensory experience, reflective suffered illness, disease, and the disease state. The first three levels characterize the manner in which the patient\textsuperscript{29} apprehends illness; the fourth, disease state, represents the physician's conceptualization of illness.

Prereflective sensory experience refers to the immediate subjective experience of feeling ill. With Crohn's Disease, pain felt in the lower abdomen is not immediately experienced as an objective "stomach pain" but rather pain is the stomach at that particular moment. Toombs uses the term "painfully-lived" to describe the experience of illness at this prereflective level.

In contrast, when one reflects upon the pain he or she is experiencing, it becomes objectified outside one's immediate subjectivity and becomes identified as pain in the stomach. Moving from the prereflective experience of the illness to the reflective consciousness, illness becomes distinct from the body and has its own form - that of a suffered illness.

At a third level of reflection one comprehends one's illness as "disease". At this level,


\textsuperscript{29}Kleinman prefers to use the term sick person rather than patient because those who are chronically ill spend much more time in the roles of sick family member, sick worker, than in the role of patient, which is so redolent with the sights and smells of the clinic and which leaves an afterimage of a compliant, passive object of medical care. He wishes to place emphasis on the sick person as the subject, the active agent of care, since in fact most treatment in chronic illness is self-treatment and most decisions are made by the sick person and the family, not by health care professionals.
illness represents an objective disease such as "bowel problems", and there is a cognitive inference that something is wrong with a specific body system. The individual who lives with a chronic illness such as Crohn's Disease is forced to attend, usually on a daily basis, to an impairment or functional change of a part of the body. With this breakdown of function, the instrumentality or mechanistic characteristic of the body announces itself. For example, the abdominal cramps and accompanying diarrhea that are often experienced following a meal focuses the attention on the stomach and intestinal tract as defective instruments of food retention.

As Toombs points out, the prolonged attention to the body which occurs in chronic illness engenders a kind of metamorphosis:

The dialectic of identification and objectification is integral to the experience of illness. On the one hand at the immediate level of bodily disruption I AM my body and I EXIST my illness; on the other hand, my impaired body demands my attention and thus I objectify it and experience a distance from it. The object-body is now something I HAVE or I POSSESS...The body is transformed into a new entity, the 'diseased body' and is experienced on an ongoing basis as an insistent presence against which all else is background. 30

Chronic illness engenders a shift in attention whereby the disruption of the lived experience of illness causes the patient explicitly to attend to his or her body objectively, rather than simply living it unreflectively.

The fourth and final level of what is essentially a progressive process of objectification of the illness experience occurs at the level of "disease state". This level is representative of the physician's conceptualization of the patient's illness - identified with pathophysiological facts. As a disease state, illness is wholly conceived of as a question

30Toombs, The Meaning of Illness, 75.
of "bacteria or lesions in tissue"31, illness is thematized in terms of theoretical, scientific constructs while the patient’s experience is wholly subsumed under the causal categories of natural scientific explanation. At this level the patient’s illness has progressed from the prereflective lived experience to an abstract entity residing in, but in some way distinct from, the body.

People who are sick, especially those who live with a chronic illness such as Crohn’s Disease, quite often do not experience their illness primarily as a disease process but rather experience it essentially in terms of its effects on everyday life. The transforming impact on the individual’s personal and social life is perhaps the most salient feature of chronic illness. The person with Crohn’s Disease will often be thrust into unfamiliar and often inhospitable worlds - frequent hospital stays and encounters with highly complex, impersonal, and often frightening modes of acute medical treatment; the daily prospect of, the threat and reality of disabling pain; a prolonged and inconvenient regimen of medication, restricted diet; a continuing round of bureaucratic hassles with a disjointed medical system; the perpetual uncertainty that comes from the intermittent flair-ups of debilitating symptoms and the occasional onslaught of an acute, life-threatening episode.32 In their article "Ethical Challenges of Chronic Illness", authors Jennings, Callahan and Caplan write that:

Chronic illness also threatens the integrity of more familiar aspects of a person’s life. It punctuates one’s life with frequent periods of restricted activity, immobility, and unwanted dependency on others. It often interferes with the ability to work, which threatens the person’s basic livelihood and economic security, to say nothing of more ambitious career plans. Chronic


illness and disability are often stigmatizing; intolerance, fear and misunderstanding, at one extreme, and well meaning but humiliating and patronizing sympathy at the other often greet the chronically ill in their everyday social lives. Lost friendships, withdrawal and isolation, and an emotionally draining struggle to sustain dignity and self-respect are often the consequence.  

For the patient then, the fundamental entity is the subjective experience or lived-experience of the illness. This is a radically different conceptualization from that of the physician whose fundamental entity is the disease state or pathophysiological dilemma.

Toombs notes that when doctors themselves become patients they immediately become aware of the distinctive gap between the qualitative immediacy of their own experience and any subsequent scientific explanation in terms of disease. Dr. Edward Rosenbaum, former Chief of Rheumatology at Oregon Health Sciences University echoes Toombs’ claim, "I practised medicine for 50 years before I became a patient. It wasn't until then that I learned that the physician and the patient are not on the same track. The view is entirely different when you are standing at the side of the bed from when you are lying on it."  

**Embodiment and the Illness Experience**

In modern Western societies, the influence of the biomedical model of illness has had a profound fragmenting effect on the embodiment of those who are ill. Sally Thorne, in her qualitative exploration of chronic illness experience, interviewed a young man with

---

Inflammatory Bowel Disease who claimed to dissociate for the duration of his hospital stay. The man recalls his experience, "I just turn into nothing, you know. For a certain period of time, when I go into the hospital, I prepare myself by saying this doesn’t exist. It's not me. It's just a body they're gonna deal with." 35

The view that the body is a discrete entity, a thing, an objective "it", composed of biological parts and mechanistic qualities, perpetuates a dualistic paradigm that separates the "physical body" from thought and emotion. Kleinman writes that this fragmented notion of embodiment that is characteristic of western medicine exists in contrast to the attitudes in many non-western societies where the body "is seen as an open system linking the social relations to the self, a vital balance between interrelated elements in a holistic cosmos. Here, embodiment is not a secularized domain of the individual person but an organic part of a sacred, sociocentric world, a communication system involving exchanges with others including the divine." 36

Within the context of illness, embodiment refers to the subjective experience in its totality. The person does not possess his or her body but rather the person is his or her body. Consequently, an individual does not so much have a bodily illness as much as he or she lives the illness. Toombs writes that embodiment is an integral characteristic of chronic illness, "In chronic illnesses patients cannot disassociate themselves from their diseased bodies and consequently they find themselves inescapably embodied, irrevocably attached to an essentially malfunctioning organism which promises to disrupt all their


involvements in the world. Such disorders are experienced as profoundly world threatening."³⁷ It may be argued then, that chronic illness is fundamentally experienced as a disruption of embodiment.

The subjective experience of illness is primarily experienced as a fundamental loss of wholeness that is manifested in different forms. Toombs writes that this loss of wholeness "manifests itself in the awareness of bodily disruption or impairment - an awareness that is not so much a simple recognition of specific symptoms as it is a profound sense of the loss of bodily integrity."³⁸ Pellegrino supports Toombs' assertion that beyond the physiological consequences of illness, what is primarily threatened is the integrity of the self and that there is a fundamental loss of wholeness. He says that "illness represents an assault on the unity of being, eroding the images we have constructed of ourselves and the world."³⁹

When ill, the person's body also seemingly assumes an opposing will of its own that is beyond control of the self. Rather than functioning effectively at the bidding of the self, the person's body thwarts plans, impedes choices, and renders actions impossible. In his article "The Nature of Suffering and the Goals of Medicine", Eric Cassell writes, "disease can so alter the relation (between self and body) that the body is no longer seen as a friend


³⁸Toombs, The Meaning of Illness, 90.

but, rather, as an untrustworthy enemy."\textsuperscript{40} Thus, illness also disrupts the unity between body and self.

Chronic illness can be seen as a threat that suddenly intrudes upon a preexisting condition of health and wellbeing. The militaristic metaphors that are found in the literature and used in the language and cultural ideology of medicine lend support to this perspective. It is often said that disease attacks the body and becomes the enemy within. The patient and physician enter an alliance in which the technical arsenal of medicine is used to defend the patient and to attack the invader. Seeing the illness as a threatening intruder serves to externalize and objectify it, and makes the illness a thing, extrinsic and foreign to the person even though it is a part of the body and a dynamic of the person's embodiment.

Martha Rogers, whose work helped lay the foundation for nursing theory, says that the underlying assumption that caregivers need to hold is that a human being is a "unified, irreducible whole... greater than and different from the sum of their parts, and cannot be adequately known, or addressed as systems, organs and cells, as in the medical model."\textsuperscript{41} While the impaired embodiment and paradoxical relation between body and self is explicitly recognized in all forms of illness, the analysis of the narratives noted in the primary research in Chapter 4 will indicate that it is felt most profoundly in chronic illnesses such as Crohn's Disease because it is often omni-present and longstanding.

\textsuperscript{40} Cassell, "The Nature of Suffering and the Goals of Medicine," 643.

Suffering

It is helpful to provide an examination of the meaning of suffering from the patient's perspective, this will add depth to the point of view of illness as the lived experience of suffering. Like the overall illness experience, suffering includes the pain and physiological effects of the illness but is not restricted to it. Suffering, as we shall see, affects all aspects of a person's life, threatening the individual's wholeness above all else.

The Patient-Centered Meaning of Suffering

The role of the physician in helping to relieve human suffering stretches back into antiquity. Despite this fact, little attention is explicitly given to the problem of suffering in medical research and practice. Eric Cassell's interest in the nature and meaning of suffering came about in part because of his frustration with the lack of resources investigating suffering and its meaning. The sources he did find often used the word "suffering" synonymously with the word "pain". Cassell argues against using the two terms synonymously; instead, he argues that the two are phenomenologically distinct. He defines suffering as "the distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person." So defined, suffering can include physical pain but is by no means limited to it.

Threat to wholeness, says Cassell is more than the biological body, it attacks the individual's concept of self. He says that a threat, by definition, refers to the possibility of

---


some future event(s) not being fulfilled, thus suffering also requires a temporal sense of future. For example, a person with Crohn's Disease may experience suffering caused simply by the fear that debilitating abdominal pain will recur sometime in the future, perhaps at an upcoming wedding or other significant social event. The individual experiences suffering even though at the present moment the person has no physical pain.

Cassell says that suffering involves aims and purposes. Purposes always refer to or arise in the past, and their enabling actions are always realized in the future. When suffering exists, the identity that the sufferer fears will disintegrate is an identity expressed in purposeful action - legs walk, hands grasp, and eyes see. It is a mistake, says Cassell, "to think only of grand purpose; daily life is filled from the first to the last second with intentions and purposes. They may not require anything from consciousness but they are nonetheless 'self' defining." I recall from my own experience an incident illustrating this point - I remember waking up after having emergency surgery, the surgery involved terminal ileum resection with insertion of ileostomy. As my first volitional act I recall calling over my wife and barely being able to talk because of the nasogastric tube in my nose, the first words out of my mouth were a telephone number and I asked her to call my friend and tell her that I would not be able to attend her wedding on the weekend; those in the room at the time found it rather humorous that this was my main concern. Nonetheless, at that moment I was still involved in the purposes of my usual self despite the state of health I was in.

Cassell adds that in the confusion that immediately follows being told of a serious

---


diagnosis, patients will frequently say that they cannot go to the hospital or be operated on because they must do some commonplace task tomorrow. They have not yet been able to give up their usual "myself" of future purposes. It is precisely the "myself" that is injured in illness and lost in suffering.\textsuperscript{46}

Suffering, then, relates not only to the pain experienced by the body but to the loss of integrity of the whole web of interrelationships of body, self and world. Suffering is thus a defining and integral part of the subjective, lived-experience of illness, experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity.\textsuperscript{47}

Few dispute the fact that physicians play a pivotal role in the relief of suffering but as Cassell indicates, they may often unknowingly contribute to the suffering of a patient. He believes that medicine's reliance on the biomedical model of illness with its accompanying cartesian dichotomy between mind and body is the source of this suffering:

\begin{quote}
Medicine's traditional concern primarily for the body and for physical disease is well known, as are the widespread effects of the mind-body dichotomy on medical theory and practice. I believe that this dichotomy itself is a source of the paradoxical situation in which doctors cause suffering in their care of the sick...Attempting to understand what suffering is and how physicians might truly be devoted to its relief will require that medicine overcome the dichotomy between mind and body and the associated dichotomies between subjective and objective and between person and object.\textsuperscript{48}
\end{quote}

The implication for Medicine and suffering is this; as long as the mind-body

\textsuperscript{46} Cassell, "Recognizing Suffering," 25.


\textsuperscript{48} Cassell, "The Nature of Suffering and the Goals of Medicine," 640.
dichotomy is accepted within the contemporary medical milieu, suffering is either subjective and thus not truly "real" and not within scientific medicine's domain or, it is identified and defined solely as bodily pain. Not only is such an identification misleading and distorting, for it depersonalizes the sick person, but it is itself a source of suffering. 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 nonmedical (the remainder) has given medicine too narrow a notion of its calling. Because of this division, physicians may, in concentrating on the cure of the bodily disease, do things that cause the patient as a person to suffer.\(^{49}\)

Suffering also arises in chronic illness because of the conflicts within the person that are generated by the simultaneous need to respond to the demands and limitations of the body and to the societal forces that encompass the person. These struggles to meet opposing needs become internalized, and suffering occurs as the integrity or wholeness of the person is threatened by the dissension.

Yet, symptoms alone do not fully explain the experiential progressions that characterize the pattern of suffering in chronic illness. Sally E. Thorne in her research on the social context of chronic illness concludes that the chronically ill must partake in what she calls health maintenance work, the work involved in preserving good health, protection against the onset of acute episodes, deterioration, or secondary effects; and following treatment plans.\(^{50}\) Thorne's research reveals that there is extensive interpersonal work


\(^{50}\) Thorne, Negotiating Health Care: The Social Context of Chronic Illness, 43.
involved in making sense of the experience of chronic illness; managing emotional responses to the course and prognosis of illness, and also organizing everyday life. The term *illness trajectory*\(^{51}\) has been proposed within the literature to explain the experiential progressions that characterize the pattern of chronic illness. Beyond the acute pain and disability of the illness, other features such as the work involved in being chronically ill, the organization of such work, and the impact of the work on the people involved are all considered significant to the way that chronic illness enacts itself in individual lives. Further, Thorne adds that "the emotional work was described (in her interviews with chronically ill individuals) with at least as much passion and detail as was the health maintenance work, suggesting its significance in the overall scheme of things."\(^{52}\) Kleinman supports Thorne's conclusion when he writes that:

> It has been said of Mozart's music that even where all seems quiet and under control it is best regarded as a formal Italian garden built on the side of a volcano. The undercurrent of chronic illness is like the volcano; it does not go away. It menaces. It erupts. It is out of control. One damned thing follows another. Confronting crises is only one part of the total picture. The rest is coming to grips with the mundaneness of worries over whether one can make it to a bathroom quickly enough, eat breakfast without vomiting, sleep through the night, make plans for a vacation, or just plain face up to the myriad of difficulties that make life feel burdened, uncomfortable, and all too often desperate.\(^{53}\)


\(^{52}\) Thorne, *Negotiating Health Care*, 44.

\(^{53}\) Kleinman, *The Illness Narratives*, 44.
What is also unique about a person who suffers with chronic illness is that he or she may be unable to resolve the ongoing internal dissension with his or her body. For example, the body may frequently be seen as an untrustworthy other. Persons with Crohn's disease never know when the pain will sabotage an event or moment in their lives. They go to bed feeling fine only to awake to an exacerbation. They look for reasons in their diet, emotional state, but no consistent explanations present themselves.

The body may not only be untrustworthy but also a source of humiliation. Control of bowel movements and flatulence is perhaps the chief source of public humiliation for the person with Crohn's Disease. Even when the disease is quiescent the fear of being embarrassed in public is a great source of suffering for the person. Thorne cites one such individual:

It's a disease that is extremely isolating, mostly because of the smell that is associated with Crohn's Disease. It's very offensive. And all the time going to the can. The bowel movements are usually quite offensive, even if it's mostly liquid. There's also a tremendous amount of gas, which is also very offensive. This is very isolating for people who are shy, who are timid, who don't know how to deal with this, who don't know anybody who can say, "look, I fart alot now, and it's pretty awful!" They've got to try and get up and run out of the room if they've got guests, or they can't go to a concert. It becomes a very isolating and lonely disease.54

Living with chronic illness inevitably means the loss of confidence in one's health and normal bodily processes. A closely related feeling is grief and wretchedness over the loss of health, a mourning for the bodily foundation of daily behaviour and self-confidence. Kleinman writes that "the fidelity of our bodies is so basic that we never think of it - it is the certain grounds of our daily experience. Chronic illness is a betrayal of that fundamental

54Thorne, Negotiating Health Care, 65.
In sum, suffering occurs when a threat to the intactness or wholeness of the person exists. I would suggest that this threat to the wholeness of the person has unique implications for the individual who suffers from Crohn's Disease by virtue of the chronicity of the illness. The nature of the chronicity of illness will be explored in the next chapter.

The focus of this chapter has been on the layers of meaning of illness. The distinctive meanings of illness to both physicians and patients have been identified and will serve as a contextual starting point for an analysis of the meaning of care in the next chapter. The prevalent conceptualization of illness as a clinically defined disease state has been shown to be incomplete in light of a broader construal of illness as lived experience. Further, the understanding of illness and suffering as lived experience are key to understanding what care means to those who suffer from Crohn's Disease and other chronic illnesses.

---

55 Kleinman, The Illness Narratives, 45.
If you miss being understood by laymen[sic], and fail to put your hearers in this condition, you will miss reality.

- HIPPOCRATES
CHAPTER 2

THE MEANING OF CARE - A REVIEW OF THE LITERATURE

The focus of the first chapter was on the meaning of illness both from a theoretical, model-based perspective and from the individual perspectives of physician and patient. It was important to begin with an analysis of the meanings of illness in order to lay the foundation for an investigation into the meaning of care. Identifying the starting points of the physicians' and patients' understanding of illness is necessary as a prelude to an investigation of the meaning of care because ultimately there is a direct relationship between illness meaning and the perception of received care as well as the implementation of therapeutic interventions.

This chapter is a survey of the literature relating to the meaning of care. It begins with an examination of the physician-patient relationship then shifts its focus to the differences between acute and chronic illness in light of the meanings of care.

The Clinical Encounter and the Physician-Patient Relationship

The literature supports the premise that social relationships, especially the health care relationships, features powerfully in the lived experience of chronic illness. While everyone within the social universe of a chronically ill person has the potential to create a positive healing environment or create havoc that is detrimental to the therapeutic milieu, perhaps none are so excruciatingly influential upon the whole experience as are the

56Thorne, Negotiating Health Care, 9.
physicians on whom the patients become so reliant.

There exists within the literature, a branch of research that has explored the attitudes of physicians toward their patients for insight about endemic problems in health care relationships. These studies reveal that physicians are often insensitive to the impact of their discourse upon patients\(^{57}\), and increasingly disinclined toward cooperative models of health care.\(^{58}\)

The biomedical model has a profound influence upon the dynamics of the physician-patient relationship. At work is the physician's conceptualization of illness as a diseased state and the patient's lived experience of illness. Studies indicate that the recurring but nonspecific bodily complaints of the chronically ill, those complaints that do not adhere to explanation by the biomedical model, are regularly dismissed by physicians as unimportant or negligible.\(^{59}\) Kleinman writes that, "If there is a single experience shared by all chronically ill patients it is that at sometime their caregivers, including the physician, will come to question the authenticity of their claim to pain."\(^{60}\) Cassell writes that on being presented with a sick person, doctors do not attempt to find out what is the matter but, rather, attempt to make a diagnosis. He says that this is not the same thing:


\(^{60}\) Kleinman, The Illness Narratives, 57.
Diagnoses are relatively sharply defined names for diseases that are believed to exist when certain criteria are met by the patient's history, physical examination, or laboratory or other tests. In the event that the criteria are not met, it may be concluded by the physician that the patient's complaint is not a bona fide illness. Nevertheless the patient still experiences him or herself as sick.  

Correspondingly, studies of how patients perceive medical encounters further document the extent of the problem. Several researchers have concluded that dissatisfaction with such encounters is widespread and that it has a detrimental effect on both the psychological and the medical effectiveness of the consultation. Such dissatisfaction is strongly linked to issues of communication between health care providers and patients.

Toombs believes there is a systematic distortion of meaning which emerges in the physician-patient encounter. Rather than communicating on the basis of a shared set of assumptions, physicians and patients routinely communicate with one another from within


the context of different "worlds".\textsuperscript{64}

The source of this difficulty may be found in the assumptions made by the patient and physician that they are discussing a shared reality, a common object. This assumption is made on the basis of two idealizations of what Toombs calls the "general thesis of reciprocal perspectives"\textsuperscript{65}. First, through the idealization of the "interchangeability of standpoints"\textsuperscript{66} an assumption is made by both the physician and the patient that if they were to change places then each would see essentially what the other sees. In this case the patient takes for granted that the physician recognizes the illness as primarily a threat to his or her personal being and the physician assumes that the patient understands the disease in terms of objective clinical data. Secondly, through the idealization of the "congruency of the system of relevances"\textsuperscript{67} the physician and patient take for granted that the difference in perspectives originating in their own unique biographical situation is irrelevant for the purpose at hand, and that both of them have interpreted the illness in an identical manner. Toombs writes that there is an "unshareability characteristic about illness which derives from its being an 'inner' subjective event rather than an 'outer' objective event."\textsuperscript{68} This unshareability of the subjective illness experience makes it very difficult for the patient and physician to establish a common ground of meaning.

\textsuperscript{64}Toombs, \textit{The Meaning of Illness}, xv.

\textsuperscript{65}Toombs, \textit{The Meaning of Illness}, 9.

\textsuperscript{66}Toombs, \textit{The Meaning of Illness}, 24.

\textsuperscript{67}Toombs, \textit{The Meaning of Illness}, 25.

\textsuperscript{68}Toombs, \textit{The Meaning of Illness}, 23.
Difficulties arise because the patient and the physician both assume that, in communicating about the illness, they are doing so on the basis of a shared understanding when in fact they are not because they do not share a similar system of relevance. Thus, the failure of the general thesis of reciprocal perspectives, which is grounded in the unshareability aspect of illness, present particular difficulties for the establishment of a shared world of meaning.\textsuperscript{69}

Incongruencies in these differing conceptualizations of illness are at the root of the fundamental distortion of meaning in the physician-patient relationship and some, including this author, would argue that these incongruencies act as a hindrance to the healing covenant. The implication here is that when physician and patient talk about illness they are not talking about the same thing. In Toombs words they are not sharing a common "reality".\textsuperscript{70}

\textbf{Acuity, Chronicity, and the Ends of Medicine}

When suffering occurs in the course of most types of acute disease, medical or scientific understandings of the body and disease seem adequate to explain why the threat to the integrity of the person exists. This is generally not the case with regards to chronic illness because the illness is generated not only in the body but it exists at every level of the human condition, from the molecular to the communal.

An important differences between chronic illness and acute illness is the presence

\textsuperscript{69}Toombs, \textit{The Meaning of Illness}, 25.

\textsuperscript{70}Toombs, \textit{The Meaning of Illness}, xv.
of a progression of symptoms over an extended period of time. Unlike acute illness, Chronic illness can be marked by acute exacerbations and periods of relative quiescence and remission yet the illness is always present in some form or another regardless of its immediate expression on the individual's body. Chronic illness is also characterized by periods during which the symptoms arise from the illness and then contribute to the continuation of the illness.\textsuperscript{71} The symptoms and abnormal functioning in chronic illness also lead inevitably to compensatory abnormalities of function or behaviour. These counteractive mechanisms then become active parts of the illness. For example, simple reduction in physical activity may begin to reduce effective muscle mass, which in turn, makes physical activity even more difficult. With Crohn's Disease the sick person may also develop reclusive behaviours that further exaggerate the social loss when symptoms such as abnormalities of chronic diarrhea, pain and flatulence make social interactions painful.\textsuperscript{72}

Suffering is common to all illness, both acute and chronic yet the unique characteristics of the chronicity of illnesses such as Crohn's Disease define suffering in a broader, and pluralistic manner, manifested not only in bodily pathology and its accompanying pain but also in the social ills of the lived experience of chronic illness.

In their article "Ethical Challenges of Chronic Illness" authors Bruce Jennings et al respond to the distinctive ethical issues posed by chronic illness. They argue that,

\begin{flushright}
71 Cassell, \textit{The Nature of Suffering}, 64.
\end{flushright}

\begin{flushright}
72 Cassell, \textit{The Nature of Suffering}, 51.
\end{flushright}
illness and disability….What is needed, instead, is a different conception of the proper ends of medicine in the face of chronic illness, and beyond that, a better understanding of the human and social meaning of chronic illness.\(^{73}\)

Typical of acute care medicine, illness is seen as an external objectified threat that suddenly intrudes upon a preexisting condition of health and well-being. The goal then of acute care medicine is to restore one's freedom from illness by curing the body of this alien threat. Chronic illness care is typically provided by professionals educated toward acute curative models, and in structures designed to provide emergency and highly technical services.\(^{74}\)

The chronic nature of illnesses such as Crohn's Disease demands a rethinking of the existing goals of medicine that primarily adhere to an ethic of cure. With comparatively less understanding of the etiology and biological pathways of the disease, variability and uncertainty of clinical symptoms, and the absence of cure, chronic illness is an omnipresent, dynamic component of the person's overall state of being.

Medical intervention for chronic illness attempts to slow the progress of the disease and maintain effective management of symptoms. As Callahan adds, "Chronic care must proceed from a starting point of recognition that chronic illness is a component of the person's overall state of being." and further that "medicine's role in chronic care is to facilitate the process of negotiation,.....diplomacy is perhaps a better metaphor than warfare for this kind of care."\(^{75}\) Pellegrino and Thomasma believe that the end goal of medicine

\(^{73}\) Jennings, Callahan, & Caplan, "Ethical Challenges of Chronic Illness," 3.

\(^{74}\) Thorne, \textit{Negotiating Health Care}, 9.

\(^{75}\) Jennings, Callahan, & Caplan, "Ethical Challenges of Chronic Illness," 10.
should entail primarily the relief of the perceived bodily disruption, the restoration to a
former or better state of perceived health or well-being. This may include, but is not
limited to, a cure of organic dysfunction. Indeed, in order to address the patient's experience of
disorder, attention must be paid not only to the manifestation of a disease state but also to
the changing relations between body, self and world. Kleinman supports this philosophy
when he writes that "the purpose of medicine is both the control of disease processes and
care for the illness experience. Nowhere is this clearer than in the relationship of the
chronically ill to their medical system. For them, the control of disease is by definition limited
and care for the life problems created by the disorder is the chief issue." 76

The importance of Medicine's acute-care focus on a "cure" cannot be
underestimated. Unlike many acute illnesses where a cure or other resolution is within the
grasp of medical science, for many illnesses such as Crohn's Disease, this is not the case
and the realization of a complete cure is unlikely, at least in the near future. This distinction
is especially important for this thesis which is critical of the existing biomedical ethic of care
that is characterized by a cure-centered, acute care orientation.

In sum, suffering and the chronicity of illnesses such as Crohn's Disease pose a
challenge to the traditional understanding of the ends of medicine, specifically the goals of
care and the nature of the physician-patient relationship. A more patient-centered ethic of
care for the chronically ill, one that accepts the reality of improbability of cure, demands a
shift from a cure-centered focus to a care-centered approach.

**Chronic Illness and Chronic Disease**

It is also helpful to distinguish between chronic illness and chronic disease for the purposes of this paper because the two are often incorrectly used synonymously. Chronic disease, as defined by scientific medicine, is that dimension of the illness experience that takes place within the parts of the body over an extended period of time.\(^{77}\)

Disease, for this discussion, is the specific entity characterized by disturbances in structure or function of any part, organ, or system of the body. Chronic illness, on the other hand, afflicts whole persons and is the set of disordered functions, body sensations, and feelings by which persons know themselves to be unwell.\(^{78}\) This thesis argues that chronic illness experience is much more than the confinement of the disease to the body and its parts. Diseases should be understood as category names that include only one in the series of events that is chronic illness. The dimensions of chronic illness extend to virtually all levels of human existence from the molecular to the social.\(^{79}\)

**Care and Chronic Illness**

Jean Watson argues that caring should be held as a moral ideal that entails a commitment to a particular end. That end is the protection and enhancement of human dignity. In this sense, an ethic of caring has a distinct moral position; caring is attending and

\(^{77}\) Cassell, *The Nature of Suffering*, 49.

\(^{78}\) Cassell, *The Nature of Suffering*, 49.

\(^{79}\) Cassell, *The Nature of Suffering*, 50.
relating to a person in such a way that the person is protected from being reduced to the moral status of object.\textsuperscript{80}

In their book \textit{Patient-Centered Medicine: Transforming the Clinical Method}, Stewart et al. state that the first task of medicine is to respond to a patient's suffering and that the failure to respond to suffering is one of medicine's perennial moral problems. The authors write that "this recognition is the beginning, middle and end of the ethic of caring."\textsuperscript{81} Kleinman, in his analysis of the central purpose of medicine, adds that there is a "moral core" to healing, common in all societies.

Sally Gadow argues that care is the highest form of commitment to patients even moreso than a commitment to cure. Gadow holds the view that care is an end in itself, defined as a covenontal relationship, with a commitment to alleviating another's vulnerability. She uses the example of surgical intervention in defence of her assertion that her definition of care is a generalized statement of all health care provision. Surgery, says Gadow, thought to be the most dramatic effort to alleviate vulnerability, is actually the opposite of the concept she is proposing because the goals of surgical intervention are achieved through the exercise of power by one person over another, and the exercise of power always increases the vulnerability of the one over whom it is exercised, no matter what benevolent purpose the power serves. Gadow goes as far as to suggest that all measures directed toward the cure of a condition require the exercise of power and thus


are the most difficult to include within the realm of care. They can be included, however, provided that the powerlessness created by the treatment is regarded as a vulnerability that calls as urgently for alleviation as the initial disease-induced vulnerability. In other words, it is only within the context of care that the overpowering of one person by another that cure entails be redeemed.

Gadow’s proposal inverts the traditional framework. In the usual view, cure is the standard, the overriding goal, and care is but a means to that end. This is the focus of acute care medicine where curable illness is seen as the morally clearest situation with the fewest issues. Chronic illness on the other hand presents a morally blurred situation because of the variety of interventions available. The eventual futility of any of them, compounded at times by the veiled character of the condition, make the morally right response very difficult to discern. In Gadow’s view the opposite is true. Acute conditions, she argues, create the greater moral problem, exactly because of the unequivocal effectiveness of the external intervention and thus the degree of power exerted over the individual to achieve that effect. Chronic illness, on the other hand, offers few possibilities to wield that degree of power over a patient’s condition and thus less temptation to risk violating the covenant of care by creating increased vulnerability in the person with whom has been covenanted to alleviate vulnerability. 82

Models of Care

In reviewing the literature on the meaning of care I discovered that this body of information is almost exclusively contained within the field of nursing ethics now commonly referred to as the Ethics of Caring.\textsuperscript{83} This reality, I believe, is further evidence of the poverty that exists within the field of doctoring in respect to the academic focus and reflection upon the nature of care. I have chosen to present a summary of some of the main perspectives on the meaning of care, while this survey is by no means exhaustive, it does offer a foundation for analysis of the primary research in Chapter 4.

A. The Cultural Model

The cultural model of care was developed from anthropological and sociological studies of caring behaviours in various world cultures. This model which is evident in the work of Madeleine Leininger and others, relates caring to cultural beliefs and practices.

Madeleine Leininger, who has written extensively on the meaning of care, maintains that caring is the essence of humanity, and that it is essential for human growth and survival. She contends that care is one of the most powerful and elusive aspects of our culture and that care must be the central focus of the helping and healing professions.\textsuperscript{84}

\textsuperscript{83}Watson, \textit{The Ethics of Care and the Ethics of Cure: Synthesis in Chronicity}, 1.

\textsuperscript{84}Madeleine Leininger has done extensive work in the area of care concluding that caring is the central and unifying domain for the body of knowledge and practices in the field of nursing. Although she believes that caring behaviour and practices distinguishes nursing from other disciplines, she agrees that caring is at the heart of all health care services. For this reason, I believe that Leininger's findings are applicable to physicians and their care of patients.
Formally, she defines care as the assistive, supportive, or facilitative act toward or for another individual with evident or anticipated needs to ameliorate or improve a human condition. Leininger defines professional care as the cognitive and culturally learned action behaviours, techniques, processes, or patterns that enable or help an individual to improve or maintain a favourably healthy condition or lifeway.\(^{85}\)

Leininger differentiates between scientific and humanistic caring. Scientific caring refers to those judgments and acts of helping others based upon tested or verified knowledge; whereas humanistic caring refers to the creative, intuitive, or cognitive helping process for individuals based upon philosophic, phenomenologic, and objective and subjective experiential feelings and acts of assisting others. Leininger sees the distinction between scientific and humanistic caring as typifying the conceptual differences physicians and nurses.\(^{86}\)

Leininger's approach to studying care has revealed that it is important for caregivers to understand the worldview of the patient. She says that the caregiver needs to understand the world of the patient; able to feel, know, and experience his or her world. In caring, Leininger writes that "one tries to get a broad gestalt of another person's

\(^{85}\)In her research on caring, Leininger has discovered the following constructs to be closely associated with care: support, tenderness, touch, compassion, empathy, stress alleviation, presence, loving acts, comfort, direct and indirect helping behaviours, enabling, facilitating, nurturance, succorance, surveillance, protection, restoration, instruction, coping, concern, interest in, trusting, and need fulfilment. See Madeleine Leininger, "The Phenomenon of Caring: Importance, Research Questions and Theoretical Considerations," in Madeleine Leininger, *Caring: An Essential Human Need*, (New Jersey: C.B. Slack, 1981), 4.

lifeways...sensitivity and attention to the aspects of values and beliefs are important in seeing the worldview of another human being, as well as the context in which that individual lives...a worldview approach is essential to conceptualize paradigms, theories and models related to holistic caring.  

Leininger argues that there is both a professional and conceptual difference between doctors and nurses in their focus of health care delivery. Her research has shown that physicians are disciplined and oriented toward curing with a focus on physical diagnoses, internal pathology and treatments aimed at cure. Typically, physicians respond to their patients with a disease oriented approach to diagnosis and treatment with the goal being to cure the individual of his or her ailment. It is this chasm separating the needs of the patient and the ends of the physician that often precludes the possibility of meaningful consensus between them.  

In contrast, nurses are more concerned with caring acts and processes focusing on multiple factors influencing wellness and illness. She writes that, "the physician often experiences considerable difficulty in being assistive to a patient's need for caring, especially with the incurably ill, for whom diagnosis or curative treatments are impossible. Nurses have never been restricted to a curative ethic and thus have always been able to...


89Leininger, Care: The Essence of Nursing and Health, 47.
care for people independent of medical diagnoses and treatment regimens".90

B. The Humanistic Model

The humanistic model typically characterizes care as a beneficent will, commitment, intention or ideal towards human beings. Caring is seen as a mode of being that calls for a philosophy of moral commitment toward protecting human dignity and preserving humanity. For the humanist, caring is defined as "the human mode of being".91 In other words, people care because they are human; caring is the defining expression of humanity and is essential to our development and fulfilment as human beings.92

Roach writes that "care, as the human mode of being, entails the power or capacity to care, a capacity linked with and inseparable from our nature as human beings". She adds that this has profound implications for those in the helping professions especially physicians, "caring should be the concept that subsumes all the attributes descriptive of doctoring as a human, helping discipline. Doctoring is the professionalization of the human capacity to care through the acquisition and application of knowledge, skills and a healing attitude."93

90 Leininger, Care: The Essence of Nursing and Health, 47.

91 Simone Roach The Human Act of Caring, (Ottawa: Canadian Hospital Association, 1987), 133.


Roach says that caring, as it applies to the health care provider, is multifaceted and involves attributes that she calls the "five C's": Compassion, Competence, Confidence, Conscience, and Commitment.\textsuperscript{94} The five C's of professional caring, while not exclusive, serve as a helpful basis for the identification of specific caring behaviours.

Care is dependent upon a trusting relationship between the patient and the physician. The hallmark of this trusting relationship is the confidence that the patient has in the physician. When considering the profession of the physician, competence demands that the physician have the knowledge, judgement, skills, energy, experience, and motivation required to respond adequately to the demands of his or her professional responsibilities.

Conscience is the moral awareness of the physician attuned to the needs of the patient. Roach writes that care "expresses itself as an affective response to something that matters, it is an intentional response, deliberate, meaningful and rational."\textsuperscript{95}

Commitment is a necessary quality of the physician where he or she invests the self in the care of the patient.

Compassion, derived from the Latin \textit{pati-cum}, meaning \textit{to suffer with}, may be defined as a sensitivity to the pain and brokenness of another, engendering a response of participation in the experience of another; a quality that allows one to share with and make room for the other.\textsuperscript{96} Roach cites Henri J.M. Nouwen who writes that compassion:

\begin{itemize}
  \item \textsuperscript{94} Roach, "The Call to Consciousness: Compassion in Today's World," 9.
  \item \textsuperscript{95} Roach, "The Call to Consciousness: Compassion in Today's World," 65.
  \item \textsuperscript{96} Roach, "The Call to Consciousness: Compassion in Today's World," 62.
\end{itemize}
involves going where it hurts, to enter into the places of pain, to share the brokenness, fear, confusion, and anguish. Compassion challenges us to cry out with those in misery, to mourn with those who suffer loneliness, to weep with those in tears. Compassion requires us to be weak with the powerless. Compassion means full immersion in the condition of being human.\textsuperscript{97}

Edmund Pellegrino, physician and humanist, believes that a physician has the obligation to promote the good of the patient with whom he or she has a special relationship. He uses the term "medical humanism" to describe the application of cognitive skills, derived from the humanities, and the compassionate response of the physician to the person of the patient. Pellegrino writes:

\begin{quote}
Medical is then all three, science, art and virtue synergistically and integrally united in the clinicians daily activities. To disarticulate one member of this triad from the others is to dismember medicine - the essential feature of which is the special relationship each holds to the other. When this happens, one becomes a scientist, an artist or a practitioner but not a physician.\textsuperscript{98}
\end{quote}

Sigridur Halldorsdottir conducted research into patients' perceptions of caring and uncaring encounters with health care providers. Based on the results, Halldorsdottir formulated five basic modes of being that a caregiver can have with a patient, namely: life-giving (biogenic), life-sustaining (bioactive), life-neutral (biopassive), life-restraining (biostatic), and life-destroying (biocidic).


The life-destroying (biocidal) mode of being with a patient is the most disintegrated form of indifference to the patient as a person, it involves harshness and inhumanity, and is characterized by various forms of inhumane attitudes.

The life-restraining (biostatic) mode of being with a patient involves the patient feeling strongly that the physician does not care and is blind to his or her feelings. Here, the physician often treats the patient as a nuisance.

The life-neutral (biopassive) mode of being is characterized by perceived apathy, which refers to the approach in which the physician is perceived to be inattentive to patients and their specific needs.

The life-sustaining (bioactive) mode of being means that the physician is skillful, knowledgeable, and committed to the provision of personalized care. The physician also knows how to safeguard the personal integrity and dignity of the patient.

The life-giving (biogenic) mode of being involves undeniable compassion, responsiveness, and benevolence. The physician seeks to connect with the patient by understanding how the illness effects the patient's whole life. The truly life-giving presence restores well-being and human dignity.

Some of Halldorsdottir's patients bore witness to the claim that perceived caring positively influences the patient's ability to recover, "it's (caring) another form of medicine of sorts...it's part of the healing, part of the getting the patient better, and it's creating the climate for the patient getting better."99 One of Halldorsdottir's co-researcher's concluded that "...the effect on the psyche of a person is very much a part of the healing, because I

---

99 Gaut & Leininger, Caring: The Compassionate Healer, 45.
believe in treating the whole person, treating them as body, mind, and spirit, not just body alone but the three of them combined, and if their psyche is being damaged or uncared for, then how can their body get well?"\textsuperscript{100}

C. The Feminist Model

The feminist model of care, with its roots in women's experience, describes caring within a feminist perspective of moral development and cultural practices.\textsuperscript{101} Because women are usually charged with the responsibility of caring for children, the elderly, and the ill, most women experience the world as a complex web of interdependent relationships, where responsible caring for others is implicit in their moral lives.\textsuperscript{102}

Carol Gilligan, an advocate of the feminist model of care, argues that there is a marked difference in moral thinking between men and women and that this distinction accounts for differences in the way men and women understand care. She found that when women are presented with moral conflicts, they tend to focus on details about the relationships that hold between the individuals concerned, and they seek out innovative solutions that protect the interests of all participants; that is, they strive to avoid bringing harm to anyone. Gilligan distinguishes this as an ethic of care in contrast to an ethic of justice, characterized by men, who tend to try to identify the appropriate rules that govern

\textsuperscript{100}Gaut & Leininger, \textit{Caring: The Compassionate Healer}, 46.


the sort of situation described; they select the course of action most compatible with the
dominant rule, even if someone's interest may be sacrificed to considerations of justice.\textsuperscript{103}

Nel Noddings believes that caring is not only morally significant but that it is the only
legitimate moral consideration. An agent's moral obligation, in Noddings view, is to maintain
conditions that permit caring to flourish. Ethical behaviour involves putting oneself at the
service of others and seeing the world from their perspective. \textsuperscript{104} For her, one cares through
the modalities of receptivity, relatedness, and responsiveness.

The feminist model contributes to the theory of human caring a call for increased
emphasis on fostering relatedness, relationship and connectedness. The ideals of human
caring that are rooted in receptivity, intersubjective relatedness, and human responsiveness
help to counteract the predominant medical ethic of rational principle, fairness, and equity
that objectifies, detaches, and distances the professional from the subjective world of the
human experience. This author recognizes the key role feminist ethics plays in defining an
ethic of care for the chronically ill because like women, the chronically ill are often
subordinated and marginalized\textsuperscript{105} by the health care system and often, upon reflection,
experience feelings of oppression.

\textsuperscript{103} Sherwin, \textit{No Longer Patient: Feminist Ethics and Health Care}, 46.

\textsuperscript{104} Sherwin, \textit{No Longer Patient: Feminist Ethics and Health Care}, 47.

\textsuperscript{105} S. Kirby and K. McKenna use the term "marginalized" as a corner stone of their
qualitative methodology described in their book \textit{Experience, Research, Social Change:}
D. The Patient-Centered Model

In his research into the nature of medical interviews, Mishler identified two contrasting voices that typify the physician-patient interaction: the voice of medicine and the voice of the lifeworld. The voice of medicine asks questions such as, "Where does it hurt?", "When did it start?", "How long does it last?" and, "What makes it better or worse?" In contrast the voice of the lifeworld asks questions such as, "What are you most concerned about?", "How does it disrupt your life?", "What do you think it is?", and "How do you think I can help you?" Mishler argues that interactions between doctors and patients are typically doctor-centered. The physician’s task is to make a diagnosis; thus, in interviewing a patient, the doctor selectively attends to the voice of medicine, often not even hearing his patient’s attempt to make sense of his or her own suffering. What is needed instead, says Mishler, is a different approach to care in which doctors give priority to patients’ lifeworld contexts of meaning as the basis for understanding, diagnosing, and treating their problems.  

The patient-centered model of care presupposes a change in the mindset of the physician. The hierarchical notion of the physician being in charge and the patient being passive does not hold here. To be patient-centered, the physician must be able to empower the patient, to share the power in the relationship. This means renouncing control that traditionally has been in the hands of the physician.

Patient-centered care focuses on the patient’s disease and illness and on the patient as a whole person. The words heal, health, and whole, are all derived from the same linguistic root meaning to restore a sense of coherence, wholeness, and connectedness.

Care and healing of a patient must involve a process of restoring the patient's loss of connectedness and control. Stewart et al. write that:

disease and illness cannot be viewed in isolation, patient-centered care includes understanding the person and the world in which he or she lives...a patient-centered ethic of care attempts to integrate illness meanings within the context of the individual's position in the life cycle and his or her life context. The life cycle includes the individual's unique personality development, the life context includes family, friendship networks, employment, school, religion, culture, and the health care system.\textsuperscript{107}

**Empathy and the Use of Narratives**

Charron identifies two distinct types of knowledge that are collected and used by physicians. The first, \textit{Logico-scientific knowledge} collects and evaluates replicable, universal, generalizable, and empirically verifiable information. The tools of such knowledge are mathematics, logic, and the sciences; its language must be nonallusive, nonambiguous, and reliable.\textsuperscript{108} The other, \textit{Narrative knowledge}, seeks to examine and comprehend singular events, contextualized within their time and place.

The patient's narrative or story includes the meanings that a particular person gives to their lived experience of illness. Clinical histories are narratives because they recount and interpret events, bound in some form of chronology, that have befallen persons with illness. Clinical medicine emerges as an activity rooted in an appreciation of meaning in the lives of others.

\textsuperscript{107}Stewart, Brown, Weston, McWhinney, McWilliam, & Freeman, \textit{Patient-Centered Medicine: Transforming the Clinical Method}, 44.

Narratives bear the stamp of their tellers, who are not detached observers but who actively participate in generating the stories they tell. They rely on such features as metaphor and allusion to convey messages about the particular and to suggest causal connections among random events. Narrative language reveals affective as well as cognitive dimensions of the teller and the subjects.\textsuperscript{109}

Charron argues that physicians need to use both forms of knowledge in their clinical work, not one first and then the other, but a weaving of these mental processes by which a physician applies what is known about the human body in general to the particular human person in question.

Well trained in the logico-scientific method, doctors have until recently paid little attention to their narrative training. Underexposed to narrative knowledge and overschooled in the logico-scientific, doctors gradually lose their abilities to tell and to be moved by stories of human suffering. Yet, when one inspects the work of the clinician, one finds that the work of medicine in considerable part rests on the physician’s ability to listen to the stories patients tell, to make sense of these often chaotic accounts of illness, to inspect and evaluate the listener’s personal response to the story being told, to understand what these narratives mean at the multiple and sometimes contradictory levels, and to be moved by them.\textsuperscript{110}

At present, the ideal clinician is depicted as being warm towards the patients feelings and concerns, and yet detached and emotionally neutral. The physician-patient relationship

\textsuperscript{109}Charron, “The Narrative Road to Empathy,” 149.

\textsuperscript{110}Charron, “The Narrative Road to Empathy”, 150.
must be reforged is such a way that misplaced concerns for sympathetic objectivity are replaced by the pursuit of an empathic understanding of the patient's personhood and how it has been impinged upon in illness.\textsuperscript{111}

According to Benner and Wrubel, care is perceived by patients to include the physician's deep understanding of them based on knowledge derived from professional education and clinical practice, as well as from listening to their story.\textsuperscript{112} It is only with narrative competence that a physician can deliver empathic care. Without the patient's robust narrative world the physician cannot enter into the patient's suffering world, cannot offer comfort, and cannot accompany the patient through the illness experience. Only doctors who have developed narrative competence will recognize their patients' motives and desires, will allow patients to tell their full stories of illness, and will offer themselves as therapeutic instruments.\textsuperscript{113}

In this chapter the literature on the meaning of care has been surveyed. Care in chronic illness includes not only attending to the suffering of the injured body but also to the biopsychosocial needs of the patient's lifeworld that are profoundly affected by the illness experience. In the next chapter the qualitative methodology used in the primary research


\textsuperscript{113} Charron, "The Narrative Road to Empathy", 150.
will be described. The protocol for carrying out the interviews will also be outlined.
Researching from the margins is a continuous process that begins with a concern that is rooted in experience...concurrently the researcher engages in a process of self-examination as one of the participants in the process of creating knowledge.\(^{115}\)

CHAPTER 3

METHODOLOGY OF THE PRIMARY RESEARCH

The focus of the previous two chapters has been on the meaning of illness, suffering, and care. The review of the literature has provided a foundation upon which the primary research can investigate the subjective meanings of illness and care. This chapter will focus on the methodology of the primary research.

Research Methodology

The type of research conducted was qualitative, in which the ultimate aim is to study situations from the participants' point of view.\textsuperscript{116} Based on grounded theory, the objective of this protocol of research methodology is to elicit theory from the data gathered using interviews.\textsuperscript{117}

The methodology that is used in this thesis was developed by Sandra Kirby and Kate McKenna in their book \textit{Experience Research, Social Change: Methods from the


\textsuperscript{117}Grounded Theory refers to a research methodology which is used to build theory based on the data collected. No hypotheses or theoretical constructs are held in view before beginning the research. Various research procedures can be used in grounded theory research including unstructured interviewing and direct observation. (See B.G. Glaser & A. Strauss, \textit{The Discovery of Grounded Theory: Strategies for Qualitative Research}, Chicago: Aldine, 1967.)
Margins. 118 Research from the margins proposes a methodology that asserts that researchers must include and account for their own experience and understanding as part of doing research. This means that researchers must invest part of themselves in the process of creating new information. Researchers are thus an ingredient of their own research.119

Kirby and McKenna describe the margins as the context in which those who suffer injustice, inequality and exploitation live their lives. This author holds the view that because of the dominant ethos of acute care medicine that guides the doctor-patient interaction, those who suffer from chronic illness oftentimes live on the margins in their day to day dealings with physicians.

This methodology thus allows for the creation of knowledge that is rooted in and representative of the experience of those who live with Crohn’s Disease. As Kirby and McKenna put it, “Research from the margins is not research on people from the margins, but research by, for, and with them.”120

I have elected to use this methodology for three reasons. First, researching from the margins is a continuous process that begins with a concern that is rooted in experience. For the purposes of this thesis that experience is the lived-experience of

118 This method involves two interrelated processes. First, research from the margins requires intersubjectivity: an authentic dialogue between all participants in the research process in which all are respected as equally knowing subjects. Second, it requires critical reflection which involves an examination of the social reality in which people exist. S. Kirby and K. McKenna. Experience, Research, Social Change: Methods from the Margin. (Toronto: Garamond Press, 1989), 34.

119 Kirby and McKenna, 7.

120 Kirby and McKenna, 28.
chronic illness. Research which is experientially based provides a richer data base with
greater detail. This research, in turn, leads to greater descriptive power in the resultant
analysis.  

Second, research from the margins recognizes the integral role of the
researcher’s experience and familiarity with the research question. The more familiar
with the experience the researcher is, the better potential understanding of it he or she
will have. The research process consists of planning to gather first-hand information,
actually gathering it and then making sense of it. Concurrently, the researcher engages
in a process of self-reflection as one of the participants in the process of creating
knowledge. Kirby and McKenna refer to this process of self-reflection as conceptual
baggage. They describe it as a form of self-interview done by the researcher
concerning ideas about the research question both at the beginning and throughout the
research process.

It (conceptual baggage) is the recognition of the researcher’s personal
assumptions about the topic and research process, assumptions that are
always present but rarely acknowledged. When the researcher makes his
thoughts and experience explicit, another layer of data is revealed for
investigation. This adds another dimension to the research, the researcher
becomes another subject in the research process and is left vulnerable in
a way that changes the traditional power dynamics/hierarchy that has
existed between researcher and those who are researched.  

---

121 Ibid., 44.
122 Ibid., 44.
123 Ibid., 44.
124 Kirby and McKenna, 32.
Unlike other research methods that frown upon researcher involvement in the research and seek neutrality or objectivity, the researcher in this methodology is encouraged to use his or her experience to guide the way the research is done and how it is understood, for this experience is at the centre of the research process.\textsuperscript{125}

This method allows for a more participative role of the researcher, an approach that allows the researcher to develop a more empathic rapport with the participants. This seemed appropriate given that the researcher in this study shared the lived experience of Crohn's Disease with the research participants. During the course of the interviews, all of the participants would comment on how much easier it was to tell their story to someone who shared their experience of living with Crohn's Disease.

Third, researching from the margins is based on the commitment to advancing knowledge through a process of exploration grounded in the experience of people who have usually been treated as the objects of research.\textsuperscript{126} This principle has direct relevance for this study which supports the thesis that the existing ethic of care that characterizes the medical community in its approach to people with chronic illness is one that by its focus on the pathophysiology of the diseased body treats the body-in-illness as object.

The research involved eight human subjects using a semi-structured, open interview style. The participants were three males and five females. Although a stratified

\textsuperscript{125}Ibid., 45.

\textsuperscript{126}Ibid., 61.
age distribution was not targeted in recruiting research participants, the resulting participant pool showed an age range between 19 and 54 years of age.

The age distribution was as follows:

<table>
<thead>
<tr>
<th>AGE</th>
<th>WOMEN</th>
<th>MEN</th>
</tr>
</thead>
<tbody>
<tr>
<td>UNDER 20</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>20-30</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>30-40</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>40-50</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>OVER 50</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5</td>
<td>3</td>
</tr>
</tbody>
</table>

Research participants were recruited by word of mouth through personal contacts in the Windsor-Essex County community and through a call for research participants posted at education meetings of the local chapter of the Crohn’s and Colitis Foundation of Canada. Following the University of Windsor’s *Guideline’s on Research Involving Human Subjects*, a consent form to be signed by the participants prior to the interview was drafted and approved by the Ethics Committee, Department of Religious Studies, at the University of Windsor (See Appendix 1).

An interview time was arranged with each of the participants at a time and place convenient to them. The consent form was signed by each research participant prior to the start of the interview. The researcher also explained the nature of the research to each participant and gave each the opportunity to ask any questions that he or she might have about the research and the implications of their involvement. The participant
was then asked to sign the consent form, a copy of the consent form was then given to
the participant (Appendix A). The interviews were tape recorded and then personally
transcribed by the researcher. Each interview lasted approximately one hour.

**Interview Format**

A semi-structured format (Appendix B) was used for interview design. This format of an
interview is one in which a topic is introduced, and the discussion is guided through the
use of open-ended questions by the interviewer. Characteristic of qualitative research,
the interview was designed in a way most conducive to allowing the participants the
opportunity to share their story and associated meanings, rather than focusing heavily
on rigidly maintaining a structured interview across all respondents.

The open-ended nature of the questions allowed for the development of an
understanding of the complex and varied meanings of illness and care held by those
who live with Crohn's Disease without imposing a pre-conceived and artificial structure.

Each interview began with general questions with the intention of giving the
participants a sense of the informal nature of the process and allowing them the
opportunity to feel comfortable with the interview process and the presence of the tape
recorder. These opening questions were of a demographic nature regarding age, marital
status, employment, family, etc. These questions also gave the researcher an
opportunity to build a rapport with the participant.

The participants were then invited to share their illness narrative. Some
clarification was given as to the open-endedness of this question. Participants were
encouraged to begin their story wherever they wished. The broad nature of the opening
question allowed the participants the freedom to focus on any particular issue or aspect of their illness experience that was relevant or meaningful to them. The researcher used these issues as prompts for further discussion in the interviews.

As the interview progressed the participants were asked to comment on some of the specific themes pertinent to the investigative objectives of this study such as their personal perceptions and meanings of illness, suffering, and care. The participants were also encouraged to share specific stories of interactions with physicians encountered over the history of their illness (see Appendix B). Each interview ended with the participants having the opportunity to ask any questions about the study.

**The Use of the Narrative**

The narrative is a way of examining the meaning of illness and care from a phenomenological perspective. It is a valuable way for individuals to communicate personal perceptions and meanings to an enquirer because individuals organize a large part of their experience in the form of a story, or narrative structure. The narrative serves as an important tool in people’s attempts to understand and give meaning to their experiences.\(^{127}\)

There are commonalities experienced by those who suffer from Crohn’s Disease and consequently their narrative framework will, to a certain extent, be shared by others who live with chronic illness. A narrative analysis will seek to establish the meanings and commonalities that tie the individual narratives together. The themes generated by the

shared experience of living with a chronic illness will hopefully lead to the formation of a group narrative. It is hoped that through a narrative analysis of the sufferers' meanings of illness and care that a group generated narrative can be accessed, one that will provide commentary on the need for a more patient-centered ethic of care.
So great is the assault of illness upon our being that it is almost as if our natures themselves were ill, as if the strands or parts of us were being forced apart and we verged on the loss of our own humanness. A phenomenon so great in its effects that it can threaten us with the loss of our fundamental humanness requires more than technical competence from those who would treat illness.\textsuperscript{128}

\footnotesize\textsuperscript{128}V. Kestenbaum, \textit{Humanity of the Ill: Phenomenological Perspectives}, (Knoxville: University of Tennessee Press, 1982), viii.
CHAPTER 4

CONTENT AND ANALYSIS OF THE INTERVIEWS

In this chapter the content of the interviews will be reported according to general themes that evolved over the course of the interviews. The thematic content of the interviews will be analyzed in light of the findings of the literature in chapters one and two.

The content and analysis is organized under two main areas; Illness Story and the Care Relationship. Discussed within the area of Illness Story the following themes were evoked from the transcript analysis: everyday living, control, pharmacological effects, social suffering, family issues, and emotional and psychological effects. Under the general heading of the Care Relationship the themes of negative interactions and positive interactions were noted.

Illness Story

Each of the interviews began with the participants being asked to give an account of their illness story. They were encouraged to begin wherever they wished and were given liberty to comment on any topic or aspect of living with Crohn's Disease.

All of the participants began their narrative accounts at a time prior to the occasion when they were given a definitive diagnosis of having Crohn's Disease. All shared the experience of going through a lengthy period from the time of the first onset of symptoms
to the time they were told that they had Crohn's Disease. For all the respondents this period of time between the early onset of symptoms and final diagnosis was marked by confusion, bewilderment and most of all fear. Two of the respondents said that they feared that their unknown sickness was indicative of a terminal illness.

...when I first got sick I thought "Oh my God, it's AIDS and I'm gonna die" I mean that's all there is to it. a lot of my symptoms were similar to the first symptoms of AIDS and so I was sure that was what it was, I mean I could have gone down a check list and I have to say I was kind of pleasantly surprised when they told me it was Crohn's Disease...

...I kept having pains and you know I even had myself tested for HIV that's how bad the pain was, I thought there's something wrong with me...that's what you think, fatigue, weight loss, fever, I mean the worst goes through your mind - Cancer, I'm dying...

All of the participants expressed a feeling of relief upon finally being told that they had Crohn's Disease. The relief came both from the realization that the disease they had acquired was not terminal and from the simple fact that the unknown had now been named. The naming of the illness was important in the illness story of the research participants for it was a tangible milestone towards regaining a sense of control in their lives, control that each felt had been lost in both the compounding build up of symptoms and their sudden immersion into the health care system, which for all in the beginning seemed almost overwhelming. The fact that all the respondents began their illness stories with a "prediagnosis narrative" did not surprise me for it is not uncommon for Crohn's Disease to elude detection for extended periods of time, and it is only in recent years that diagnostic procedures have become reliably definitive in identifying the disease.
A. Everyday Living

All of the respondents made repeated reference to the effects of chronic illness on their everyday lives. One individual, in particular, talked at length about how living with Crohn's Disease affects the "little things" of daily routine.

...It means that you don't have a so-called "normal life". There are things that you have to constantly think about that other people don't...When I wake up in the morning I have to think about what I'm going to eat today keeping in mind the activity schedule that I have, I get up earlier than most people so that I can take the necessary medication so that I can feel well enough to go on with my day...knowing where washrooms are wherever I go, travelling...thinking that I need to get this amount of sleep, on and on...

One of the participants lives with a colostomy, an opening into the large bowel that is usually brought out through the skin on the lower side of the abdomen. She commented on the embarrassing effects of having her colostomy appliance unexpectedly detach from its adhesive flange.

...I've had my colostomy blow four times when I've been out, that means rushing home real fast and having a towel with you at all times...(laugh) if you can't laugh about it you have to cry, you have to be always vigilant and I hate that...

One of the respondents, a man in his mid thirties, expressed anguish at having his career ended because of IBD.

...I had to quit my job because I had been in the hospital so much, it was a mutual departure because I had been sick so often and my employer couldn't rely on me and so I collected unemployment insurance benefits, when that ran out I still couldn't work and so I had to apply for disability benefits because I had arthritis in my legs, my feet and my hips and it was because of my Crohn's, all of these other secondary problems that come with Crohn's Disease, the arthritis, the ostomy, they all take their toll on my daily life...

The respondents' narratives gave support to a conceptualization of illness that is less
concerned with the disease process. While all of the respondents were well informed on the
dynamics of the disease process at work within them it was clear from the very start of the
interviews that the focus of their experience of chronic illness was not confined to the
pathophysiology of their bowels and intestinal tract but rather on its limiting effects on their
everyday lives.

B. Control

Similar to the recollection of one of many life milestones, all of the participants were able to recite the time in their lives when they realized definitively that they were ‘uncharacteristically’ ill. They recalled an awareness that they were unwell beyond what they would consider to be the normal litany of life’s illnesses. Normal illness was typically defined in terms of acute maladies such as colds, the flu, and viral infections.

All of those interviewed were also able to vividly recall the time in their lives when they were ‘healthy’, a time identified prior to the initial onset and impact of Crohn’s Disease on their lives. Although all of the participants had experienced varying periods of symptomatic remission since the first onset of their Crohn’s Disease (two of the participants had gone in excess of four years without experienceing any physiological symptoms of disease recurrence), none would concede to having returned to a state of being healthy during these periods of disease quiescence.

When asked why they did not see themselves as being healthy during the time periods when there was a notable absence of tangible symptoms all participants said that they felt a continued absence of control over their lives. When asked to clarify what they
meant by control they identified it as being their ability to live their lives with an acceptable degree of predictability. That being, an ability to make decisions or choices about going about their day to day living without apprehension or caution for fear that their Crohn’s Disease would flare up and debilitate them.

Living with active Crohn’s Disease, with its immediate debilitating physical symptoms, made the participants feel powerless or a sense of diminished control in terms of their ability to conduct themselves in what they see as normal day to day living. This feeling of loss of control remained even when the Crohn’s Disease was in remission. Having had already experienced a mode of being they knew as health the participants found it difficult to lay claim to a return to this experience because the new experience of living with an incurable chronic illness had created in each of the participants a realization that it (the disease) could return unannounced at any time. The mere unknown threat of the return of the symptoms was its own source of disempowerment.

The acute physical pain of Crohn’s Disease at times becomes secondary to the feeling associated with loss of control. The unpredictable nature of Crohn’s Disease is such that over time the person begins to experience a profound loss of control over the predictability expected in day to day living. One woman commented on the frustration of no longer having control of her life,

…I lay on my couch in pain…not being able to do anything and not being able to have any control over what is going on, any control over my body or what I want to do with my life or where I want to go that day…

Another woman commented on how dealing with perianal ulcers influenced her sense of control of her life,
...I had painful perianal ulcers that finally healed after two years, that time was very stressful emotionally, the excruciating omnipresent pain, dressing changes were very frustrating. I had no control of my life at that time, I was an emotional basket case...

At times it may be necessary for a person with Crohn's Disease to receive nutritional requirements through a tube which is placed through the nose into the stomach. This type of feeding usually starts at bedtime and continues through the night. One of the women expressed how she feels that she has no control of her life because she is confined by a rigid nasogastric home feeding schedule,

...Recently I feel that I've been losing control, I don't have control any longer, having to be home on NG tube feeding, this is my second month of NG tube feeding, I don't know how long I'll be on it...

The more one listens to the narrative accounts that make reference to issues of control the clearer becomes the realization that what the respondents seek to hold onto or reattain in a return to health is their autonomy or sense of self direction, a freedom that seems to come to people when they are healthy and unconfined by the unpredictability and chronicity of illnesses such as Crohn's Disease. The chronic nature of the this illness makes the return to such a life of complete autonomy difficult, if not impossible.

A woman in her twenties who had been living with Crohn's Disease for 7 years discussed her struggles to maintain control of her life in light of the undenying influence of the illness,

...I have to be able to still do things, I have to be able to still go to work and go out and do things with my friends or I don't consider it living...I'll put up with pain in order to do all those things. My doctor is always on my case because I put off admitting how truly rotten I feel until I am to the point where I really have to be admitted to hospital for a long period of time because I don't want to have to give in to it...I don't seem to be able to predict it one way or the other, I usually sort of gauge it - when the pain gets so bad that I can't sleep
or the diarrhea gets so bad that I can't do what I want to do throughout the day, then I go for help - otherwise I live with it. Everyone defines their own threshold...

Another woman commented on her struggle for control in her life as she attended university. Her account illustrates how she engages her illness with the processes of concession and negotiation. She also uses the terminology of bereavement to describe her experience of loss. The implication of this young woman's account is that she, like others who suffer from chronic illness, are inescapably embodied with their illness.

...it was really hard for me and still is really hard for me making that realization that it's ok that I can't do everything all at once or immediately, I found it really hard in my undergraduate years, I'd lose concentration, I'd be reading for twenty minutes then I'd need to have a nap. I think I slept about a year and a half of my life away and that's a loss that I'm still dealing with. that's what it is, living with IBD is learning to deal with losses on many levels, I need to have a sorrow for that and allow myself the opportunity to grieve my losses then I can work on getting beyond them...

The participants who had lived with Crohn's Disease for a longer period of time seemed more resigned to the fact that a complete return to a time when they perceived a greater sense of control of their lives, present prior to them becoming ill, would not occur and that for their purposes of maximizing control of their lives in the present, in the face of the dictation of their illness they must move to a language, not of regaining autonomy, but of negotiation where he or she seeks to live their lives on their own terms within the restrictions, limitations, and even dictations placed upon them by the chronic illness. One of the women interviewed, who had lived with Crohn's Disease for 42 years described it as "making friends with the devil". An attitude of negotiation was not only an adaptive strategy adopted by the sufferer to maximize the sense of control of one's life but it is also evidence
of the evolving impact that chronic illness has on its host. The illness that has become a part of who he or she is, it speaks to the person, makes demands, sets limits, and defines new boundaries. Accepting the imposed limitations of the illness on one's life and negotiating with its demands is an integral component in maintaining a realistic sense of control. The stories of the respondents suggests that there is a definite link between feeling a loss of control of one's lifeworld and the experience of suffering. There is a similarity between Cassell's description of suffering which is viewed as a threat to wholeness, and the loss of control, a symptom of diminished autonomy.

C. Pharmacological Effects

It is generally accepted among the medical community that there are two basic treatment options in managing Crohn's Disease: surgery and/or pharmaceutics. Surgical interventions are generally seen as a last resort in the management of Crohn's Disease, at least where the small bowel is affected. This is due to the fact that removal of the small bowel is irrevocable and the possibility of a bowel transplant is still not a feasible option. All effort is made to avoid removing any small bowel without first exhausting other medical options such as drug therapies.

There have been many pharmaceutical advances made in the use of drug therapies with the advent of new drugs like the 5-ASA and others. For many sufferers of Crohn's Disease, drug therapy does provide a potent relief to debilitating symptoms. But the therapeutic effect of drugs such as prednisone and others is not without its side effects. These side effects are diverse and affect each individual in different ways. In their
narratives, all of the respondents made reference to various pharmaceutical interventions used in their treatment regimens. Each identified the side effects of medication as an important issue that sufferers of Crohn's Disease must deal with.

Analgesics are an important part of the 'pharmaceutical arsenal' used in the treatment of Crohn's Disease. One woman talked about her addiction to pain relief medication.

...the drug dependency was a big issue because when I took my pain medicine my problems went away, of course only until they'd wear off and I'd be on an up and a down and I couldn't handle that...

Prednisone, an anti-inflammatory corticosteroid, is one of the most popular and potent drugs used in the management of Crohn's Disease. Many sufferers attest to its effect in reducing inflammation of the bowel and providing relief of debilitating symptoms. It is also a drug that carries with it an infamous list of side effects which can include, weight gain, acne, susceptibility to infections, osteoporosis, rounding of the face, changes in blood pressure, and serious personality changes. One woman recalled the impact of the side effects of prednisone during her already turbulent adolescent years and how this had an adverse effect on her body image resulting in a decline in self esteem.

...I went through my teenage years with Crohn's Disease...I had no concept of my body image whatsoever because of being on Prednisone...my clothes said I was this size one day and this size another, those were troubling times for me in terms of my self esteem and confidence...

One of the participants, who has worked as a volunteer in supporting people who have been newly diagnosed with Crohn's, spoke of the effects of prednisone,

...when I was counselling teenagers, some of them told me that their worst nightmare, especially the girls, was to go on Prednisone because they knew what it would do to their bodies, the bloating, the moon face, the acne, they all knew what being on prednisone meant, they knew it would help them but
they were more concerned about the side effects... My mother puts up all my class pictures when I was in grade school and high school and you can tell from my face when I was ill and when I was in good health...

Another participant commented on the moods swings that affect many who take prednisone,

...I would go from euphoria one moment where the world was a beautiful place, the pain was gone and everything was wonderful to the next moment where I almost felt homicidal and that I could kill someone... all of my emotions were extremes at opposite ends of the spectrum...

A variety of other medications have shown promise in preliminary studies in treating some individuals with Crohn's Disease. One such drug, Methotrexate, was used for a number of years to treat different cancers,

I'm taking Methotrexate by injection now and I know that Sunday is a complete write off because I'm so sick. I've figured out my time schedule, I take it Friday night and then by Sunday I know that I'll be in bed sick most of the day. By Sunday I am so nauseated I can't even drink anything, I'm just wiped out, I sleep a lot of the day...

It is not uncommon for an individual to be taking several types of medication at the same time, three of the participants made note of the difficulties encountered when different medication are "piggy backed" or taken simultaneously,

...when I was on the prednisone it had a bad effect on the methotrexate that I was on... I was sick in bed every day after taking it, I'd be vomiting for hours but I never was sure what would be causing it... The doctor told me I needed to take all of them in order for the medicines to take effect...

The patient's management of his or her medication cannot be underestimated in terms of the effort needed to live with the toxicity and other unwanted side effects of the drugs. At times unending nausea, fluctuations in appetite, weight, and the individual's psyche, as well as effects to other biological processes must be endured for the sake of
reduction in the inflammatory process. Side effects of medications continuously tax the energy reserves and will of the individual. Sally Thorne's reference to health maintenance work, the work involved in preserving good health, should be expanded to include the energies needed to deal with the unwanted side effects during the course of pharmaceutical treatment plans. For many patients, the routine of ingesting medication continues even after the symptoms of the bowel inflammation are relatively quiescent and so even during periods of good "health" there is a continual reliance on medicines for health maintenance.

All of the respondents conceded that although the medications they take do not work to cure them of Crohn's, they do not mind having to take them. When effective, the alleviation and relief of debilitating symptoms and their restoration to even a temporary period of better health warrants the energies needed to deal with the unwanted side effects. Three of the respondents said they were currently participants in drug studies and welcomed the opportunity to volunteer in test trials for what one individual referred to as his hope that the next one might be the "wonder drug", the cure.

D. **Family Issues**

A recurring theme that was present in the illness stories of all the participants was that living with a chronic illness has a profound impact on all of their interpersonal relationships, especially those involving other family members such as the relationship with a spouse. One of the women voiced the added stresses on married life and family life,

...If I go out for two hours I have to call my husband, only to help him because he worries about me, he's taken care of me for a lot of years so he's under a lot of stress, so to ease his worries I call...he's got to trust me more and I've got to appease his stress more too, this is all part of living with Crohn's - it's all part of chronic illness...
...I'm supposed to be healthy now to enjoy my grandchildren, it's supposed to be the best times of my life but my kids won't leave grandchildren with me (laugh), they think it'll be too much for me...I don't think it will, I guess I have to go out and prove to them that I can do it which I thought I had done all these years...

Like the colostomy, an ileostomy is an opening made in the skin in abdominal region that drains faeces from the ileum or small intestine. One of the women told how having an ileostomy adversely affected her body image and subsequently affected her relationship with her husband.

...after my first surgery and having the ileostomy I think the feeling of being mutilated was difficult to accept. I had an incision about fourteen inches long and three inches deep hanging open too, plus an ileostomy and I'm pregnant too, which doesn't do your body image any good to start with. Well needless to say it didn't turn my husband on, I mean lets face it its tough to be romantic towards a woman who looks like that...it was also difficult for him to accept and I think long after I had accepted the ileostomy I think he continued to struggle with it, he just couldn't get past that very well, I mean he did but you could tell it was an effort...

One woman shared that she would vent her frustrations on her husband when he seemed to mismanage tasks that she felt were routinely her domain and responsibility,

...It's frustrating being stuck in the hospital and not being able to do what you want to do, you get mad because they come in to visit and your kid's hair isn't combed or they're not dressed nice...I mean the poor guy, he's doing the best he can...I got all my Christmas shopping done early, I had everything wrapped and I had my daughter's stocking, we always hang socks at Christmas, I had spent some time picking out things she really wanted like mittens, stockings are a big part of our Christmas morning and then it ended up I was stuck in the hospital for Christmas, I was still on TPN, I talked the doctor into unplugging the TPN lines for the afternoon and letting me go to my sisters' for a couple of hours for Christmas day. My husband was bringing all the gifts down to London but he forgot the socks! and he forgot some of the gifts and I was just livid!! I went out half-dead to buy those things so they'd be there and he forgot them, I mean the poor guy, as if he had nothing else on his mind you know, sometimes I find it hard to have sympathy for my husband and understand what he's going through. I found that difficult and in retrospect at times I was unfair to him...
While being chronically ill plays havoc with their married and family lives the participants also spoke of the pivotal role their partner played in helping them manage and cope with Crohn's Disease,

...I told my fiance that I might have to have an ileostomy, and I asked him if he would leave me. What if I was sick to the point where wasn't able to manage it for myself. He had no problem with it, what a relief, he's great, he's helped me handle it better...

...I think that if I wasn't married to a nurse my marriage would have been over, she's very understanding and we've been through a lot, she has made life bearable for me...

...I was only married three months when I had a bowel resection, I also had an ileostomy put in and I had to depend on my wife to help me with the maintenance of it. Some days I would get so angry at the disease and what it was doing to me. It makes it so much easier when you have a spouse who is gentle and compassionate, I don't know what I would have done without her...

Over the course of the interviews there emerged two distinct themes involving familial issues that should be identified. The first is what I have termed the invalid-burden syndrome the second theme is pregnancy and motherhood. The invalid-burden syndrome describes instances where the individual feels at one time or another as if he or she is an invalid and a burden to others. All of the male participants gave unsolicited accounts of experiencing these feelings while only one of the female participants made reference to this experience, suggesting perhaps the influence of traditional male role expectations,

...It bothers me that my wife has to be the breadwinner in the family, it's not so much the fact that she works but that I feel like an invalid, a burden to the family at times...
...I have a homemaker who comes in here and I feel like I am two inches high when she comes in because I feel useless but what am I going to do I just have to accept it and try to do something like put my time into charity work. But there are days when I really feel like a burden and I've had really bad days where I've had emotional breakdowns...

...For me I sometimes have a hard time with the role of the invalid, watching my wife work full time then do all the things around the house, then take care of the baby, there's a real feeling of helplessness that comes over me. As a man I sometimes feel like a burden...

The woman described her reluctant resignation to the fact that her spouse has assumed all the duties and tasks involved in the care of their home. The account articulates Cassell's understanding of authentic suffering, she has lost a part of her self in being ill,

...when the disease is in remission and I'm feeling good I'll try to do something like prepare a meal, but my husband's been cooking for me for so long so he'll say to me 'I don't use that frying pan', so I take a deep breath and I put my frying pan back, the one I've used for so many years. Now I don't bother anymore, I just lay back and if he doesn't feel like cooking we just order out because I'm not strong enough to fight for my role back yet. I appreciate what he did for me when I was really sick, it's hard on him and he doesn't know how to let me get my freedom back either so we have to learn together...that's the chronic nature of this disease, that's like an elderly man taking care of his elderly wife who's a complete invalid and can't do anything for herself and I'm only 49...

Three of the female participants were mothers, each offered stories of how living with Crohn's Disease had impacted their experience of pregnancy and being a mother.

...trying to get pregnant can be more difficult because of this disease, it's not fair. It makes deciding to have a baby a difficult decision, it shouldn't be such a burden when deciding to start a family is supposed to be such a happy time. When you want to make that decision you have to sit down and think about all the possibilities of what could happen if my Crohn's acts up during my pregnancy. Who wants to be pregnant and on all that medication, the good things that should be happening in my life are either being taken away or are less of an excitement because of this disease...
...when I gave birth all I was worried about was did the baby live or not because I didn't expect the baby to survive what she had been through...there were weeks of debilitating disease that I had gone through and then the ruptured ileum on top of it and then all the drugs. I'm a pharmacist and so I know what kind of toxic effects drugs can have, who knows the effects that these drugs were going to have on my baby because I mean the list (of medications) was as long as your arm...they tell you not to drink diet coke during your pregnancy because of the potential harm and here I was taking all these medications with toxic side effects but you don't have much of a choice...

...I was at the point where I couldn't even change my baby's diaper, I couldn't even get up out of bed, in the prime years when a baby needs his mother. My own mother had to take care of my son and that just tore me apart inside because I should have been the one who was there...that was taken away from me. My son is four now, he doesn't want to cuddle with me the same way he did when he was an infant, I just didn't have the energy, I couldn't do it, it seemed like I was either in the bathroom, vomiting or sleeping, those early years were taken from me...

What was significant about these parts of the women's narratives was that it showed once again that suffering is clearly not limited to the experience of one's own physical pain. During the interviews these women eloquently described their aspirations of motherhood, their dreams and anticipations and how mothering was so intimately connected to who they were, almost self-defining. The lived experience of illness during their pregnancies and throughout the early years of their children's lives represented a threat to their wholeness as women and as mothers, this for them was the true essence of suffering.

E. Psycho-Social Suffering

The most dominant theme that came up during the interviews was that of the impact of the emotional and psychological suffering. Consistent with the work of Cassell and Toombs, all of the participants' stories supported a patient-centered meaning of suffering,
one that was described only in part by physiological torment. With the exception of my
direct request to articulate bodily dysfunction, all of the meanings of suffering described by
the participants were given within the context of social losses. One of the women
interviewed recalled how her wedding day was plagued by worries. Despite being in
remission, the fear of an untimely flareup of the illness had a profound effect on her,

...most brides are worrying about the weather and if it will rain or not but not
me, I was standing at the back of the church and saying to myself 'oh my God
what if I have to turn around and come back because I need to rush to the
washroom', it was almost impossible for me to relax and enjoy what was
supposed to be the happiest day of my life...

Several of the participants commented on the social consequences of Crohn's Disease
being an "invisible" illness. Unlike other diseases that are more easily recognized in their
manifestations, sometimes the person who is ill because of IBD may look fine and "healthy"
to others. One man who was interviewed had to give up his job because he was always off
sick and although his co-workers never said anything to him he sensed that they questioned
the seriousness of his illness. One of the men, who at the time of the interview was dealing
with yet another acute flareup of Crohn's was asked to describe what suffering meant to
him,

...suffering goes beyond the physical pain I am in, I'm at the point now where
I'm so used to feeling like shit all the time that suffering has been redefined
in terms of social losses, in other words I've become accustomed to the
abdominal pain and the nausea and everything else, I'm accepting the fact
that my body lets me down, but if I have to miss a family function or an outing
with my wife or friends then that's when I really feel like I'm suffering...

One of the woman gave an account of what she considers to be the most difficult part of
living with IBD that seemed to crystallize the patient-centered meaning of suffering,

...the emotional suffering is the worst, there was one time when I was in
hospital in London and I had already been in the hospital five or six times in
the last little while, I had a five year old at home, my husband was trying his best but after weeks and weeks he couldn’t take any more time off work, he had to go back to work and my mother was looking after my daughter for a while, then my brother was looking after her for a while - she had caregivers coming and going. Eventually my husband just couldn’t handle trying to find caregivers for her and working and running to London to see my daughter went to stay with my sister, we put her in a school in London and so my daughter was living in London, my husband was living in Windsor driving back and forth...knowing your family is ripped apart, everybody's life is in an uproar...my daughter had had enough she would come in to visit me in the hospital and we would try to have toys in there for her that we would leave there so that she would know she was coming back to see me but she would cry she was so afraid she'd never see me again, she wondered if she was going to have to get a new mom and was I going to die and all this kind of stuff. It was really tough to field those types of questions from a little child who wasn’t old enough to understand what was going on, I wanted to see her but it would break her up when she left, she was almost better off not seeing me...and it made it really tough on me...my life and everything that was important to me was being ripped apart, it was emotionally devastating for me, it affected me long after my Crohn's had went into remission...

The narratives given by the participants served to illustrate that living with a chronic illness such as Crohn's Disease has implications far beyond the injured body. Their illness stories lend support for Kleinman's suggestion that those who live with chronic illness are inescapably embodied by their illness. Further, the illness causes a fragmented concept of self identity,

...it (being ill) splits you apart, your body's been invaded and mutilated so many times that your sense of who you are and your self esteem is just terrible...

...I had to have all my teeth removed due to malnutrition, I lost all my sense of dignity...

The subjective experience of illness, representative of the patient's illness story is experienced as a loss of wholeness that is expressed in terms of its effects on everyday living. This reality was the fundamental message given by the research participants in their
illness stories. With this established, it is appropriate to move on to a discussion and analysis of the Care Relationship between physician and patient. Keeping the patient-centered meaning of illness at the forefront will help in the analysis of the physician-patient relationship.

2. THE CARE RELATIONSHIP

Although the respondents were not asked specifically to evaluate their interactions and experiences with physicians as negative or positive, the comments made in respect to physicians generally characterized one or the other. There were five sub-themes that surfaced under the heading of negative interactions, namely; issues around credibility, clinical competence, omnipotence, doctors in training, and bedside manner. Their responses offer a rich commentary on the meaning of care.

Negative Experiences

A. Narrative Credibility

All but one of the respondents made reference to feeling frustrated with physicians who doubted or even dismissed their symptoms. This was most often experienced prior to being diagnosed with Crohn's,

...my family doctor thought that I was just nervous about going to high school, that's why he thought I was getting sick all the time. So he just dismissed it but it kept getting worse all throughout high school...

...I was in for a week and they told me there was nothing wrong with me. They did all these tests but the disease was masked, I said to the doctors I've got to be crazy then, there's no way I'm imagining this pain there's just too
much pain and they kept saying we can't find anything and so they sent me home and then it got to the point where I was so sick that my parents thought I was going to die...they got me back into hospital and that's when they did a colonoscopy and that's when they detected the Crohn's...

One woman's account demonstrated how a physician's reliance on quantitative science as sole indicator of the presence of illness was put above her own description of how she was feeling in determining whether or not she was legitimately ill. In this case the physician gave little credibility to his patient's account and was primarily focused on test findings.

...I kept telling the doctor over and over there's something wrong with me, I was in excruciating pain and I would start crying every time the doctor would come in and say that the tests were negative and that there was nothing wrong with me. You get so angry at these doctors when they tell you there is nothing wrong with you just because it doesn't show up on a test, you feel that you're on your death bed and they don't listen or put value on what I'm telling them...

In this case the doctor's reluctance to adopt his patient's narrative knowledge proved to delay the diagnostic process and ultimately damaged the therapeutic relationship between he and his patient.

Even after being diagnosed with Crohn's and living with it for several years one woman still faced occasions where her credibility was questioned by an attending physician.

...When I was at University there were alot of times where I'd have to go to the emerg to get a shot of Demerol for pain. On one occasion I went in because the pain was intolerable, I happened to have an exam the next day and I said I needed a note saying that I'm not going to be able to write this exam and he started questioning me, believing that I was there because I wanted to avoid writing the exam. I left there all upset and crying because he didn't believe me, I felt worse than before...

In this case, the physician failed not only to honour his patient's integrity despite the obvious nature of the pain she was in, but also neglected to see the connection between the patient's illness and her life. The alleviation of the pain seemed like an isolated acute
incident to the physician who reacted with detached precision. The fact was that the woman had spent the entire night in the emergency room prior to going home. The restless night coupled with her groggy state would have made it very difficult for her to undergo an examination at the university. Common sense would seem to indicate that she be at home resting following her visit to the emergency room. Regardless, in his inability to recognize the connection of the patient's illness to her day to day life the physician caused unnecessary suffering to this woman.

B. Clinical Competence

Oftentimes taken for granted in the physician-patient relationship is the clinical competence of the physician. Several of the research participants reported encounters with physicians that had them questioning the skills and knowledge of the practitioner.

The insertion of a Nasogastric tube or NG tube is sometimes necessary in the nutritional management of Crohn's Disease. Despite its necessity, the procedure is unpleasant. One man recalled his experience,

...I had never had an NG tube before and he (the physician) didn't explain what he was going to do. I began to panic when he inserted the tube in my nose, it took a long time for him to put it in and I could tell by his face that he was getting frustrated at how long it was taking, he kept telling me to keep still, but it was hurting really bad. I was crying the whole time, then after it was in, my throat started to get sore, after several hours my throat was unbearable and when my wife looked inside my mouth she noticed that the tube had knotted and was grating against the back of my mouth, the doctor hadn't checked it when he put it in, I didn't even know he was supposed to look in my mouth until the nurse told me when she came in to fix it...

Living with an illness over an extended period of time, which for all but one of the research participants in this study spanned a minimum of five years, allows the individual...
the opportunity to acquire a certain degree of knowledge about the illness. It would be accurate to say that the patients to some degree become experts. This is not to suggest that they should be diagnosing and prescribing treatment plans for themselves independently of their doctors, but merely that they have a first hand familiarity with their illness and its effects on their bodies and lives. One of the women interviewed illustrated the value of her subjective lived experience of chronic illness,

...I had been vomiting profusely all day long, and had diarrhea for a couple of days prior so I went to the hospital and the doctor looked me over then he gave me some fluids through an IV and some graval for nausea, that's it...I got no vitamins, no electrolytes, this went on for a week and then my heart started skipping beats and it was becoming more frequent and I thought surely he's checked my electrolytes but he hadn't, I mean I watched...he never gave me any potassium or anything, so the next time the nurse came in I told her my concerns...about a half hour later she comes in and starts an IV in the other arm and she proceeds to tell me that my potassium is low. You'd think that anybody that had been dealing with somebody with severe nausea and vomiting, whose patient had been ill for the past six weeks had lost forty five pounds would at least check her electrolytes. That ticked me off, thank God I knew something about what goes on, I often wonder what happens to people that are less informed about their illness and are not capable of being advocates for themselves...

The valuable experiential knowledge of the patient should be an important part of a collaborative partnership between the patient and his or her physician. A well informed patient is also enabled and empowered to act more effectively as his or her own advocate in ensuring competent and appropriate care.

C. Omnipotence

The review of the literature showed that the primary focus of the dominant model of care, an acute care model, is oriented towards cure. It was also shown that chronic illness demands a rethinking of this orientation because for many illnesses a cure is neither a
reality nor imminent. The socialization of the physician towards a cure-focused ethic of care has its genesis in the early days of the medical training. I would suggest that this focus creates an orientation in practitioners to "solve the puzzle" that the sick patient presents to them. Further, the drive to find the cure, so ingrained in the psyche of the physician, creates a false sense of omnipotence that is betrayed by the baffling characteristics of illnesses such as Crohn's Disease. In practical terms, this "attitude" of a large number of physicians is a source of frustration for their patients who oftentimes are reconciled to the fact that no cure exists.

...some of the physicians that have treated me seemed reluctant to admit that they didn't know something about the ongoing of my disease, somehow feeling they should have and as a result have put me in a very precarious health and physical situation...

The proliferation of modern medicine into specialties and subspecialties reflects the compartmentalization of the vast amount of knowledge that allows doctors to become more intimately familiar with the science of disease, making them experts in a particular field. While few would argue the value of being under the care of someone whose main interest and skills lie in the bodily system most affected, it does present an important problem identified by some of the participants. One of the men made the following observation,

...it's strange that the doctor you see only wants to deal with the area that he specializes in, when you go to see a surgeon he doesn't care about your skin problems or your arthritis...

The difficulty with the specialization of medicine is that it creates a fragmented approach to care delivery. Chronic illnesses like Crohn's Disease affect more than the target area of

\[129\] See Kleinman, p.21
the body that the disease itself is limited to. This situation may force the patient to seek medical care from multiple sources creating a disintegrated cycle of care with each specialist operating out of their own perspective on the management of the illness' manifestations.

D. Doctors in Training

All of the respondents had on at least one occasion been treated in hospitals in London, Ontario. Due to the proximity to and collaboration of London hospitals with the medical school at the University of Western Ontario, all of the respondents had at one time or another encountered physicians in training. Those who are admitted to teaching hospitals inevitably come under the care of medical students, interns, and residents. While all conceded that there is a need for medical students to develop and hone their skills on real life people with real life illnesses, there was also a consensus among the participants that they have, at times, paid a hefty price in providing a learning medium for doctors in training. One woman who needed TPN, a nutritional supplement given through an IV tube, described the ordeal of having the IV central line put in by residents,

...Two residents came in to put in a central line, the senior resident proceeds to instruct his junior in sterilization procedures and I'm saying to myself 'Oh God the guy doesn't even know aseptic technique please get me somebody who knows what they're doing!' These guys are trying to get this thing in and this is killing me, I mean the pain is intense! I kept asking for more morphine. They took over two hours trying to get it in, I thought they were really going to puncture something, when they finally got it in I got this awful pain in my ear so I pleaded with them to check it. I told them that they were not going to put anything into the tube until they found out what was wrong. They wouldn't believe me when I told them my ear hurt so bad. I told them it felt like it was in the wrong place so they sent me down for an x-ray and came back and started pulling it out because it had been inserted wrong. They went to try again and I said no way you're not trying again...I finally refused, I said no...
The technical mistakes made by the doctors in training seemed to be more easily tolerated and forgiven than the omissions made in the art of interpersonal communication.

...the resident comes in at 5:30 in the morning, turns on all the bright overhead lights, there's a whole team with him, he doesn't even say good morning! He walks in, takes my bed covers off me without asking, then he proceeds to rip off the dressing on my incision and says "look at that, it's all abscessed and infected we're going to take all these steristrips off" and then he just starts ripping them off, my skin is coming with these things, he hasn't even said good morning, I felt like a piece of meat...

The content of the interviews involving the patients' interactions with doctors in training lends support to the idea that there exists, even during a physician's developmental years, a chasm of miscommunication between doctor and patient. Groomed from the early beginnings of their medical education by a biomedical model of illness, doctors in training undergo a process of socialization where they are subjected to the rigours and demands of an educational marathon. Concurrent with the student's technical and clinical development is his or her adoption of a conceptualization of illness that is markedly different than that of the patient.

E. Bedside Manner

The physician-patient relationship has many defining moments but perhaps none are so critical as those interactions that take place at the hospital bedside. At moments when the patient is particularly vulnerable, the conduct of the attending physician leaves a lasting impression on the ill person. One participant was angered at the way her doctor gave her the news that she had Crohn's Disease,
The doctor just came into my room and announced that I had Crohn's Disease then walked out of the room, I was in shock...

Two of the women interviewed shared similar accounts of how insensitive their surgeons were in telling them that the results of their surgery had indicated they may encounter difficulties in having children,

...he had the nerve to tell me that I should reconsider having any more children because my ovaries "are shot". I just woke up from surgery, you don't say something like that...

...When I woke up he told me I had a cyst the size of a grapefruit. He told me that if I plan on starting a family I'd better start now because I probably wouldn't have much luck later. He said this right after I woke up from surgery, he didn't even ask me how I was feeling, I mean I was depressed enough I didn't need to hear something like that. There was no need to say that the way he did...

In sum, a perceived lack of empathy in a variety of situations was the main reason given by the participants in describing what characterized a "negative" interaction with a physician. The physician was seen as being insensitive or unable to enter into the patient's illness story. When the individual sensed this distance it became a profound block in creating a positive healing relationship between physician and patient.

Positive Experiences

The interviews also provided insight into what constitutes a positive experience with a physician. This aspect of the narratives also provided further information that is valuable in helping to determine and articulate a patient-centered meaning of care.
A. **Active Listening**

The respondents said that they prefer a doctor who listens attentively and actively to their illness history. Two of the women interviewed said that their doctors paid close attention to their description of an acceptable quality of life before responding with a plan of care,

...when I go in for my checkup my GI asks me how I am dealing with the Crohn’s emotionally and psychologically and then he asks if it is to a point where it is interfering with what I want to do in my life, so that helps him to know how I am doing and what he should do next...

...my doctor’s philosophy is to listen to my goals, dreams and ambitions that I have for my everyday life, he gets a sense of what I myself define as an acceptable quality of life and when the flare up of Crohn’s Disease starts to affect my quality of life and what I want to do with my life then its time to do something about it...

A physician’s ability to actively listen to the patient describe how the illness affects his or her life is a vital first component in the delivery of empathic care. It is only through the development of a narrative competence that the physician can enter the patient’s lifeworld. In connecting with the patient in this way the physician can better respond to the needs of the patient as a whole. Further, respect for the knowledge that the patient has acquired simply by living with the illness assists in establishing a collaborative approach to care,

...you have to approach the patient knowing that the patient often knows a lot about what is going on, they are pretty knowledgable at what works and what doesn't work. Doctors need to really communicate with the patient, ask them what they want or what might work for them or what might not work. And also realize that there is a whole emotional side that goes along with it because of the stigmas of this disease, they have to take that into consideration...
B. Personal Presence

Like active listening, the interviews revealed that doctors who allow themselves to be truly present to their patients are recognized as being better caregivers. Two of the participants observed that their doctors took the time to sit and be with them for a few minutes. In both cases the doctor was able to communicate to his patient that he was not in a hurry and that despite his busy schedule it was important for him to spend time with his patient,

...my surgeon was superb, he was very caring and understanding, most of all he gave me the impression that he was never in a hurry,...he would come in and he would sit down on the side of the bed, he'd hold my hand, he'd talk to me, explain what was going on, check with me as to what I understood and what I didn't understand, what they were going to try, he'd ask me if I had any questions and he'd just sit there and listen...

...after my operation my Gastroenterologist sat at my bedside and said "you're very sick right now but you're going to get better" he said this to me even though he knew that I was right out of it because of the morphine, at least he talked to me you know, he didn't even know if I knew what was being said but at least he sat with me and showed compassion, I understood him...he treated me like a human being, with dignity, even though he knew I wasn't getting it all...

C. Honesty, Compassion and Empathy

Many of the participants stated that honesty was an important characteristic of care. Linked to their realization that there is yet no cure for their illness, they want a doctor who is honest with them in all aspects of the therapeutic relationship.

...she was straight forward with me, she told me the way it was, she didn't try and hide anything. She said that she wasn't sure but she may have to put in an ileostomy once she sees what's inside, and I left my life in her hands because I trusted her...
Despite the oftentimes dramatic reversal in symptoms that can be obtained through surgical intervention, Crohn's Disease can recur again. One of the men gave an account of how troubled his surgeon was in having to tell him that the disease had returned at the point of anastomosis where his last surgery had been done. The doctor was aware of the suffering his patient had endured prior to the surgery and then also in the post-operative period.

...he realizes and is sensitive to the whole picture of what I've been through, he felt so bad when he had to come in and tell me I had it again, I could tell he really wanted me to be well...

Sensing such empathy from his doctor, he said that it somehow made it easier to accept the return of the disease. Knowing that his caregiver had some sort of beneficent investment in him was uplifting and placed him in a positive frame of mind to deal with the illness again.

D. A Holistic Approach

Attuned to the way their illness affects all aspects of their lives the respondents identified the need for a more holistic approach from their caregiver,

...I was under the care of this one intern who seemed to be authentically concerned about his patients. He started asking me a lot of relevant questions about how the illness affected my life. I realized that was what had been missing from some of the other doctors - it was a genuine holistic approach to me as a unique person and how Crohn's Disease effects my whole life, not just my body. He also seemed to have a really clear idea of what kind of questions he needed to ask to get the most concise answers, but I didn't feel coerced into my answers at all, they were just really practical questions. It had a whole lot to do with maintaining my integrity and dignity...

...the key to caring is for the doctor to have a basic sensitivity to how Crohn's Disease throws your whole life into turmoil. I think that it's really important for
doctors to realize the holistic element of it, I mean this is something that is part of my being, it is who I am and how I function, it is what dictates to me what I can and what I cannot do. It is a very important part of my life and I think any doctor that is genuinely interested in caring for people with a chronic illness needs to understand that it is an intricate part of them and cannot simply be removed and put on a diagnostic table...

The call for clinicians to move towards a patient-centered approach and away from the biological model was echoed by all of the respondents. Similar to the skills of being an active listener and being present with the patient, the research participants showed an affinity for physicians who understand the far reaching effects of chronic illness beyond mere biological pathology.

In the following chapter the summary and conclusions of the primary research will be given. Some recommendations for those who care for the chronically ill, primarily physicians, will be offered in light of a patient-centered ethic of care.
CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

The purpose of this study was to investigate the meaning of care from the perspective of the chronically ill patient. To this extent it was also an investigation of the meaning of illness and the physician-patient relationship. The question of the need for a more patient-centered ethic of care for the chronically ill had its genesis in both my own experience living with Crohn's Disease and also in the stories (narratives) of illness I had encountered as a volunteer with the Crohn's and Colitis Foundation of Canada. It had become obvious to me that there was a perceived breach between the ethic of care that was guiding the physician's delivery of care and the ethic of care that was desired by and born of the patient's experience of illness.

Using the narratives of eight individuals who live their lives with Crohn's Disease, this investigation has confirmed that there exists in clinical medicine problems of both perception and practice in the delivery of care from physicians to their chronically ill patients. Consistent with the findings in the literature, the narratives painted a landscape of differing perspectives on the meanings of illness and care between physician and patient.

What then is a patient-centered ethic of care? The primary ground of this ethic of care must be rooted in the patient's discourse on illness. The patient gives meaning to the illness and provides a voice for the suffering caused by Crohn's Disease. Physicians need to pay attention to that discourse to accurately diagnose disease. Yet they must go beyond
this concern, important as it is, and focus on listening to the illness stories of their patients with great intensity, with something approaching awe in respect for hearing the patient's story in his or her words, and with deep concern for the human condition of suffering. In the patient's story the physician can find the meaning of illness and suffering beyond that which can be determined by any other diagnostic tool.

Truly effective medical practice and beneficent care require that the physician interact with the patient on both an observer-to-subject basis and a person-to-person basis. The goal should be to achieve a comprehensive understanding (both cognitive and affective) of the patient's problems. This research has shown that caring is ultimately relational, and the compassionate healer is one who attends to the sufferer's wholeness.

Recommendations for Future Research

The Socialization of Doctors

This paper has been in no way exhaustive nor conclusive in its scope of investigation into the meaning of illness and care. As is the case with many research initiatives, the point of initial inquiry serves only to uncover further questions in need of analysis. The findings of this research would indicate that there is a need to continue further investigation into the reasons perpetuating the continuation of the existing ethic of care in clinical medicine.

The results of the research together with a review of the literature has shed light on

the need to further investigate the existing methods of medical education delivered to physicians-in-training. Questions surrounding systemic pressures such as time constraints and unrealistic work load expectations that are imposed upon doctors during their formation years are in need of further inquiry. I would suggest that these variables do in fact play an important role in the orientation of physicians towards a detached and primarily bio-centric ethic of care.

**Nursing Theory and Practice**

As indicated in chapter two, the research available in the literature on the meaning of care is found almost exclusively in the discipline of nursing ethics. Although the primary focus of this study was on the care delivered by physicians, the findings of the primary research (interviews) indicated that there may be a need to explore the relationship between nursing care theory and its integration in praxis.

Through their narratives the participants gave accounts of other health care providers, especially primary care nurses, who were consistently not providing care that was rooted in the patient's experience of chronic illness. The issue of patient care as it moves from nursing theory to the nurse's bedside practice would seem to be in need of investigation in terms of the external factors that may be affecting the nurses' delivery of patient-centered care.

**Financial Resources and Bedside Care**

Finally, one other pressing area that needs to be more thoroughly investigated
involves the issues surrounding the allocation of financial resources within the health care system. Such an inquiry may ultimately prove fruitful in exposing the inadequacies of resources, both financial and human, in meeting the demands of the health care system in general and the care of chronically ill in particular.
APPENDIX A

INFORMED CONSENT FORM FOR RESEARCH PARTICIPANTS

MASTERS THESIS: Living With Chronic Illness: Subjective Contributions Toward a Patient-Centred Ethic of Care With Crohn's Disease as the Focus

INVESTIGATOR: John McCann, Graduate Student, Department of Religious Studies, University of Windsor

INSTITUTION: University of Windsor, Department of Religious Studies

This Consent form is meant to give you, the participant, the basic idea of what the research project is about and what your participation will involve. Please take time to read this form carefully and if you would like more information about the research project please feel free to ask.

The purpose of this research is to explore the reality of living with Crohn's Disease in contemporary society. It is conducted in partial fulfilment of the requirements for a Master of Arts degree at the University of Windsor.

The procedure for research will be an interview through informal questions and discussion. The interview will be recorded using a tape recorder. Confidentiality of the subject will be maintained. The names of the subjects or any other identifying factor will not be used.

Participation will involve a single time commitment of approximately one hour. The interview will take place at a time and location convenient to you. The interview may be a source of emotional strain given the personal nature of the investigation. The investigator will make himself available should the subject desire a second meeting or some kind of follow-up as a result of material raised in the initial interview.
You may find that talking about your experience of living with Crohn's Disease is beneficial both in terms of having your lived experience of chronic illness recognized as inherently valid and also as a legitimate and immeasurably valuable source of knowledge. The results of this study may lead to a better understanding of the needs of chronically ill individuals.

You have the right to withdraw from the study at any time and/or to refrain from answering any questions you prefer to omit.

Any complaint regarding any procedure used that you feel violates your welfare should be reported to the Office of Research Services (253-4232 EXT.3916) for referral to the Ethics Committee, University of Windsor.

The thesis will be directed by Dr. Maureen Muldoon, Bioethicist, Department of Religious Studies, University of Windsor. The results will be made available to the participant upon request.

I ___________________________ have understood to my satisfaction the information regarding my participation in the research project and I agree to participate as a subject.

________________________________________
Participant Signature
APPENDIX B

INTERVIEW PROTOCOL

1. OPENING QUESTIONS
■ Can you tell me a little bit about yourself?
■ How old are you?
■ Are you married?
■ Do you have a family?
■ Do you work? If so, where?
■ How is your Crohn’s Disease at present?

2. ILLNESS NARRATIVE QUESTIONS
■ How long have you lived with Crohn’s Disease?
■ When did you first realize you were sick?
■ When were you told you had Crohn’s Disease?
■ Starting wherever you wish, can you tell me your story of living with Crohn’s Disease?
■ I would like you to tell me about your experience(s) living with a chronic illness.

3. THEMATIC PROMPTS

A. THE MEANING OF ILLNESS
■ What does illness mean to you?
■ What does ‘being ill’ mean to you?
■ What is it like living with Crohn’s Disease?
■ How do you suffer?
■ In what ways has Crohn’s Disease impacted your life?
■ What changes, if any, have you had to make to accommodate your illness?

B. THE MEANING OF CARE
■ Can you tell me about good experiences you have had with physicians in dealing with your Crohn’s Disease?
■ Can you tell me about some of the bad or negative experiences you have had with physicians?
■ How do you know if you are receiving good care from your doctor?
■ When you think of the care you expect from your doctor(s) what comes to mind?
■ What characteristics make up a good doctor?
BIBLIOGRAPHY


VITA AUCTORIS

John James McCann was born in Glasgow, Scotland in 1962. His family immigrated to Canada in 1967. He grew up in Scarborough and graduated from Cardinal Newman Secondary School in 1981. In 1982 he began his post-secondary studies at the University of Toronto completing two years in the Society, Values, and Medicine program. John graduated from the University of Windsor in 1987 with a B.A. in Psychology. In 1989, he received a Certificate of Proficiency in Religious Studies from the University of Windsor and in 1990 he graduated from the Faculty of Education with a B.Ed. He successfully defended this thesis and graduated with a Master of Arts degree in Religious Studies in the fall of 1999.