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UMI
PHARMACISTS' ILLNESS EXPERIENCE
AND THE PHARMACIST-PATIENT RELATIONSHIP

by

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A thesis submitted in conformity with the requirements
for the degree of Master of Science
Graduate Department of Pharmacy
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CHAPTER 4  ILLNESS EXPERIENCE AND PATIENT RELATIONSHIPS

4.0 Overview.................................................................43
4.1 Illness Story Types and Patient-Pharmacist
   Relationships...........................................................44
TABLE 2: Participants by Type of Illness and
   Reported Change in Patient Relationships
   After Exposure to Illness............................................47
4.2 Stories of Minor and Acute Illness..............................48
4.3 Stories of Chronic Illness.........................................52
   4.3.1 Chronic Illnesses of Family Members.....................53
   4.3.2 Pharmacists with Chronic Illnesses......................55
4.4 Life-threatening Illness Stories..................................67
   4.4.1 Cancer Stories................................................70
   4.4.1.1 Pharmacists and Family Cancer.........................70
   4.4.1.2 Pharmacists with Cancer................................81
   4.4.2 Pharmacists with Gynecological and
      Obstetrical Experiences.........................................88
4.5 Summary...............................................................98

CHAPTER 5  DISCUSSION: ANTECEDENTS OF CHANGE IN
   PHARMACIST-PATIENT RELATIONSHIPS

5.0 Overview...............................................................101
5.1 Professional Activism and Patient Advocacy.................103
TABLE 3: External and Internal Antecedents to
   Perceived Change or Barriers to Change in
   Patient Relationships...............................................103
5.2 Antecedents of Illness and Practice Change..................107
   5.2.1 The Social Context of Pharmacy Practice.............107
   5.2.2 Antecedents of Personal Transformation..............112
   5.2.3 Antecedents of Lack of/ Barriers
      to Change in Patient Relationships.................115
5.3 Change in Patient Orientation, "World View" and
   Discrimination.......................................................116
5.4 Summary...............................................................119
CHAPTER 6  SUMMARY AND IMPLICATIONS

6.0 Introduction...................................................... 121
6.1 Summary and Theoretical Interpretation of Findings..................... 121
  6.1.1 Recovering the Pharmacist's Relationship with the Patient............. 123
  6.1.2 Self-Identity and Relationships................................. 126
  6.1.3 Pharmacists Narrate their Illness Experiences: Summary................ 128
  6.1.4 Antecedents to Change in Pharmacist Patient Relationships............. 129
6.2 A Model of Transformation........................................ 131
6.3 Implications for Pharmacists and Recommendations for Pharmacy Educators 132
6.4 Pharmaceutical "Care" as an Area for Future Research........................ 134

REFERENCES.......................................................... 135

APPENDICES
A: INTERVIEW QUESTIONS FOR KEY INFORMANTS 142
B: ETHICS APPROVAL.............................................. 143
C: CONSENT FORM................................................... 144

TABLES
  TABLE 1: Participants by Decade of Graduation, Education, Professional Activism and Practice Site........................................... 30
  TABLE 2: Participants by Type of Illness and Reported Change in Patient Relationships after Exposure to Illness.................................. 47
  TABLE 3: External and Internal Antecedents to Perceived Change or Barriers to Change in Patient Relationships............................. 103
ABSTRACT


In this study of 18 pharmacists including 16 women, illness experience and subsequent changes in patient relationships in the pharmacists' professional practices were explored. Three types of illness accounts were identified: (1) minor/acute; (2) chronic; and (3) life-threatening. Four pharmacists transformed their self-identity (Giddens, 1991) and became "empathetic advocates" for their patients as a result of being ill or caring for a family member. One became more sympathetic and seven more empathetic; the other six remained essentially unchanged. Obstacles to the development of empathy included type of illness, lack of social support, self-reflexivity, energy level and working conditions. This study was informed by symbolic interactionism as well as by feminist and other critical approaches; thematic analysis was performed on the interview transcripts which recorded the pharmacists' illness narratives. The thesis concludes by recommending changes in pharmacy education, including exposure to the feminist theory of "relational" caring (Gilligan, 1982).
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CHAPTER 1
INTRODUCTION

Illness is the night side of life... (Sontag, 1979:3)

1.0 Overview

Pharmacists, as the dispensers of drugs, possess expertise and knowledge concerning appropriate drug use. But physicians, who diagnose disease and prescribe drug treatment, are the gate-keepers in our health care system. Drug-taking is commonly expected of patients seeking cure or relief from their symptoms. Since pharmacists are "drug use experts" and also have access to drugs, I wondered when and how they decide to enter the formal health care system by consulting a physician, rather than self-diagnosing and treating their own illness. How do pharmacists, as knowledgeable professionals within the health care system, experience being patients? How does being a patient change the pharmacist's relationship with other patients in subsequent practice?

When individuals experience ill health, the meaning of which is personal, socially constructed and culturally influenced, they first seek relief in their everyday world. As a classic study shows, only 10 to 30 per cent of self-diagnosed illness prompts people to access the formal health care system (Kleinman, Eisenberg and Good, 1978). There, they encounter physicians who interpret illness as "disease" and the sufferer as a "patient". This experience of becoming a
patient can be seen as an aspect of allopathic medicine\textsuperscript{1}, which dominates our health care system. Following the theory of a specific etiology for each disease, which parallels the prevalent Western ideology of individualism, allopathic medicine represents the human body as a mechanical structure. This way of viewing the human body is scientific and reductionist.

Pharmacists may also view the human body in scientific, reductionist terms, since their education is similar to medical training, with an emphasis on the basic sciences. As health care professionals, pharmacists are "inside" the health care system but "outside" the patient experience until an illness occurs which requires medical intervention. Becoming an "insider" (Clarke, 1990) through caring for a family member or becoming a patient oneself, may change how pharmacists relate to other patients. In this chapter, I will review my personal orientation to pharmacist-patient relationships and provide an historical context for this study.

\textsuperscript{1} In allopathic medicine, disease is treated by a licensed expert by means which oppose the symptoms or their cause. For example, antibiotics which kill bacteria are prescribed when infection is diagnosed.
1.1 Why Study How Pharmacists Experience Illness?

During my first 25 years as a pharmacist, I was focused on the appropriate use of drugs in curing disease by collaborating with physicians and nurses in hospital practice. Meanwhile, I felt an unrest within myself, a sense that there was more to patient care. It was not until I experienced my father's death from coronary artery disease in 1992 that I came to realize how much more was involved in healing than just drug therapy. In 1993, I enrolled in graduate school and, at the same time, supported my elderly mother through heart surgery and bowel surgery within the first seven weeks. I realized how little my pharmacist knowledge contributed to caring for my parents; I also saw how helpless they were as patients in the health care system.

I am concerned for the future of pharmacy as a profession. The technology for automated drug delivery systems, prescriber decision-making aids and patient-specific information already exists. Educated into the biomedical model of health and disease, I now see that paradigm as inadequate, since it does not consider the patient's social context; I recognize that being trained as a scientist is not enough. I am curious about alternative or complementary therapies which actually pre-date Western medicine and are more often consulted, world-wide. I see more female pharmacists but those with power are often male. As a woman conscious of our inter-dependence, I recognize that health is socially determined.
I now believe that health and illness are socially constructed (Berger and Luckmann, 1966) and result from the interplay of self with others; psychological and emotional events have an effect on the physical self as do relationships and interactions. Illnesses are culturally defined (Mishler, 1981). This approach contrasts with the biomedical model of disease and the concept of body-as-biochemical-machine (Turner, 1987), which excludes consideration of the whole person in his or her social/cultural context.

In order to learn how other pharmacists view health and illness, I conducted interviews and analyzed their narratives. Meaning making is automatic and uninterrupted, continually adjusting as we reflect on events and relationships in our lives. Self-reflexivity is enabled by being cared for and supported by others, since we re-define ourselves by sharing our experiences with others and making meanings as they reflect back to us that which we have shared. Other professionals, such as doctors (Hahn, 1985) and sociologists (Davis and Horobin, 1977) have written about the tensions which surround being a knowledgeable patient and negotiating one's own care, as a way of making meaning of their illness experiences. However, I am not aware of literature written by pharmacists which explores the meaning of being a patient or how relationships with patients in practice may be affected by the illness experience of pharmacists.
1.2 The Pharmacist's Historical Relationship with the Patient

In the early 1900s, pharmacists or druggists were accessible community caregivers; they looked after those who couldn't afford the physician's fee, prescribed herbal or chemical treatment and then compounded and dispensed that treatment. The division of labour which granted physicians the exclusive right to diagnose and prescribe, gave pharmacists the monopoly over the compounding and dispensing of drugs and assured the dominance of medicine in the hierarchy of the professions (Freidson, 1970).

The growth of the pharmaceutical industry following World War II made a significant impact on the profession of pharmacy. In response, pharmacy educators changed the curriculum to reduce the compounding component and increase the science content. The clinical pharmacy movement of the 1960s and 1970s capitalized on this scientific emphasis by promoting the pharmacist's role as "drug use expert" and "therapeutic advisor" to the prescriber (Muzzin, Brown and Hornosty, 1993). With the advent of the consumer movement, pharmacists were required to include drug names on prescription labels and to inform patients about possible drug side effects. More recently, Hepler and Strand described a model of practice called "pharmaceutical care," which is defined as "the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient's quality of life" (1990:539). This patient-focused
practice model has been endorsed by licensing and professional bodies. The Ontario College of Pharmacists now requires that pharmacists develop relationships with patients, educate them about their drug therapy and protect them from unwanted drug effects. The Ontario Pharmacists' Association encourages pharmacists to advocate for patients with physicians in order to optimize drug use.

1.3 Pharmacist-Patient Relationships and Contemporary Pharmaceutical Care

In the past few years, legislation around treatment decisions has become more explicit in North American health care. There is an onus on the health care professional proposing treatment to be certain that the patient is fully informed of potential risks as well as benefits and also alternative treatment plans. This "informed consent" carries with it ethical obligations as well. However, in Ontario, pharmacists are reimbursed only when they dispense a prescription; intervention on behalf of the patient with the prescriber is not rewarded. Since drug therapy is part of many treatment plans, this has considerable implication for pharmacy practitioners.

Unlike the situation in the recent past, pharmacists are now developing counselling relationships with patients. "Dialogue" between pharmacist and patient is expected to take place whenever a new prescription is filled or over-the-counter medication is sold, according to the Ontario College of Pharmacists. However, in Freire's terms, "dialogue cannot
be reduced to the act of one person's 'depositing' ideas in another, nor can it become a simple exchange of ideas to be 'consumed' by the discussants" (1997[1970]:70). Historically, this model of "information transfer" dominates the pharmacy literature; the patient becomes an "informed consumer".

The concept of an "information transfer" between patient and pharmacist can be contrasted with a different model which posits that in order for pharmacists and their patients to be able to communicate, a caring relationship must exist. "Caring cannot be achieved by formula. It requires address and response..." (Noddings, 1992:xii). But how is caring to be achieved? An idea from popular culture is that "walking a mile in his shoes" can promote empathy and caring. For example, this emerges from accounts written by physicians in recent years. One of these became a movie, "The Doctor." This film explored the impact of having cancer on the life and practice of a surgeon who was supported by another cancer patient, enabling him to change how he related to others, especially patients.

Following this line of reasoning, I chose to investigate how illness events provide the pharmacist with the opportunity to experience what it means to be a patient. What meaning pharmacists make of this illness experience may influence their relationships with both patients and physicians afterwards. Telling others the story of their illness experience has helped physicians to be more aware of and concerned for their patients (Hahn, 1985).
Telling the story of one's experience may help the storyteller to reflect and make sense of the body's suffering and change in self; it is an opportunity for healing and also one for teaching. Frank (1995) suggests that personal experiences of pain and illness on the part of healers must ethically be made public. Illness narratives may help other health care practitioners who have not experienced an illness themselves to become more empathetic\(^2\), thus facilitating more caring relationships with patients.

As defined earlier, pharmaceutical care is a practice model describing a relationship between pharmacists and their patients. In order to fulfil the obligation of this model, the pharmacist must have a collegial relationship with the prescribing physician and access to the patient's clinical information. Many have neither. As the dispenser of prescription drugs, the pharmacist is obliged to educate the patient, who may have already made the treatment decision in consultation with his/her physician. Thus, opportunities for conflict arise when pharmacists identify necessary changes in drug therapy; how the pharmacist deals with this conflict may be influenced by previous life experience, particularly as a patient.

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\(^2\) Empathy, in psychological terms, means identifying oneself with and comprehending the person or object of contemplation. However, I use empathy in the sense of feeling connection with others and wanting to help them, much like Charon's (1996) use of empathy as compassion or being able to experience with someone what she is suffering. Caring also embraces compassion, inclining one to be helpful. On the other hand, I use sympathy as meaning the sharing of an emotion without the intention to act.
In my view, the term "pharmaceutical care" focuses on the drug product—how it is provided and taken as well as the outcome of its use—rather than the patient, the drug taker. Providing drug-related information takes time; many physicians are unwilling to spend this time with their patients and may signal the end of the consultation by writing a prescription, thereby dismissing the patient (Svarstad, 1974). Pharmaceutical manufacturers are concerned about optimizing drug use, and so they also have a vested interest in assuring that patients are informed about prescription drugs; thus, they provide extensive product information in their drug packaging. However, package inserts can be overwhelming to patients unless the information is interpreted for them.

The pharmacist who "cares" for a patient, as I am developing the concept in this research, suspends her self and her world construct in order to receive the one presented by the patient. She thus interprets the drug information in the patient's context, thereby helping the patient to incorporate more information about his illness and treatment (after Witherell and Noddings, 1991:263). This is the caring part of pharmaceutical care.

1.4 Research Questions

This research will explore how pharmacists make meaning of becoming a patient and how that meaning is incorporated into their professional relationships with other patients. By
giving voice\(^3\) to individual experiences of illness through their narratives, this thesis will look at the opportunity for transformation or metamorphosis of self provided by an illness experience. Questions that will be addressed include: Does being a patient enable pharmacists to become conscious of the oppression\(^4\) of patients in our health care system? What meaning do pharmacists make of illness? Are some pharmacists more likely to be transformed by illness than others? Why? What factors shape this transformation or maturational development?

1.5 Organization of Thesis

Chapter Two briefly reviews concepts related to my research questions on illness, self-identity, caring, advocacy and patient-practitioner relationships as they appear within various theoretical perspectives, including the symbolic interactionist, relational feminist and critical sociological literature.

Chapter Three describes the research design and how the data was collected. My choice of exploring themes in the narratives of the pharmacists rather than a more structured "grounded theory" approach is explained. Participants are

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\(^3\) Voice connects mind and body, joins psyche and culture; voice changes depending on whether one is heard or not and how one is responded to by self and others (after Brown and Gilligan 1992:20).

\(^4\) Oppression refers to lack of power or control. I believe that patients in our health care system are oppressed because they have little or no control over their own privacy or space, when they eat, when they sleep, etc. Oppression exists as an interdependent relationship between the oppressor and the oppressed (Freire 1997[1970]).
introduced here, and a natural history of this research is outlined to provide a framework for the data presented and analyzed in Chapters Four and Five.

Chapter Four presents the participants' illness experiences, grouped by types of illness stories as minor/acute, chronic or life-threatening. Changes in relationships with patients, as reported by the informants, are summarized in this chapter.

Chapter Five looks in more detail at the illness accounts of pharmacists and examines antecedents reported by pharmacists about the change or lack of change which they identified in their orientations towards patients as a result of their illnesses. After a brief consideration of the relationship between professional activism and patient advocacy, two types of influences are discussed: those external to the pharmacist, as part of the context of their lives (e.g. the influence of practice site, working conditions and the availability of social support) and those internal to the pharmacist (e.g. experiences, self-reflexivity and advocacy and changes in "world view").

Chapter Six summarizes the findings of this research, its implications for pharmacists and suggests areas for future research.
CHAPTER 2
THE LITERATURE ON SELF-IDENTITY, ILLNESS, CARING, ADVOCACY
AND PATIENT-PRACTITIONER RELATIONSHIPS

2.0 Introduction

The various literatures on self-identity and illness, empathy and caring and patient-practitioner relationships each provide concepts that are useful in understanding how pharmacists might make meaning of their illnesses and how this could affect their relationships with patients.

Self-identity may be defined as "the self as reflexively understood by the person in terms of her or his biography" (Giddens, 1991:53). Self-identity presumes reflexive awareness; it must be created and sustained by active reflection. As researchers in various theoretical perspectives have observed, one's self-identity may be challenged by unexpected illness. If recovery is delayed, re-definition of self may be required as "the sick role" (Parsons, 1951), or being a patient, continues. Such crises disrupt life but also provide an opportunity for self-change; a more valued self may be the result (Charmaz, 1994b).

Professional and personal identity and patient relationships are discussed in diverse ways in the literature, as I will show in this chapter. As outlined in Chapter One, health care professionals develop relationships with each other and with their patients. There is an hierarchy in health care and medicine is dominant (Freidson, 1970). Narratives of
their illness accounts have been published by several physicians, including Oliver Sacks (1984). One outcome of life-threatening events may be the questioning of the biomedical way of viewing the world and re-orientation towards a more relational\(^5\), caring approach (Noddings, 1984).

Pharmacists have not been well-studied in this regard as compared to physicians. However, it is not unreasonable to expect that pharmacists, like physicians, will tend to view illness in themselves and their families within the biomedical or traditional science world view\(^6\).

The understanding of empathy and caring is advanced by Belenky et al.'s (1986) concept of critical thinking about self leading to empathy for others. Noddings (1984) promotes the concept of empathy as bringing the other into self as well as caring for self. The concept of empowerment\(^7\) from the health promotion literature further develops these diverse ideas. Using these perspectives to view the impact of illness on pharmacists, I think it is possible to contribute to the understanding of how pharmacists experience being a patient and how that experience impacts on their relationships with patients.

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\(^5\) A relational, caring approach differs from "taking care of" the patient. The patient is considered as a person rather than the object of care.

\(^6\) Boon and Muzzin (1996) use Miller and West's definition of world view: a particular set of mental constructs that make one's world meaningful. A world view acts as a "filter" through which phenomena are perceived and comprehended (1993:3).

\(^7\) "Empowerment exists in power being simultaneously taken and given" (Labonte 1994:261).
2.1 Symbolic Interactionist Perspectives on Illness

Symbolic interaction theory is an appropriate starting point for examining illness and identity. Within such a theoretical framework, identity and caregiver-patient interactions can be seen as dynamic processes involving ongoing negotiation of meanings. Identity, self-esteem, friendship and role-conflict resolution are all addressed by symbolic interactionism. Mead's (1934) framework accepts the reality of the objective world while it recognizes the importance of the individual's subjective interpretation of that world (Tourigny, 1988). According to symbolic interactionist theory, both self and identity are social products; "the looking glass self" (Cooley, 1964:183-4) has three components: how we imagine we appear to others; how we imagine others judge that appearance; and a self-feeling, such as shame or pride. As social agents, we choose how we react to feedback from others around us; by reflecting on the meaning of events in our lives, we also choose how to incorporate those meanings into our "self." The self is both a process and a product, an ongoing activity as long as we live. Illness may

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Based on the social psychology lectures of George Herbert Mead, which were published after his death and elaborated in the writings of Herbert Blumer, the three basic premises of symbolic interactionism are:

1. Human beings act towards things on the basis of the meaning those things have for them;
2. The meaning of such things arises out of the social interaction one has with one's fellows;
3. Meanings are handled and modified through an interpretive process applied by the individual in dealing with the world (Blumer, 1969:2).
provide us with an opportunity to reassess who we are as caregivers, by "being on the other side" of the caregiving relationship.

The topic of transformation of identity through illness has been studied by a number of symbolic interaction theorists. Responding to the diagnosis of a life-threatening illness which invades the body provides the opportunity for a "renewal" of self, revised, not merely restored (Charmaz, 1994b: 240) or an "epiphany", Denzin's term for a life experience that radically changes how one sees herself or the world around her (1994:510).

2.2 Professional Identities: How Pharmacists View Themselves

One logical question to start with in examining how pharmacists experience illness is: how do pharmacists value themselves? Further, are pharmacists able to separate the illness from who they are, a self which is "distinct" from their body (Charmaz, 1994b:240)? In view of the emphasis on objective, value-free science in their education up to and beyond the "clinical pharmacy" movement of the 1960s, it might be argued that pharmacy graduates are hampered in making this distinction. Feeling good about one's professional identity may be a challenge when one's skills as a pharmacist are inhibited by physical disabilities, for example.
Heather Boon (1996) studied professional identities developed by naturopathic practitioners. They were identified as having either "holistic" or "scientific" world views, which had implications for how they saw themselves relating to patients and how they conducted their practices. Specifically, the "holistically-oriented" naturopaths saw themselves treating the "whole patient," while "scientifically-oriented" naturopaths tended to use interventions such as manipulations that dealt with bodily symptoms, much as practitioners of scientific medicine. In a later study of the world views of pharmacy students (Boon and Muzzin, 1996), it was argued that pharmacy students experience a sharp move away from "holistic" and toward "scientific" thinking in encountering a curriculum emphasizing molecular science. When they become ill, do pharmacists see their bodies in objective, medical terms? How do they integrate being ill into their self-identity? Do they expect to be "taken care of" or "cared for" when they become patients in our health care system?

2.3 Feminist Perspectives on Identity

A growing body of feminist literature critiques the pervasiveness of scientific ways of thinking in our society. Chodorow's (1978) object relations theory defines the basic

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"Caring for" another in a caring relation requires contribution from both parties in the dyad. The one-caring responds to the needs of the second, displacing her motivation so that she feels with the other; the second member, the cared-for, contributes to this relation by recognizing and responding to the caring (Witherell and Noddings 1991:6). In a mature relationship, the two parties may exchange places in the relation.
feminine sense of self as "connected to the world," whereas the basic masculine sense of self is separate or objectified. Women are taught at a young age to "be nice" as a way to control their feelings, thoughts and behaviour (Brown and Gilligan, 1992:52). This presentation of self corresponds to the "social distance" model of the health professional (Haas and Shaffir, 1981) in which health care providers remain detached from the patient's experience of illness, focusing instead on the objective treatment of the ailing organ.

In more general terms, feminist authors have critiqued the medicalization or objectification of health and illness. One example is the development of hospital "birthing centres" as an alternative to home birthing. This enables the continued medicalization of birthing and reduces the opportunity for women to consult midwives (although a midwife may attend a hospital birth, under the supervision of an obstetrician). Many other normal functions of women's bodies are also being medicalized, including menopause and osteoporosis. In fact, women's health centres are now being marketed using language from the women's health movement, as co-opted by the (predominantly male) medical establishment (Worcester and Whatley, 1988).

More so than men, women learn through relationships, crises and their communities. Identity develops as women experience themselves through attachment in relationships (Gilligan, Lyons and Hanmer, 1990). Thus their self-identities
and ways of knowing\textsuperscript{10} are intertwined. In our male-dominated culture, men have constructed theories, history and values, devaluing women's epistemologies, or ways of knowing, and contributions in favour of rationalism and objectivity, which are highly valued in our technology-oriented society.

A particularly useful feminist treatment of self for understanding caregiving is presented by Noddings (1984). She critiques the traditional view of ethics, expressed in male language, as "failing to capture the receptive rationality of caring that is characteristic of the feminine approach" (Noddings, 1984:1). Before someone can care for others, she must attend to her ethical self and her physical self. In Noddings' terms, empathy is receiving the other into myself as

\textsuperscript{10} In a book titled \textit{Women's Ways of Knowing}, Belenky and colleagues develop a categorization of five perspectives from which women view reality. The five categories of knowers (or "ideal types") are:

1. silent knowers, who have no voice nor sense of self, adopt notions and question or replace them according to their life experience;
2. received knowers, who learn by listening and see themselves reflected in the eyes of others;
3. subjective knowers, who develop a self and inner voice, learning from the experience of others, and begin to become reflective, critical thinkers;
4. procedural knowers, who use feelings and intuition to develop reasoned reflection, viewing knowledge as a process; they may be further categorized as separate (suspicious of knowledge from others, individuals who may have been tomboys as girls) or connected knowers (who use empathy to share the experiences of others and collaborate with them);
5. constructed knowers, who have integrated their experiential and academic knowledge and reclaimed their self; they realize that all knowledge is socially constructed and culturally defined. Constructed knowers attend to other people in an empathic way; they are able to care for others and listen fully and they use their voices to speak out on behalf of others. They want "to make a difference," to make their world better.
opposed to projecting myself into the other. Caring for another is engrossing and flexible; I consciously attend to the other's needs and allow myself to be transformed by the other. Institutionalized health care risks being rational and objective rather than responsive and caring; the cared-for is no longer an individual (Goffman, 1961) because all patients are fed or bathed or medicated at a standard time. Noddings defines "[t]he ethical self as an active relation between my actual self and a vision of my ideal self as one-caring and cared-for." I am connected through the other, to myself. "As I care for others and am cared for by them, I become able to care for myself" (Noddings, 1984:49). If the person cared-for is not treated as an individual, then he or she becomes an object. The one-caring sees the potential best self in the cared-for and helps him/her to actualize that self. Pharmacists may be able to care for their patients, despite the constraints in their practice, once they develop other caring relationships and become connected to their larger community.

2.4 Oppression and Advocacy: Paulo Freire

The work of Paulo Freire also provides concepts which describe identity and self. Freire showed that even people oppressed and submerged in a "culture of silence" can find their voice and look critically at the world, once they have become aware of self. Becoming self-aware enables workers to transform the world as they come to see themselves as no
longer mere objects in it. He also states that the oppressed have a duty to humanize both themselves and the oppressors; oppression cannot change until those oppressed revolt. He is critical of the "banking" concept in education where knowledge is poured into receptive students; he views education ideally as a dialogue between student and teacher where both are learning and participating. Another of his concepts, that of "housing the oppressor" suggests that people who are oppressed have a copy of the oppressor within themselves; in other words, they are alienated from self. Becoming conscious of oppression and dealing with alienation\(^\text{11}\) must precede identifying with oppressed others. In order to be an advocate\(^\text{12}\), one must "love" the oppressed. That is, Freire claims that only a benevolent orientation can transform the world, not a fatalistic one.

As mentioned above, I would argue that patients are oppressed in our health care system. They are "taken care of" --rather than being "cared for"-- by well-intentioned professionals who remain detached from attempts to engage them in meaningful social interaction. Pharmacists employed by corporate chains may also be oppressed by their employers and their working conditions; Freire's concepts may apply "twice-over" to these pharmacists who become ill.

\(^{11}\) I use alienation here in the sense of estrangement or detachment from self.

\(^{12}\) An advocate is one who takes the side of someone with less power in opposition to someone with more power, in an effort to influence the second (after Labonte 1994 and van Willigen 1993.)
2.5 Advocacy and Empowerment

Advocacy in the anthropology literature is a concept that describes professionals working for social change on behalf of disenfranchised others; that is, privileged groups working for disempowered groups (van Willigen, 1993). This model does not readily fit the one-on-one relationship between the pharmacist and the patient, although the Ontario Pharmacists' Association urges pharmacists to become involved in program and policy reform on behalf of vulnerable groups. On the other hand, empowerment, or enabling others to gain control over their life or disease, fits with the contractual model of pharmaceutical care, described above, in which the pharmacist enters into a dialogue for the purpose of informing and empowering the patient in a covenantal relationship. This concept is found in the health promotion and wellness literature and the World Health Organization's definition: "health promotion is the process of enabling people to increase control over, and improve, their health" (cited in Anderson, 1996:697). In her critique of health promotion, Anderson argues that notions of empowerment become interwoven with the discourse of individualism, disregarding how illness may prevent people from solving their own problems and meeting their own needs. As she continues, "by focusing on empowering the individual, we risk glossing over the institutionalized practices that perpetuate inequity and that are barriers to health and well being" (Anderson, 1996:699) including race,
Similarly, Grant (1988) argues that those most in need of health care are least likely to get it.

Life-threatening illness may present an opportunity to reflect and become conscious of the oppression of being a patient and to identify with other patients, perhaps forming coalitions. The possibility of social or political action then enables the pharmacist to become more powerful by sharing power with other group members. "Empowerment exists in power being simultaneously taken and given" (Labonte, 1994:261).

2.6 Patient-Practitioner Relationships

The literature on doctor-patient relationships is one place to search for ideas about the self and professional identities. However, little is said about these social processes in this literature. For example, Emanuel and Emanuel outline four models of the physician-patient relationship which differ in: (1) the goals of the interaction; (2) the physician's obligations; (3) the role of patient values; and (4) the conception of patient autonomy (1992:2221). The 'paternalistic model' is similar to Veatch's (1972) 'priestly model' and the 'informative model' corresponds to his 'engineering model.' The 'interpretive model' views the physician as counsellor, helping the patient to elucidate his/her values so that self-understanding is achieved. Lastly, the 'deliberative model,' which is preferred by the authors, portrays the physician as friend, guiding the patient towards the right course of action. The two extremes--patient autonomy
and physician paternalism--are criticized, as is the 'informative model' for reducing the physician's role to that of technologist. None of these models adequately addresses the self in either the patient or the health professional; however, each provides useful "sensitizing concepts" (Blumer, 1969) for approaching a study of self, professional identity and illness.

In an American study of pharmacists attempting to implement pharmaceutical care, Lambert (1996) observed the historical tensions between pharmacists and physicians and how pharmacists (politely) managed their interactions with physicians who could be threatened by the intervention. In a hypothetical drug allergy scenario, hospital pharmacists were found to be more assertive than community practitioners; older pharmacists were more likely to make recommendations about changing the prescription than younger; no recommendation was made in 60% of the cases. (Note: 69% of the sample were men. Women in the sample tended to be Pharm.D.s working in hospital settings; the men were older, baccalaureate-educated and employed in community practice.) Avoiding conflict and being polite may serve to perpetuate existing roles and power dynamics. In the context of this research, it might be asked how illness impacts on subsequent relationships with physicians and willingness to intervene on behalf of patients.
2.7 Summary

This literature review is an eclectic one, borrowing from diverse traditions. These include: the concept of illness as an opportunity for transformation; professional identities and ways of viewing the world; critical perspectives from the feminist literature; useful concepts from the education literature of Freire and Noddings; and the health promotion literature, dealing with empowerment. These varied ideas will be applied to an understanding of how pharmacists experience illness and how that experience impacts on their relationships with patients.
CHAPTER 3
METHODS AND METHODOLOGICAL ISSUES

3.0 Introduction

In order to understand the meaning of illness to pharmacists and to explore how these experiences affected their relationships with patients, I chose the qualitative research method of semi- and unstructured interviewing about retrospective experience, or narrative. These qualitative methods elucidate meanings as they: (1) allow in-depth exploration of a complex process; (2) allow the participant to structure the discourse of the interview and reflect her perspective; and (3) make visible the social, cultural and illness contexts (Charles, Gafni and Whelan, 1997). Since this is a first study investigating these research topics, the use of semi- and unstructured qualitative methods is appropriate, in order to generate data that can be analyzed for common and divergent themes.

Although participants were originally selected for interviews on theoretical dimension of whether they were "active" or "inactive" as professional leaders, this selection criterion did not prove to be predictive of how they saw their illness experiences nor whether they changed their view of patient-pharmacist relationships as a result of their exposure to illness. Neither was it possible to isolate a sampling
criterion that unproblematically predicted such patterns. I instead opted to compare the illness narratives of participants for common and divergent themes.

My method of asking the 18 participants to tell me the "stories" of their illness experiences and subsequent professional practice in their own words, and recording and transcribing the results, yielded a series of narratives about illness that could be grouped by type and theme. Telling about their experiences was difficult for some but all chose to continue rather than cease the interview. They were able to give meaning to events by talking about them.

This chapter explains in more detail how participants were selected, how data was collected, how the quality of transcription was assured and how data were analyzed. Themes and hypotheses that emerged from the data related to: (1) becoming a patient; (2) changing self-identity; and (3) changing relationships with patients. In the last part of the chapter, the emergence of these themes is set within the context of what Becker and colleagues (1961), in their study of medical school, have called a "natural history" of the research process.
3.1 Research Methods

3.1.1 Access to the Field and Selection of Participants

There are about 7,000 practising pharmacists in Ontario. Since I have practised pharmacy for nearly three decades in this province, my network in, and knowledge of pharmacy circles is well developed. Following my initial hypothesis that leaders in "pharmaceutical care" within the profession of pharmacy would also be those who applied caring in their practices, I sought participants with illness experience who were leaders in the profession (pharmacists who were active in role development, continuing education and professional associations) as well as those who were less active. I did this in order to compare and contrast the narratives of active and inactive pharmacists, as well as to examine the relationships among professional activism, patient advocacy and illness. I approached some participants directly because I knew of their recent illness. Others were referred to me by pharmacists who knew of my research project.

Another theoretical dimension of interest, I reasoned, might be the setting within which pharmacists practised. For example, I wondered, was it more likely that those who had empathetic relationships with their patients could be found in hospitals rather than commercial settings, since community pharmacists may be distracted by business concerns? Thus participants from community and hospital practice sites were
interviewed. Some were managers and some were in staff positions. (Observations on this point are discussed in Chapter Five.)

As the interviews progressed, and particularly, after I interviewed two male pharmacists, I became aware of gender and power issues in understanding the role of women in pharmacy. Also, my explorations in the caring literature served to reinforce my hypothesis that gender and power were very important. Although I did not exclude male pharmacists from this study, I became more interested in the way women spoke of caring as the research progressed, and ultimately, 16 of the 18 participants I recruited were women. Both male participants were employed in administrative positions, rather than in patient care roles. They were concerned more about "macro" issues facing the profession of pharmacy rather than "micro" issues facing individual pharmacists in their daily practice. Perhaps their jobs as well as their gender contributed to this orientation.

Participants are described in Table 1 (page 30). Each was assigned a pseudonym in the interests of confidentiality. Their ages ranged from 25 to 62 years. Half of those interviewed were highly visible professional activists (involved in pharmacy education, associations or practice change promotion), while others were not involved in these
activities. Most of the participants graduated during the 1970s; it could be predicted that, as pharmacists age, they would be more likely to encounter illness in themselves or their families.
### TABLE 1: Participants by Decade of Graduation, Education, Professional Activism and Practice Site

<table>
<thead>
<tr>
<th>Name</th>
<th>Graduation Decade</th>
<th>Highest Degree</th>
<th>Professional Activism</th>
<th>Practice Site</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nan</td>
<td>1950s</td>
<td>baccalaureate</td>
<td>active</td>
<td>Hospital manager/ staff</td>
</tr>
<tr>
<td>Belle</td>
<td>1960s</td>
<td>baccalaureate</td>
<td>inactive</td>
<td>Hospital manager</td>
</tr>
<tr>
<td>Opal</td>
<td>1960s</td>
<td>baccalaureate</td>
<td>inactive</td>
<td>Community staff</td>
</tr>
<tr>
<td>Jane</td>
<td>1960s</td>
<td>baccalaureate</td>
<td>active</td>
<td>Not employed</td>
</tr>
<tr>
<td>Ann</td>
<td>1970s</td>
<td>baccalaureate</td>
<td>inactive</td>
<td>Hospital staff</td>
</tr>
<tr>
<td>Fran</td>
<td>1970s</td>
<td>baccalaureate</td>
<td>inactive</td>
<td>Community staff</td>
</tr>
<tr>
<td>Irene</td>
<td>1970s</td>
<td>baccalaureate</td>
<td>inactive</td>
<td>Hospital manager</td>
</tr>
<tr>
<td>Lynn</td>
<td>1970s</td>
<td>baccalaureate</td>
<td>inactive</td>
<td>Hospital manager</td>
</tr>
<tr>
<td>Penny</td>
<td>1970s</td>
<td>baccalaureate</td>
<td>inactive</td>
<td>Community staff</td>
</tr>
<tr>
<td>Rose</td>
<td>1970s</td>
<td>baccalaureate</td>
<td>active</td>
<td>Hospital manager</td>
</tr>
<tr>
<td>Mark</td>
<td>1970s</td>
<td>PharmD</td>
<td>active</td>
<td>Hospital manager</td>
</tr>
<tr>
<td>Sam</td>
<td>1970s</td>
<td>PharmD, MBA</td>
<td>active</td>
<td>Industry</td>
</tr>
<tr>
<td>Gail</td>
<td>1970s</td>
<td>baccalaureate</td>
<td>active</td>
<td>Hospital manager</td>
</tr>
<tr>
<td>Helen</td>
<td>1970s</td>
<td>baccalaureate</td>
<td>active</td>
<td>Hospital manager</td>
</tr>
<tr>
<td>Kate</td>
<td>1970s</td>
<td>baccalaureate</td>
<td>active</td>
<td>Community owner</td>
</tr>
<tr>
<td>Dale</td>
<td>1980s</td>
<td>baccalaureate</td>
<td>inactive</td>
<td>Not employed</td>
</tr>
<tr>
<td>Eve</td>
<td>1980s</td>
<td>PharmD</td>
<td>active</td>
<td>Hospital manager</td>
</tr>
<tr>
<td>Chris</td>
<td>1990s</td>
<td>MSc</td>
<td>inactive</td>
<td>Student</td>
</tr>
</tbody>
</table>

* Each participant was given a pseudonym.
3.1.2 Interviewing Procedures

Following Berg's "Ten Commandments of Interviewing" (1995:57), I endeavoured to make the interview experience comfortable for each pharmacist and to ensure collection of data. A semi-structured interview format using a list of open-ended key questions was used (see Appendix A; questions were modified as data collection progressed.) Participants were as fully informed as possible about the goals of the study. Of 20 pharmacists approached, 18 agreed to be interviewed and two refused to participate. A copy of the ethics approval and consent form may be found in the Appendices.

With the informant's signed consent, each interview was audiotaped to allow me to prepare a written transcript, in order to facilitate data analysis. Interviews were done in the informant's home or place of business, as preferred. Interviews were spaced so as to allow for transcription time and consideration of emerging categories and themes before the subsequent interview. I transcribed the interviews myself.

3.2 Data Analysis and Quality Issues

Field notes were prepared immediately following each interview. Initial field notes included a description of the interview setting, the personal interaction between interviewer and interviewee, the body language and the researcher's perception of the interview (Charmaz, 1994a). More extensive field notes which began the coding process were
then written to allow for preparation for subsequent
interviews. Time between interviews was planned to enable note
preparation and transcribing to take place. Concern about
quality issues around representing participants' voices and
recording their stories led me to review methodological
suggestions made by Corbin and Strauss (1990), Poland (1995)
and Strauss and Corbin (1990).

Transcribing my own interviews gave me the opportunity
to re-live the time spent with each individual. Once
transcribed, each transcript was checked on the computer
screen against the audiotape for accuracy prior to the
audiotape being destroyed. A sincere attempt was made to
include the pauses, inflections, laughter/ tears and
interruptions which were part of the voice of each
participant. Transcripts were assigned a numerical code and
each participant was assigned a pseudonym for ease of
reference without betraying confidentiality. The 18
interviews, ranging in length from one to three hours,
provided 33.5 hours of audiotape which became 512 pages of
text when transcribed.

In order to maximize the quality of my transcriptions:
(1) I routinely checked the placement of the tape-recorder to
assure adequate pick-up of voices. Despite this, I had
difficulties transcribing two interviews because the
voices were occasionally barely audible. This related to physical setting/placement and also, to emotion (weeping voices dropped in pitch and volume);

(2) since I transcribed most of the interviews myself, this provided me with a re-enactment and also gave me control of time between interviews;

(3) I reviewed the quality of each transcript soon after transcribing it, but not immediately, since a break from hearing the audiotape would make me more aware of discrepancies between what was said and what was written than would proofing it immediately upon completion of transcription;

(4) since I was both interviewer and reviewer of most transcripts, the interpretation would be more likely to be consistent;

(5) field notes were written prior to transcribing; these were useful in interpreting parts of interviews where responses were less audible;

(6) in several meetings with my advisor and advisory committee, the emergent categories and themes were discussed and compared.

3.3 Using a "Grounded" Approach to Thematic Analysis

As the title of this section suggests, my approach is a blending of diverse methods. I began the study attempting to use the comparative method, grounded theory, but, when this
appeared inappropriate for reflecting the voices of participants, I kept the comparative method but focused more on interpreting the narratives of participants. Whereas the voice taken in grounded theory studies is that of the analyst (cf. Atkinson 1990 cited in Charmaz, 1993:15), my thematic analysis is the product of selective interpretations of pharmacists' lived experience, not the presentation of lived experience.

"Grounded theory is a general methodology for developing theory that is grounded in data systematically gathered and analyzed" (Strauss and Corbin, 1994) and is referred to as the constant comparative method. Grounded theory is derived from pragmatism and symbolic interactionism. Two basic principles are involved: (1) the method allows for continual evolution of how phenomena are understood; (2) determinism is rejected, since actors make choices from among the options they encounter (Corbin and Strauss, 1990).

"Sampling in grounded theory proceeds not in terms of drawing samples of specific groups of individuals, units of time and so on, but in terms of concepts, their properties, dimensions, and variations" (Corbin and Strauss, 1990:8).

Interviews were planned to collect additional data on emerging themes (Charmaz, 1994a). "Emergence" is a key concept that refers to the transformation of meaning of a situation over time as new information is acquired and related to
information already collected. Topics which appeared in one account explicitly but were absent or hidden in other accounts were pursued with additional participants (theoretical sampling). Reasons for choosing to become a pharmacist, for instance, emerged as important in Irene's account. Thus, in subsequent interviews, I encouraged each participant to share with me their reasons for choosing pharmacy. For example, when I observed that no one mentioned being motivated to care for people as a reason for becoming a pharmacist, I began to see the relevance of Boon and Muzzin's argument (1996) about the importance of the "scientific" world view in orienting pharmacists towards professional practice. This enabled further linking of themes emerging from the transcript data. "The grounded theorist's simultaneous involvement in data-gathering and analysis is explicitly aimed toward developing theory" (Charmaz, 1994a:7). Consequently, the interview questions were modified as shown in Appendix A as concepts and themes emerged from the transcripts of completed interviews.

"Thick description" (Geertz, 1973) of actual situations and behaviours was sought in order to group the narratives as a whole, rather than dividing them by theoretical instances, as is often done with grounded theory methods. My approach, on a spectrum of alternative inquiry paradigms (Guba and Lincoln, 1989:109) in which "grounded theory" is located as postpostivistic method (or method that involves verification of hypotheses), tends more towards the "dialogic,"
"hermeneutic" or interpretive. That is, the narratives were interpreted, but were kept largely intact in the analysis so that the voices of the participants could be heard. They were compared holistically. For example, I asked participants how they reacted to their diagnosis and what it meant to them in the context of their lives. Every effort was made to compare responses from pharmacists dealing with similar situations in their various life journeys.

3.4 Natural History of This Research

This section contains a brief account of the process of my research, following Becker's suggestion that it should be presented as a "natural history" (1958). During a two-year period, the direction of my inquiry was shaped by my findings, just as the findings were shaped by my participants as well as my own experience. I will describe the sequence of events in my data collection and analysis as it came to my attention, in order to provide a rationale for my major decisions regarding sampling and interviewing.

On initiating this research, I wondered how a previous illness experience might enhance the pharmacist-patient relationship as pharmacists became more accountable to patients in the practice model "pharmaceutical care." I expected that a diabetic pharmacist could better relate the diet, drug and monitoring information to newly diagnosed diabetics, for instance. I anticipated that all pharmacists
who had been patients would have been somehow influenced by that experience to the extent of realizing that empowering patients or "creating autonomy" by sharing knowledge was more important than "respecting autonomy," as stated by Seedhouse (1988:141).

But, from the first few interviews, it was apparent that pharmacists predominantly used the biomedical model when speaking of illness in themselves or significant others; the social context of illness was not acknowledged. Whether or not they were influenced in their way of describing illness by this interviewer also being a pharmacist, I am not certain; I introduced myself as a pharmacist interested in learning about the social psychology of health and illness. During the interviews, I noticed that the pharmacists tended to describe their own bodies in objectified, functional terms. For example, Nan, describing a very rare muscle disease, said, 

"[T]here's a failing that exists--it has to do with electrolytes--I think it's a calcium transfer in the muscle."

Whether this scientific world view coexists with or replaces a more holistic/reational world view remains to be researched. However, as suggested above, I was alerted to the commitment of the pharmacist to a scientific world view and began to look for evidence of how this affected relationships with patients as well as their own self concept.
The importance of the acuity of illness was a variable which I had not anticipated. Examples of acute, chronic and life-threatening situations were presented in the course of my interviews. As I eventually determined, incidental acute illnesses from which recovery was complete were not as likely to promote change in self-identity and patient relationships as illnesses from which recovery was neither prompt nor complete. When I had approached each pharmacist about being interviewed, I explained that I was researching how pharmacists experienced illness and whether that experience had any impact on their professional practice after the illness onset; each pharmacist was then free to "make meaning" of that question (including acuity of illness) and their own life experience before agreeing to be interviewed.

In applying grounded theory to my transcripts of participants' accounts, I encountered some difficulties during the process of coding in order to develop categories. I became concerned that coding was deconstructing the flow of the narratives. Meanwhile, I was reading feminist writings on knowledge and power, education and moral thinking, and critiques of science as a masculinist construction. I made a conscious decision to attempt to preserve the voices of my participants, with whom I had developed a relationship during our interview time and my subsequent audiotape transcription.
As stated by Lashley, Neal and Slunt:

Voices sound multiple subjectivities and biographies and place persons in relationship to one another through history and experience.... Through voicing, meanings are affirmed or questioned. (1994:191)

I felt an obligation to these pharmacists who had shared their stories with me so I determined to preserve their voices and the meanings they ascribed to their illness experiences in this research. As such, I used a thematic approach to analyzing the participants' accounts.

The full range of illness type and personal involvement was described in the narratives that I collected. Four pharmacists told me about how they managed health and illness in their families; recovery from these brief, acute episodes was complete. Four pharmacists told me about their chronic illnesses and one told me of the mental illness of her two brothers. Nine pharmacists shared with me their acute, life-threatening illness episodes; six involved self, two involved spouses and three involved parents. Six accounts described cancer diagnoses and their aftermath. Four involved gynecological or obstetrical events. One parent died of complications due to diabetes. When I began to compare these diverse accounts, it was clear that the careers and lives of those with chronic illness changed because of their diagnosis (Charmaz, 1994b).

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13 Two pharmacists experienced a self-illness as well as illness in parents.
I had not considered the possibility that practitioners might become sick because they were pharmacists. Two pharmacists with chronic afflictions gave me that insight in their stories. My informants helped me to realize that pharmacists were: (1) members of a profession which was marginalized and struggling to find a role in health care; (2) mostly women in a feminized profession where men held positions of power; and (3) workers in an occupation constrained by their employers' financial concerns.

As a female pharmacist who tried, unsuccessfully, to find employment as a manager during the 1980s, when men were hired in each case, I am aware of some of the difficulties female pharmacists encounter. While writing this thesis, I have experienced several changes in health status myself, as well as losing friends and relatives to heart disease, cancer and mental illness. Through these and other losses, I have developed my listening and reflexive capabilities revising my self, as a result, through making meaning of these events and identifying with others. I acknowledge that my life experience influences my interpretation of the narratives of the participants in this study.

One of my participants provided a central theoretical insight. When Dale's cancer recurred, her identity and her life were threatened. With the support of her family and new friends, she then began the process of transforming her 'self,' becoming more holistic in her world view (Boon, 1996),
leaving pharmacy behind. Jane also found her 'self' after leaving pharmacy. How each pharmacist situated his or her self in the world became crucial to my analysis.

From my analysis, I attempted to explicate the meaning of becoming a patient and how that is transferred into professional practice by pharmacists. As might be expected, pharmacists, like most people, became more sympathetic towards others with afflictions once affected themselves. Sympathetic pharmacists continued to be information providers to their patients. Sympathy did not become empathy unless a relational interaction occurred; this was more likely to happen in those who were already cared for in supportive relationships. Pharmacists who became more empathetic were more aware of the pain of others because of their intimate experience. However, as will be described in the following chapters, I finally determined that for empathy to become "empathetic advocacy," there had to be some shift towards a more embracing world view which recognized others as part of one's self.

A final insight that directed questioning in the interviews involved hypothesizing about the relationship between pharmacy education and pharmacists' relationships with patients. Educated in the basic sciences and socialized into the hierarchical health care system, I realized that pharmacists are accustomed to structure. Pharmacy students are taught what to think and how to act, rather than how to think
and be in the context of a given moment (after Neal, 1994). For pharmacists, the dialectic between Turner's "communitas" or communion of equals and "social structure" is a difficult balancing act (Turner, 1969, cited in Neal, 1994). I saw that once they became aware of this communion with others, several pharmacists were then able to "care for" their patients.

3.5 Summary

This chapter explains the selection of participant pharmacists and introduces them in Table 1 (page 30). The means of data collection are then described, followed by a discussion of data analysis methods. The blend of comparative and narrative methods that led to the identification of themes in the pharmacists' narratives is described, with examples of how the choice of participants, questioning and analysis proceeded and changed during the course of the research. The brief natural history of this research that appears in this chapter was presented to illustrate the sequence of emergence of my theoretical thinking about pharmacist illness and patient advocacy.
CHAPTER 4
ILLNESS EXPERIENCE AND PATIENT RELATIONSHIPS

Character cannot be developed in ease and quiet. Only through experiences of trial and suffering can the soul be strengthened, vision cleared, ambition inspired and success achieved. (Keller, 1995)

4.0 Overview

This chapter describes the illness experiences of participant pharmacists, grouped by type of illness narrative, with analysis of how the illness impacted on their self-identities\(^\text{14}\) and how they perceived that illness did or did not affect their relationships with patients. The first category of illness narrative contains stories of brief, acute and/or minor illnesses followed by recovery: four pharmacists each described episodic events followed by a "curing" intervention which restored bodily function. These events had little impact on self-identities or on patient relationships. The second category includes chronic illness, meaning an illness for which no cure was anticipated: six pharmacists told stories of the ongoing need to adjust both body and self during long-term, progressive illness. Some of these pharmacists also described changes in their patient care practice. The third category consists of accounts of life-threatening illnesses: six participants told of encounters with cancer and four

\(^{14}\) Self-identity is defined on page 12.
participants described acute obstetrical or gynecologic events. Life-threatening illness impacts both body and self which may be connected by "voice" (Brown and Gilligan, 1992) which attempts to make meaning of life experience. Data are presented in this chapter which suggest that the mind-body dualism of medical science may become an "embodied self" in feminist terms (Lester, 1997) for these pharmacists, through exposure to illness which may challenge this compartmentalization\(^\text{15}\) or division of self from body. Changes in self concept may also shift how pharmacists relate to patients.

4.1 Illness Story Types and Patient-Pharmacist Relationships

Each category of illness story was characterized by a particular way of relating to patients, although there was wide variation within each group. The patterns will be explored in this chapter and some of the reasons for the variations will be the focus of the next chapter. In recounting brief acute and minor illness episodes pharmacists tended to speak of relationships with patients as opportunities for the imparting of "information." For example, Ann and Belle spoke of their children's illnesses and how they as mothers and pharmacists managed these illnesses and relationships with family physicians. As "knowledgeable

\(^{15}\) Gilligan and Pollack (1988) use "compartmentalized" as the opposite of "connected;" perhaps "compartmentalization" occurs in those with a scientific view of the world, reducing nature, life experiences and bodies to components.
caregivers," they were well-informed and able to "broker care" for their children. Mark and Sam described healthy families in which occasional acute illnesses were managed by accessing professional networks of physicians--"the old boys club."

Neither Mark nor Sam had personal experience with acute personal illness or chronic parental illness at the time of the interview. Further, none of these four pharmacists identified a change in their relationships with patients in their professional practice as a result of their illness experiences.

Chronic illness stories were related by six informants. Penny talked about the impact of mental illness on the lives of her two brothers. Jane shared her experience as caregiver to her diabetic mother. (This story is covered in the last section of the chapter, since Jane also experienced an obstetrical emergency.) Chris, Nan and Opal described living with chronic illnesses themselves. Irene told of her long term hearing loss and the abrupt onset of being labelled "deaf."

Once exposed to chronic illnesses, these women pharmacists tended to report a questioning of medical approaches to information-giving and an empathy for how the ill person feels; they were starting to think of new ways of relating to patients in their role as pharmacist. Active advocacy developed in one of the participants as described in 4.3.

Ten life-threatening illness accounts were provided by nine pharmacists. Like those facing chronic illness, those who had experienced life-threatening situations tended to change
the way they related to patients based on their insights about what it feels like to be a patient. Although not everyone in this category actually transformed their ways of relating to patients, three reported that they did. Others also changed their ways of relating to physicians and of conceptualizing their own identities. Kate and Rose cared for parents dealing with cancer. Both Fran and Lynn supported their husbands during their cancer experiences. Dale and Gail told their own cancer stories; Dale's cancer had recurred after 11 years whereas Gail had been cancer-free for four years. Helen and Kate told of their major gynecological surgeries. Eve and Jane described their obstetrical experiences during which each faced death. In general, these pharmacists moved in the direction of sympathy or empathy for their patients and were able to apply these experiences to their patient care practice.

Table 2 (page 47) summarizes the type of illness and patient orientations of the 18 pharmacists, noting any reported change as a result of illness, and placing their accounts into the story categories outlined above. Three individuals who gave accounts of more than one type are listed at the bottom of the table.
**TABLE 2: Participants by Type of Illness and Reported Change in Patient Relationships After Exposure to Illness**

<table>
<thead>
<tr>
<th>Name and Illness</th>
<th>Type of Illness in Self or Others</th>
<th>Nature of Patient Relationships; Change Reported as a Result of Exposure to Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ACUTE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ann</td>
<td>minor, family</td>
<td>intervention when asked - no change</td>
</tr>
<tr>
<td>Belle</td>
<td>minor, family</td>
<td>&quot;informed consumer&quot; - no change</td>
</tr>
<tr>
<td>Mark</td>
<td>sudden, family</td>
<td>&quot;born to care&quot; concept - no change</td>
</tr>
<tr>
<td>Sam</td>
<td>minor, self</td>
<td>&quot;informed partners&quot; - no change</td>
</tr>
<tr>
<td><strong>CHRONIC</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Penny</td>
<td>brothers’ schizophrenia</td>
<td>more sympathetic towards others with mental illness</td>
</tr>
<tr>
<td>Chris</td>
<td>musculo-skeletal, self</td>
<td>more intimate knowledge, empathy¹⁶</td>
</tr>
<tr>
<td>Nan</td>
<td>musculo-skeletal, self</td>
<td>more intimate knowledge, empathy</td>
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<tr>
<td>Irene</td>
<td>deafness, self</td>
<td>&quot;empathetic advocacy&quot;¹⁷ for the Deaf</td>
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<tr>
<td>Opal</td>
<td>musculo-skeletal, self</td>
<td>more intimate knowledge, beginnings of empathy</td>
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<tr>
<td><strong>LIFE-THREATENING</strong></td>
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<tr>
<td>Fran</td>
<td>husband’s cancer</td>
<td>&quot;informed consumer&quot;, personal experiences compartmentalized</td>
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<tr>
<td>Rose</td>
<td>uncle, father, mother’s cancer deaths</td>
<td>&quot;empathetic advocacy&quot; based on palliative care work</td>
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<tr>
<td>Lynn</td>
<td>husband’s cancer</td>
<td>more empathetic and contemplating advocacy and physician &quot;informing&quot;</td>
</tr>
<tr>
<td>Dale</td>
<td>own cancer</td>
<td>more empathetic</td>
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<tr>
<td>Helen</td>
<td>own gynecological surgeries</td>
<td>&quot;informed consumer&quot; - no change</td>
</tr>
<tr>
<td>Eve</td>
<td>own obstetrical emergency</td>
<td>&quot;empathetic advocacy&quot;; conscious of patient needs and collegial with physicians</td>
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<td><strong>MIXED</strong></td>
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<tr>
<td>Gail</td>
<td>own cancer and daughter’s heart</td>
<td>&quot;empathetic advocacy&quot;</td>
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<tr>
<td>Jane</td>
<td>mother’s diabetes and own obstetrical emergency</td>
<td>conscious of elder needs; &quot;informed consumer&quot; model but more empathetic</td>
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<tr>
<td>Kate</td>
<td>mother’s cancer and own surgery</td>
<td>&quot;informed consumer&quot;; more empathetic</td>
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¹⁶ Empathy, in psychological terms, means identifying oneself with and comprehending the person or object of contemplation. However, I use empathy in the sense of feeling connection with others and wanting to help them, much like Charon’s (1996) use of empathy as compassion or being able to experience with someone what she is suffering. Caring also embraces compassion, inclining one to be helpful. On the other hand, I use sympathy as meaning the sharing of an emotion without the intention to act.

¹⁷ "Empathetic advocacy" occurs when the pharmacist becomes connected with the patient and intervenes with the more powerful physician on behalf of the patient.
4.2 Stories of Minor and Acute Illnesses

Ann, Belle, Mark and Sam told of family illnesses in which health was restored. Health was interrupted by an event or breakdown in a body viewed as a machine. After temporarily adopting the sick role (Parsons, 1951), each patient was envisaged, in these pharmacists' accounts, as being restored to health and function. Sickness as an interruption of everyday routine was temporary and correctable. The social, environmental and psychological roots of health and illness do not appear to have been considered in pharmacist accounts grouped in this category.

Both Ann and Belle talked about their children's illnesses during my interviews with them. Ann was confident of her own ability to assess her child's need for medication but she reported that she had hesitated to challenge her male doctor when she disagreed with his prescription, opting to adjust the dosage herself. In dealing with physicians, Ann attempted to be "very tactful" in order to avoid "a clash" or "another awkward situation," in her words. She represented herself as adopting the "being nice" attitude described by Brown and Gilligan (1992) in their account of how little girls learn not to challenge authority. How did her tactful attitude affect her relationship with patients? According to her account, she didn't intervene on behalf of a patient "unless the mother had expressed concern." Thus Ann's form of advocacy--"I am always trying to be a patient advocate"--was available upon request.
Belle, on the other hand, had developed an egalitarian relationship with her family physician, of whom she said, "as one female to another...she related to me from her own experience." Belle's attitude towards her patients appeared to involve a generalization of her information-seeking approach to her own health care. Her lack of intervention with patients was based on the "informed patient" scenario. For example, on the topic of hormone replacement therapy, she said,

> everyone, with the help of their physicians, has to read and get as much information as they can on their own, so they're becoming their own experts for themselves, to determine what their risk profile is, in terms of osteoporosis and heart disease and then they figure out whether they're a candidate for hormone therapy.

Neither Belle nor Ann displayed a sense of community with their patients, but rather, saw the pharmacist's role as provider of information, much as Emanuel and Emanuel (1992) describe this role, whereby patient autonomy is respected but not "created" as distinguished by Seedhouse (1988).

Mark was the first male pharmacist I interviewed. He closely controlled how he presented himself; that is, he was attentive to "impression management" (Goffman, 1959) throughout the interview, only disclosing details of his children's interaction with the health care system after an hour of discussion. As a hospital pharmacy manager, he had developed a considerable network of physician peers with whom he could consult on personal health matters. In Mark's family, several elderly members had died, but each did so abruptly. Mark had no experience with chronic illness, except for his
diabetic mother who lived at some distance, cared for by his sister. Mark expressed the idea that pharmacists who care for patients are born, not made; in his words,

> it's instilled by your family over generations, almost within the genes. I have seen a lot of personal tragedies in others who are also in health care, that hasn't done anything to advance their relationships with their patients and the patients' families.

This statement suggests that Mark doesn't believe in adult learning or personal transformation. His view of health and illness fell within the medical model: since he relied on evidence-based medicine, he was sceptical about the value of herbal remedies, seeking scientific proof of efficacy. Mark saw the sale of herbal products by pharmacists as problematic and commented that physicians viewed it "as a fast buck to replace cigarettes."

Sam was in good health, caring for his elderly parents and working in the pharmaceutical industry at the time of the interview. He defined illness as meaning "that an individual is limited in what they can do or limited in their willingness to do it because of disability." In terms of personal experience, Sam occasionally medicated himself for stomach or musculo-skeletal symptoms; in his patient care role, Sam described the "partnership" which he developed with patients in rehabilitation. His greatest concern in practising pharmaceutical care was the delay caused by waiting for physicians to act upon the pharmacist's recommendations. Sam
advocated prescribing by pharmacists, within established
guidelines, such as allowed in Florida, as a way of reducing
the delay in implementing treatment changes.

Sam expressed concern for the future of the pharmacy
profession. He complained that lack of access to patient
information hindered pharmacists attempting to provide
pharmaceutical care. He also cited physician resistance to the
expansion of the pharmacist's clinical role as the reason why
one of his pharmacist-friends had quit the profession. In a
recent conversation with a community pharmacy owner, Sam
summarized that pharmacist's position:

[H]e's happy to keep a competitive edge by his
value-added services which include pharmaceutical
care; on the other hand, his dispensing fees have
been reduced and he's letting go some staff and his
duties are increasing and he feels like the meat in
the sandwich!

These four stories focused on minor and/ or acute
illnesses which only temporarily interrupted the lives of
pharmacists and their families. Treatment enabled restoration
of function or cure of disease, without necessitating
significant change in life style or self. Relationships with
patients were reported not to have been affected by these
brief or minor illness episodes of others. In their
pharmacist-patient relationships, autonomy is "respected" but
not necessarily "created" through the giving of information to
a patient envisaged as a well-informed consumer. These stories
contrast with those in the next two sections, which include
stories about chronic and life-threatening illnesses; in these stories, in most cases, changes in self and life style are evident for both patient and family.

4.3 Stories of Chronic Illness

As shown in Table 2 (page 47), Penny told a story of her family members' experiences of chronic illness—schizophrenia—while four other pharmacists had lived with chronic illness personally. Three had progressive musculo-skeletal disorders (Chris, Nan, Opal) and one was deaf (Irene). When reflecting on their stories, these pharmacists recalled specific points in their experience of chronic illness which sparked sympathy (Penny) or empathy towards others. They reported that they were better able to relate to their patients with chronic illnesses than they had been prior to being exposed to chronic illness. It can be argued that this empathy was based on their own knowledge of these illnesses and on an appreciation of how the illnesses were played out in everyday lived experience.

The orientation of these pharmacists towards those experiencing chronic illnesses either in themselves or family members contrasts with the conception of the "informed consumer" who can look out for his or her own welfare that characterized the accounts of pharmacists who had only experienced acute or minor illnesses. The identification of a particular point at which change occurred in their conception of how the pharmacist should relate to the patient with
chronic illness --as an "advocate" rather than an "information giver"--lends support to the idea that pharmacist-patient relationships change in the direction of empathy and advocacy when the pharmacist herself experiences chronic illness.

4.3.1 Chronic Illnesses of Family Members

Penny's account of growing up as the eldest child of five in a family with two brothers who were diagnosed as schizophrenic at the ages of 19 (in Grade XIII) and 22 (in second-year university) emphasized that she was made aware of the stigmatizing label of "mental illness." As Penny related, her brothers had been bright and attending school when diagnosed and her older brother became very angry and never accepted the illness:

[H]e'd be okay for a while then he'd just go right off his medication. It was a terrible thing; the hard thing was you couldn't reach him.... [H]e ended up being killed by a train. It was a very sad situation and he was only 36!

She understood that some individuals are more accepting of such a label--for example, her surviving brother, about whom she remarked,

I have another brother who is completely different. He still has the illness and he's still living; he's 42 and, of course, he hasn't worked in a long time-- he did work with my older brother who had his own business--but he's more accepting of his illness--he can talk about it.

How did these experiences affect Penny's reaction to those with similar problems? She described her efforts to "understand" people with mental illness, rather than brush them off as she felt that others had done to her brothers.
"[T]hey [those with schizophrenia] are very misunderstood in our society," she mused. In addition, she had first-hand experience with the side-effects of medication prescribed for her brothers. As regards the treatment of schizophrenia, Penny observed that

the pills they put them on have such terrible side effects--really, really bad. And because of the terrible side effects, they go off [the medication] and they're okay for a while. Then they have a big downer and they end up back in the hospital or [sigh] they end up living out in the street.

At the time her brothers were diagnosed, Penny was busy with her own children. She admitted that her parents had handled the situation without her help. She had focused on raising her children for several years, working only occasional part-time hours. Only when her brother died, eight years prior to the interview, did Penny recall that she became conscious of her sympathy for those with schizophrenia.

Late in my interview with her, when discussing working conditions, Penny also recalled her attitude towards people with mental illness before her brother's death, remembering a specific incident that illustrated this more detached attitude. In this scenario, Penny's pharmacist/manager, who was younger than her and female, had received a complaint. In Penny's words,

[S]he had a complaint about me from a mentally ill patient--that type. And she [the patient] said that I had done something which I hadn't and [my boss], because of her inexperience, believed this patient--this person who was in that classification. And [the patient] asked if there was any place that she could complain about me and my boss gave her the number for the Ontario College of Pharmacy and [my
boss] told me that if [the patient] did go and complain about me, she [pharmacist/boss] wouldn't stand behind me!

This account reflects a detachment from the patient and a type of adversarial reaction, which, Penny claimed, after her consciousness-raising through her brother's death, shifted towards sympathy.

4.3.2 Pharmacists with Chronic Illnesses

The accounts of those who themselves had chronic conditions were similar to that of Penny, who had experienced her brothers' chronic illness. That is, these accounts typically described the growth of sympathy towards patients with chronic disease. However, the understanding was more intimate, involving a knowledge of how the person with chronic illness really feels, particularly the "knowledgeable" patient with chronic illness. These pharmacists with chronic illness knew first-hand about their patients' challenges and became empathetic in their patient relationships.

A critique of the social distance of physicians was also a common theme in these accounts, although pharmacists stopped short of entirely rejecting a medical approach to their problems. In the case of musculo-skeletal diseases and depression, the pharmacists felt that their conditions of work had contributed to the illnesses. In one case, this recognition had changed the pharmacist's attitude of activism.
in her profession to a more passive role, as well as deepening her understanding of the passivity she saw in many of her coworkers in pharmacy.

These pharmacists understood the "good days" and "bad days" that are encountered with chronic illness and that must be managed in order to continue functioning. They particularly understood the disruption caused by work interruption. These pharmacists personally experienced the feelings of sorrow and shame that may accompany interaction with others when crises occur. In the case of the deaf pharmacist in the group, she had taken the opportunity to renew self and transcend loss (Charmaz, 1994b), and thus also understood this potential in others.

Even though she was the youngest informant, Chris had many experiences to share, all related to her lifelong musculo-skeletal disorder. She reported that she had tried to maintain a positive attitude in order to cope with the good and bad days. As a knowledgeable professional, she occasionally disagreed with her physician's recommendations, to his annoyance. Like Penny, Chris recognized that most patients were disadvantaged by their lack of knowledge but she minimized the pharmacist's advantage and criticized the "social distance" of the doctor:

[We're just pharmacists and he is the physician.... Physicians always know the exact answer to everything and it's up to pharmacists to follow their particular manner.... [They promote a] know-all, God-type scenario.
Chris empathized with others in pain and believed that her own illness assisted her in relating more effectively with patients. At home, Chris used herbal remedies. However, she stopped short of critiquing the medical model when she admitted that she would like to see a scientific basis explaining the action of these products. She speculated "this is the scientist part of me sneaking out."

Chris generalized her own experience of being a knowledgeable health professional to the experience of her mother, a nurse. She thought that her mother, like herself, had found having the knowledge of a health professional a kind of curse in that she knew beforehand about the deterioration that her father's cancer would involve. As her mother cared for Chris' father at home, this "allowed our family to interact more and was more comfortable for him than being in hospital." However, Chris empathized that the situation was also difficult for her mother, the knowledgeable caregiver, since "she worked in urology and she had seen a lot of patients suffer through cancer and she knew what was coming.... [S]he knew what to expect."

Nan shared with Chris a critical perspective on the "social distance" exhibited by the physicians who had dismissed her fatigue and pain as a "female problem." Not long before the interview, Nan had returned to full-time employment as a hospital pharmacist following a bout of what was finally diagnosed as fibromyalgia--it had been severe enough to require a prolonged leave of absence. As Nan recalled,
I got really annoyed at the men, because, in my mind, it was a typical male mindset; it's not that they were incompetent, it was not that they were unkind or disbelieving, but it was a simple male mindset that they couldn't get over and therefore, they didn't listen when you told them what the symptoms were.

I would label what Nan described as 'male deafness' which served to 'silence female complaints.' Or did it represent the medical response to anyone with fibromyalgia? How did this affect her relationships with patients? Nan advised other women to seek female rather than male physicians (although she admitted that "some women aren't so great either"). She also advised patients to get a second opinion if they were unsure of what they were told. Her conception of the doctor-patient relationship was clearly different than simple provision of information. She understood from personal experience that who you are and who the doctor is can affect the diagnosis and treatment.

Her chronic illness had caused Nan to change her work and her life so that she understood the disappointment that those with chronic illness feel when their work is disrupted. Comparing full-time to part-time work, she decided that:

I didn't like part-time because there's no job satisfaction in it for me.... You've either got to fix other people's leftovers or if you were lucky enough to get to start a job or a new project...you never get to finish it!

She also experienced a loss of energy which had changed her original activist approach to her profession to a more passive one. Three decades ago, when she spoke out for the rights of women pharmacists, Nan had seen herself in the forefront of
the women's movement and the clinical pharmacy movement. Recognizing both change agents and resistors, Nan had critiqued those who resisted change, stating that:

[T]here were two kinds of pharmacists around then; there were those of us who wanted to move in that direction [clinical pharmacy] and then there were those who thought it was a new-fangled idea and why bother, kind of thing!

But, at the time of the interview, she was less critical of those who resisted change, recognizing that the difficulty of "making a difference" in the pharmacy workplace could sap one's motivation and could itself contribute to the development of chronic illness. In the current climate of hospital re-engineering, as Nan expressed it,

I think it would be hard for even the most capable, competent change-agent sort of person to accept that what you spent 20 years building you now have to tear down.... I think the stress of working and everything hits us and contributes to all those illnesses.

Thus Nan saw that there might be more than a physiological basis to a chronic illness in a pharmacist, and that passivity increased the potential for illness in a situation that she could not change. From her experience, Nan learned that

[1]illness can do strange things to you! I think I have definitely lost most of my 'Type A' drive and have gotten more accepting and more passive; you know, even at work now, all of those stresses are bothering people and I think, "Hey! I'm not the director any more! I'm going to do my best but I am not going to worry about what doesn't happen!" So, life is a lot easier for me; I very rarely get stressed out at work.

Extending her knowledge of what it feels to be depressed with a chronic illness to the patient-professional relationship,
Nan recommended that patients should seek professional caregivers with personal experience of their particular problem:

[People have said this to me about other diseases, but (this applies to) depression, in particular; no matter how good a health care worker or pharmacist you are, you will never understand what depression is until it happens to you.... I don't think I was an uncaring, unfeeling person. But no matter what you read, you cannot possibly imagine how it really is. (For any health care worker), until they've been there, they aren't going to be as good as they can be! If they had had that kind of experience themselves, they just sort of have a new picture of the whole thing.

In this passage, Nan was describing the change of a person's whole gestalt of what chronic illness involves. She was arguing that there was more to being a professional caregiver than taking merely a scientific approach; as she emphasized, until health care professionals experience illness themselves, they cannot really empathize or connect with patients. This has been the message of self-help groups for years.

The third pharmacist experiencing chronic illness and work disruption related the most spectacular change of work routine, self-concept and attitudes towards patients of the four, and indeed of all those in this study. At age 17, Irene went to see her family doctor, complaining of ringing in her ears, for which she was prescribed Valium. As she said, "I took, I think, about two and I was just a basket case.... They're still ringing; they never did stop!" Irene described being deaf as being very noisy:
If you could just stop the noise, I know I could hear! I can't hear because it's too noisy!
[Tinnitus is really hard to live with and if I had a choice of getting my hearing back or getting rid of the ringing, I'd go with the silence.

There followed a lifetime of disrupted activities and adjustments to her chronic problems from day to day. For example, as a pharmacy student, Irene coped with being hard of hearing by sitting in the front row, lip-reading (which was difficult with moustaches and beards on the male professors during the 1970s) and writing whatever notes the person beside her wrote. She recalled that: "I found first year really difficult" but then she learned how to study and graduated "with fairly decent marks."

Still coping, Irene acquired hearing aids after she was married. For the next 17 years, her hearing level remained stable until she suddenly developed congestion in her ears in 1988. Irene was referred by her family doctor to a specialist who told her that there was nothing wrong and she should learn to live with her hearing loss. Not satisfied with this response, Irene requested a second referral and was told by this specialist: "You are not hard of hearing; YOU'RE DEAF! But look how well you cope!" During a period of two months, she went from a label of being hard of hearing to a label of being deaf. This upset her very much. Irene's loss also affected her husband and her children; they all had to make changes and also support her.
With the support of her husband and children, Irene began to construct a new identity for herself. As she explained about their support:

I went and took speech reading classes first and then my husband and I both took sign language classes for two years.... The kids are really good about interpreting for me if I need it or taking phone calls.... Sometimes they phone me at work just so they can show their friends how the TDD [a teletypewriter] works!

As to how she accounted for her hearing loss, Irene said that her mother attributed it to allergy shots Irene took as a teenager. But Irene, like Nan and Opal, saw the disease as caused by her workplace. She linked her loss of hearing to the noise in the pulp and paper mill where she worked as a teenager and she recalled hearing ringing in her ears after high school dances.

Since being labelled "deaf," Irene had noticed many changes in her self. She was able to relate to patients in her care by empathizing with persons with schizophrenia who hear voices, counting herself fortunate that she heard only noise, not voices "telling me terrible things! It's just a ring!" She also described herself as more outgoing than before her consciousness of illness, now introducing herself as: "I'm Irene; I'm deaf. Look at me when you're talking to me."

Concerned about her ability to practice pharmacy, Irene had voiced self-doubts:

I went through quite a phase where I wondered if I would lose my license to practice.... [Since] communication is such a big part of pharmacy, am I even competent any more? Can I even do my job? Can the licensing body refuse to renew my license?
Irene had consulted a human rights advisor who assured her that so long as she was gainfully employed and doing her job competently, her license was not at risk. The official said "They can't take your license away just because you can't hear."

Although Nan had experienced disruption of her work and had to take a less responsible position because of her chronic illness, Irene fought back when this happened to her. She became acutely conscious of discrimination in the workplace when she was "passed over" for the manager's job, because she was told "it's just too much trouble to accommodate your deafness." But when the new manager quit, Irene applied again for the promotion and was named acting director then director. In her account of her life, she became an advocate for herself then for other Deaf, because of this experience and her consciousness of discrimination in the workplace towards other Deaf. As Irene explained it:

It was kind of funny, because I don't know, if all this hadn't happened if I would have even applied for it [the manager's job]! But you just get so angry when somebody tells you that you can't do something because you're deaf...and that's sort of how I ended up where I am, and actually, I think I can do a better job in the administrative role than I did as a clinician because it seems to be easier to get the staff to accommodate my deafness than it was to get the patients to accommodate.

Also unlike the other three pharmacists in this study who had experienced chronic illness, Irene moved beyond understanding of illness and empathy for patients to apply her experiences of fighting for her rights to an attempt to achieve broader
changes in attitudes towards the Deaf. She became involved with the Deaf community and saw how "ghettoized" (her word) deaf people were in the workplace because of the attitudes of others (particularly those in power) towards their "disability." Irene made her disability meaningful by developing a presentation about hearing loss and being deaf; she spoke to health care professionals and to community groups, together with a friend who had recently lost her sight, educating people about the abilities of those stigmatized as disabled.

Why were the changes in attitudes and actions towards others who are deaf so proactive in Irene as compared to the others? There are a number of possibilities. It might be that the other pharmacists with chronic illness had less energy to pursue the path that Irene took. It might be that she had the opportunity to relate to others like herself which the three other pharmacists did not have, except as they encountered other individual patients. Her proactive stance may also be related to the support of her family, which the others did not receive in similar measure. In addition, being deaf is a noticeable disability, stigmatizing in itself. Alternatively, it may be that the discrimination she felt at work, in being "passed over" initially for the manager's job, was more acute and identity-threatening than that experienced by Chris, Nan and Opal, who also told of chronic illness.
The insights displayed by Nan and Irene did not occur automatically, as illustrated by the case of Opal. Opal had also been diagnosed with fibromyalgia and depression; like Nan, she was diabetic as well, although about 10 years younger. Like Nan and Chris, Opal offered some criticism of medicine. She critiqued the care given her mother, who had been convinced by the surgeon to undergo cardiac bypass graft surgery and then developed complications and died within four months. Opal regretted not having been more involved. Two years later, when her father became ill with cancer, she took a leave of absence from her manager's position with a large, corporate chain in order to care for him until his death.

When Opal tried to return to work after caring for her father, she experienced the same type of work disruption that Nan had experienced. She similarly learned how working conditions can contribute to chronic illness. Upon her return to work, she said, "I was basically asked to step down as manager and told that this job [relief pharmacist] was available." Although she had built up the business for five years as manager, Opal was demoted for being absent to care for her dying father; like Penny, Opal's contribution went unrecognized. (Nan chose to assume a less responsible position when she returned to work from her absence.) In her relief position, Opal had worked for pharmacists who had been on maternity leave, or quit or were fired. Being in different communities around Ontario nearly every week, Opal had little opportunity to form relationships with her co-workers or her
patients; she also had little control over her working conditions. Eating was a problem for Opal because she could not leave the pharmacy during her 12-hour shifts and she was often too busy to eat even when she had picked up a sandwich at breakfast time. Standing for all those hours was hard on her circulation. Like Nan, these conditions of work contributed to her chronic fatigue. As she explained,

> The valves in the veins don't work at all, so the blood can't get back up! So these stockings cost $100 a pair--and I'm very faithful about wearing them to work but on days when I can keep my feet up, I don't [wear them].... [T]hey're very, very hot and they are frustrating.

Like Nan, Opal also experienced depression with her illness and unhealthy working conditions. When I asked her what she did for fun and relaxation, Opal replied,

> I haven't had time to do much of anything. That is the biggest problem right now. I have no life. When I get home, there's always things I have to do, like laundry, do my expense account, get ready for the next trip. I should be reading journals; I've got a stack of newspapers I haven't read. I don't have time for a life!

As regards her future plans, Opal said,

> I decided a few years ago, that I wanted to go into the ministry and I want to get back to that idea because, I thought, maybe one of the reasons why I've been so depressed all these years is that I didn't do what God wanted me to do!

Since her pharmacy degree did not include any humanities courses, the theology school asked Opal to take a credit course in order to prove that she could write essays. However, the sociology course which she completed ended with a multiple choice exam; she "did really well--83%--second in the class."
Five years later, at the time of the interview, Opal's plans for continuing her education were on hold; as she said, "It's all about time."

What effect did Opal's experience of illness and work disruption have on her orientation towards her patients? She did not describe the degree of empathy that was found in the accounts of Chris and Nan and certainly did not develop the advocacy demonstrated by Irene. But she had been asked just prior to our interview to cover a pharmacist's bereavement absence, a situation which brought forth an empathetic response. As she said, "This is the first time I've actually had a chance to help somebody who needed me in this way."

Opal's case suggests that if the pharmacist works in a particularly isolated or disempowering work situation, and does not have the energy or support to reflect on self and others, that the development of empathy that is seen in the case of Chris, Nan and Irene may be impaired. However, Opal's story is not over. Her parting comment suggested that she was caring for a colleague.

4.4 Life-threatening Illness Stories

Table 2 (page 47) shows that nine pharmacists in the study faced life-threatening illnesses, four dealing with cancer in family members (Rose, Lynn, Fran and Kate) and six dealing with personal life-threatening illness, including two with cancer (Dale and Gail) and four with gynecological/obstetrical events (Eve, Helen, Jane and Kate). Although there
is some overlap between the cancer and obstetrical-gynecological stories, and among those who were dealing with illness within themselves versus caring for family members, an attempt has been made to separate these categories in order to explore unique themes in each subset. This categorization of narratives also demonstrates that within each type of illness, some pharmacists report significant changes in their orientations towards patients, while others do not. As the table shows, just as with chronic illness, there is a tendency for the pharmacists to report an increase in empathy as a result of facing life-threatening illnesses, but this is not a given. In addition, the report of active advocacy for patients is nearly as rare for those with life-threatening illnesses as it is for those with chronic illnesses. The "informed consumer" concept of patient-pharmacist relationships is prominent in the accounts of those who have only dealt with minor or brief acute illnesses; in the accounts of those who have experienced caring for others, sympathy or empathy emerge. This pattern can be seen in all but one pharmacist dealing with her husband's cancer (Fran) and one with gynecological surgery (Helen).

Of the six cancer stories, four involved a family member and two were personal. Both Kate and Rose cared for parents with cancer, but each seemed to approach their advocacy for the parent differently, with Rose reporting herself as more "tactful" when dealing with physicians than Kate. Fran and Lynn each experienced cancer through their
spouse; anger towards the medical handling of their case was part of that experience as well for both of them (just as in the stories of chronic illness and in the cases of Kate and Rose) but how they managed their anger differed. The encounters of Dale and Gail with bone and breast cancer gave them the opportunity to confront their own mortality and provided the opportunity for self-identity change as well as influencing interaction with patients towards empathy and caring.

Thus all of the themes developed in the accounts of those experiencing chronic illness were present in those experiencing life-threatening illnesses. These included: (1) a critique of the medical responses to their problems; (2) the recognition that they now made more empathetic responses to their patients than they had exhibited before their illnesses; and (3) an intimate understanding of the life and work disruption that such illnesses involve.

A theme that was prominent in the life-threatening accounts (where, unlike chronic illness, the situation calls for action) included references to alternative ways of dealing with physicians in advocating for patients, some of which were more effective than others. The approach described by a number of pharmacists that took into account the power of physicians in advocating for patients (rather than merely critiquing it) can be called "empathetic advocacy". Unique themes around

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18 "Empathetic advocacy" occurs when the pharmacist becomes connected with the patient and intervenes with the more powerful physician on behalf of the patient.
"women's illnesses" included a critique of the medicalization of women's bodies and functions; an understanding of the link between self-identity and reproduction; and concern over a lack of control of the process by the women patients. Helen and Kate shared their stories of gynecological surgery, telling of major operations which exposed them to the risk of complications or death. Jane and Eve related accounts of their complicated birthing experiences through which they became responsible for caring for their children and others.

4.4.1 Cancer Stories

Cancer is a stigmatizing disease (Goffman, 1963). Persons with cancer are marginalized; that is, their "social identity is vulnerable and changeable and [their] social position is unclear and ambiguous" (Clarke, 1985:4,5). A cancer diagnosis may be equated with a death sentence; both the patient and spouse may react traumatically to news of cancer. Women with cancer have been found to become more aware of their identity (Clarke, 1985; Tourigny, 1988) as the result of their existential self being threatened by the disease; they also perceive that others regard them differently (Trillin, 1983).

4.4.1.1 Pharmacists and Family Cancer

Kate was a professional activist who worked part-time as a community pharmacist and pharmacy educator. In this respect, she was like Sam or Nan before her personal exposure to illness. She reported that she had had an "inform the
client" approach to her relationships with patients. Kate promoted the pharmaceutical care model of practice, which she defined as "helping [patients] achieve their outcomes with their medication." When her mother's cancer was diagnosed, Kate became involved. Anticipating that her mother would seek more information, Kate became proactive; in her words,

I found a nice booklet for her that explained chemotherapy.... [I]t's been my idea that I'd rather know up front so I know how to deal with illnesses, but I guess I expected too much of my mother, cause I don't think she really ever got into it.... [I]t made me a little bit more empathetic to people with cancer and family members that have to deal with relatives or parents with cancer and I could give my own personal experience when I talked to them about medication.

Kate attended medical appointments with her mother and criticized what she perceived as the physician's uncaring manner. When Kate attempted to intervene on her mother's behalf with the oncologist, however,

she [the oncologist] really downgraded my opinion.... I figured that she didn't feel that my mother was a worthy candidate for [Taxol, a drug that was favoured for her type of cancer].

Kate also requested psychological support for her mother "because you know when you are in a better frame of mind, some medications work better," but this was never arranged. According to Kate, the oncologist was basically making treatment decisions without involving Kate's mother. While criticizing the physician for her paternalistic attitude towards decision-making for the patient, Kate praised the nurses, whom she perceived as caring and empathetic; in her words, "they exuded warmth but the oncologist didn't exude any
warmth!" By living through this experience, Kate said that she came to realize that medicine isn't all it's cracked up to be and if people don't start learning better interpersonal skills with the patient, I think they're just writing themselves out of the equation. There are people with computer technology that can come along and take over from them.

Thus she moved from an "inform the patient" stance to one of greater empathy. She critiqued medical approaches, but stopped short of feeling able to deal with physicians in such a way as to address these problems in a completely satisfactory way.

Fran's situation was similar to that of Kate. In this case, it was her husband, a teacher, who was diagnosed with colon cancer six months after he first visited his family doctor. The physician had discounted his patient's concern over his rectal bleeding, saying, "Because you are the age you are and there's no family history, we'll take the wait-and-see approach and treat you as if you have a hemorrhoid." When the "hemorrhoid" failed to improve, Fran's spouse was referred to an out-of-town surgeon, to receive his diagnosis from a stranger; Fran and her husband have considered suing their family physician for negligence in this case. As a health care professional, Fran realized that:

any of us are capable of making an error in judgement. But when we do so and we realize our error, we go to that person and we try to make amends in whatever way we can:...damage control, so to speak. In fact, he [family physician] just obviously knew the situation, so quite often, I would just lie awake at night, I would just be so angry and just be wanting to face him and just tell him what I thought of him...but I decided that I just had to go on and forget about it. [My anger]
wasn't doing us any good but actually added even more stress to the illness.

Like Kate, Fran was personally affronted by the physician's dismissal of the concerns of her family member but did not address the physician with these concerns. Neither was she able to involve others. With no extended family nearby, and being unwilling to "burden" friends with their concerns and being very private people, Fran and her husband were quite isolated, experiencing a kind of "social death." As she said, "both of us almost had a breakdown." With two young children to care for, Fran found it difficult to accompany her husband to his medical appointments; she said:

We needed people to baby-sit the children [but I feared] burdening other people with your children and that I found very stressful because you could feel, after a while, that people aren't as accepting of that. So you almost felt like your children were being rejected. And that was really hard and still is. (near tears)

The neighbour who was a baby-sitter for their two children withdrew from Fran's family entirely. As well, Fran spoke of her husband, who was,

not a strong person [or]...a fighter and his cancer had affected him physically, you know, the surgery [a colostomy] and so on, permanently, so he has to adjust to that as well. His feeling of self-esteem...will just take a long time [to recover].

Financial difficulties added to the stress felt in this family, where Fran's part-time employment as a pharmacist provided most of the household income at the time of the
interview. She was so visibly distressed that I offered to shorten the interview, but she replied: "No, it feels good to talk about it."

As regards her identity as a pharmacist, Fran said "I love my work and I enjoy helping people." However, she did admit that her husband's illness had influenced her patient interactions negatively:

When we were going through our hardest times, last year, through the [chemotherapy] treatments, if patients came in moaning, I found that it took everything I had to be sympathetic. I felt like saying, "You think you've got problems?"

Rather than sharing her cancer experience with her clients, Fran compartmentalized her personal life from her professional role; as she said,

I don't share my experience with [my spouse], you know. I'll share about the children so that they [clients] realize that I do have personal experience and that I can be sympathetic...when I pass on my knowledge, I can be empathetic. But I generally don't [share] because I feel that that's burdening other people and I don't feel that's right, to make them feel that way [supportive] towards me. [As regards being sympathetic], I would feel badly if [this cancer experience] hardened me in that way, that I couldn't be sympathetic and feel like I was just sort of putting it on every now and again. But I'm also encouraging them [clients] to be more active in their own health care.... I don't want other people to experience what we had.

Thus, Fran continued to hold to an "informed patient" model of dealing with patients. She seemed unable to apply her critique of her physician towards a more empathetic way of dealing with her own patients, and indeed, was aware of the risk of becoming "hardened" towards her clients and their needs,
further adding to her isolation. Rather than increasing her interventions with prescribers, Fran was choosing to urge clients to take charge of their own health care. She encouraged them to become "informed consumers". This orientation towards patients may be seen to involve "respecting" patient autonomy but only "creating" it in a limited way.

According to Fran's account, her professional relationship with patients and physicians had not changed as a result of exposure to illness. As she said, "I've never held physicians up on a pedestal; I've never been intimidated by them." She recounted an incident involving a client who was experiencing drug side effects one weekend when the prescriber was not available; Fran directed the patient to cut her dosage in half and contact the physician Monday. However, in discussing treatment options with her husband's oncologist, she was silenced, telling me that "[Y]ou just have to be somewhat accepting of [what physicians do and why]." Her outlook regarding her family's health is fatalistic: "We feel our environment is full of chemicals and when your time comes, it is going to come." Although she had researched antioxidants and dietary changes, "that lasted about a month" until they reverted to their usual eating habits. One glimmer of hope was on the horizon because Fran described their new family physician, who had been recommended by her clients when she consulted them as an "information-giver"; she saw him as
aggressive and thorough—quick to refer yet willing to spend the time to share information and relate stories from his own experience.

Unlike Fran, Rose enjoyed family support in her caregiver role. Like Kate, Rose was an outgoing hospital pharmacist; she was involved in palliative care and community activism. Also like Kate, she was assertive in her relationships with physicians, although she laced the assertiveness with tact. One example of her "take charge" manner was the selection of her family physician: she telephoned three general practitioners and requested a 15 minute appointment with each—offering to pay cash—in which to interview them. The one she chose told her "he wished more of his patients did that!" In describing the relationship between a physician and pharmacist and patient, Rose said,

> I think you can be a little bit pushy, more assertive, when you are acting as the pharmacist [whereas] in the patient-physician relationship, I don't know that that is appropriate.... I find that they're more responsive to sort of a teaming thing, like "I need to know, I need to understand why you are making this decision; I want to participate, I want you to give me the information that I need to make a decision about what I should do."

In this consideration of the power relations between the professions of medicine and pharmacy, Rose showed respect for the physician's turf as well as outlining her expectations of the doctor. Thus her approach differed from that of Kate, who merely complained that she offered an opinion which was ignored.
Where did Rose learn her variety of "empathetic advocacy"? When asked about her education, Rose recalled several "consciousness-raising" experiences as a student which broadened her perspective on patients. Serving on the cardiac arrest team, as she recalled,

really changed me in a way, cause nobody ever touched the patient. And I found that I always seemed to be positioned near, because I had to record the respiratory thing and the pupil response, so I was sort of up close. So, I always found that, afterwards, I always held their hand, because, you never know.... I think it's a terrible thing to be in that one-way mirror, like marooned, and to be dying and not to have somebody with you.

During the years prior to the interview, Rose had also cared for her uncle, her father and her mother, while each one died of cancer, a few years apart. Speaking about her mother's death, Rose said:

I had promised that I would be there for Mum. She told me that she felt really safe when I was there...she knew I would be her advocate. [Because of caring for family members], in retrospect, things changed in both my sister's and my life, because I had wanted to do an MBA and I never did it because every time I got things togeher and I'd apply and get ready to go, something would happen--a crisis would occur. So I put my personal stuff away--I had to! My older sister [a psychologist], was really excellent; she did all the everyday stuff, taking her [mother] to the appointments and all this. When we got to the blood and gore, she said that was my role.

Rose had had some palliative care experience before she cared for her family members and reflected that she was better able to "deal with all this baggage and stuff" as a result. In addition, she felt that she had used her experience of her mother's cancer situation to change her attitude towards
hospital patients in later years to one of greater empathy. Her personal and professional lives could be described as "connected" rather than "compartmentalized."

Lynn's husband, also a pharmacist, died of a treatable cancer that was diagnosed--too late--a year prior to the interview. She and Fran thus were in the same situation, although Lynn dealt with the misdiagnosis more like Rose, with tactful assertiveness, rather than with Fran's anger and self-isolation. As Lynn said, "We realized that the symptoms had been misdiagnosed--not just by the doctors but by ourselves." Lynn's spouse had treated his illness with non-prescription allergy medication and environmental changes, seeking medical help only when his symptoms were not relieved. Two years earlier, he had had a CAT scan when his symptoms first appeared; Lynn believed that the scan had been misread at that time but she convinced her husband not to have it re-read two years later. Rather than blaming others for his delayed treatment, Lynn and her husband decided to engage in some advocacy that would educate the physicians involved about his delayed diagnosis. In order to educate other health care providers about this type of cancer, Lynn had prepared a presentation which she planned to give to various groups; she had also become involved in a widow's support group, as a part of caring for herself. As she said,

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19 CAT is the acronym for computerized axial tomography, sequential radiographic/ X-ray "slices" of the body's interior, taken to expose tumours or other abnormalities.
I am actually tired of grieving [laughing]. I don't want to read any more books on parenting or grieving or healing! I never used to read novels or romance. But now I have this desire to read junk! What I used to call junk... I try to swim twice a week... I don't even know if I actually like doing it! I used to force myself to go or, if I didn't go, I would feel guilty about not going. But, now, I'm being more relaxed with myself... I'm learning to be nice to myself!

In terms of patient-pharmacist relationships, while Fran persisted in thinking that all patients need is "information," Lynn recalled that when her pharmacist-husband was diagnosed with cancer, his identity changed and he "became" a "cancer patient." She had the insight that in this state, he no longer wished to be an "informed consumer." As a patient, she noticed,

he did not really want to know [more about his cancer], 'cause as long as you don't know, there is hope... [T]heir psychology changes; it doesn't matter how educated they are--how professional they are or what kind of decisions they made in life before the illness struck--they become a patient and I think they have a different kind of psychology and it's all totally different. It's very humbling and very frightening to them and, I think, whatever choices they make, they should be respected.

As regards use of medication, Lynn also learned to empathize with the patient. She said that,

being pharmacists, we are used to looking at gentamicin and the NSAIDs\textsuperscript{20} and talking about groups of drugs without really looking at the patient as a whole. Now, being a patient or the patient's family, the priority is different.... I had difficulty understanding because [my spouse] was only taking a PORTION of his morphine; then I said to him, "Why do you suffer? You are in pain." And he said "I don't want to feel drowsy; that is worse than pain!" It was amazing! Listening to the

\textsuperscript{20} NSAIDs is the acronym for Non-Steroidal Anti-Inflammatory Drugs.
patient and what they want— it's not necessarily what the pharmacist wants to achieve, nor the doctor!

Lynn believed that she had become more patient-focused in her outlook, as well as more proactive in her relationships with physicians. Although as a pharmacy manager, she was not providing direct patient care, she was able to influence patient care pharmacists. Lynn expressed her new outlook on life in this way:

[Going through your spouse dying and all that, I have this philosophy: that every day is a good day, regardless of what happens! And you have a decision to make: you can choose to have a good day or a bad day. So, I have less patience with people that complain about a sunny day and having to work.... I just tell them to get on with it!]

Why were the approaches of Fran and Lynn so different? It is worth noting that, unlike Fran and her husband, Lynn and her husband were supported by their adolescent children, family and co-workers. At the time of her spouse's diagnosis, Lynn was about to change jobs. In her words,

the families of cancer patients advised me I should step down... from a supervisor to a staff position. [But, instead, I became pharmacy manager in another hospital, because] I was thinking, if I ever needed a job, this is the time when I REALLY need a job! And it worked out very well, because the [manager's] job had more flexibility; as long as I get the job done, it doesn't matter when I do it!

This meant that, in contrast to Fran, Lynn had more control over her work and hours, so that she could accompany her husband to medical appointments; because her children were older, there was no need for baby-sitters. Neither were finances a worry. Finally, unlike Fran, Lynn said that she was
able to accept her husband's death because they were able to find comfort in the years they had shared, their children and the opportunity to say good-by.

Thus the development of "empathetic advocacy" tended to follow the caring for family members with cancer, but this is not a given. Just as with chronic conditions, the absence of social support seems to block the insights that some pharmacists caring for those with cancer had about relating to patients and doctors.

4.4.1.2 Pharmacists with Cancer

One element that was pronounced in the stories of those who experienced cancer directly (as with those who experienced chronic illness directly) was the difficulty of adapting to work, which included facing discrimination due to disability. However, these situations also tended to spark sympathy and support from others, as well as opportunities for personal transformation. This is illustrated in the career of Dale, who first experienced cancer at the age of 23, following her graduation from pharmacy. After a lump developed in her hand, her left forearm was amputated. She then returned to community practice for 11 years, wearing a prosthetic hand. As Dale recalled,

when they amputated, it never ever crossed my mind that it [cancer] would ever come back. I thought that was it. That was devastating enough.... I never thought it would be my life on the line at any particular point.
She considered herself 'cured', drawing the line at the loss of her hand, denying the possibility of recurrence. As she resumed her active life, which later included marriage, divorce and business ownership, Dale realized that the loss of her hand had changed how she was viewed by employers and clients as well as changing her "embodied self." In Dale's words:

I went back to where I had worked before but my boss didn't want to take me back. There was no way that he could tell me that, but I found out afterwards... And since then, I went to another job and the guy hired two people and his daughters worked there as cashiers. And they were the ones that told me their father hired the two pharmacists 'cause he wanted me--like I did better in the interview personality-wise--but he didn't think I could hack the pace with the one hand, so he hired the other guy to see which one of us would work out better, and I didn't find out until he let the other guy go. And I've applied for a few other jobs that I didn't get and they never tell you why. I don't know whether it was because of my hand.

On another occasion, Dale concealed her prosthesis during the first part of an interview but when it sounded like she would get the job, she said:

"There's just one thing that I haven't told you that might affect you. It doesn't affect me cause I've been working with it for eight years." So I told him I had a prosthesis. And he said "Oh, that doesn't bother me at all." But then, at the end, he says, "Well, let's both think on it" and I thought, "Oh no," but then he called me about three weeks later and offered me the job. But then people up there told me he couldn't find anybody else to go out there.

Like others with cancer coping with a disability (Muzzin et al., 1994), Dale experienced discrimination. Was there any basis for this discrimination? Dale felt that losing her hand
did not affect performance of her role as a pharmacist, although she admitted that some tasks were more difficult to perform, such as

[when] I was trying to do something, whether it was a staple or get a label off or something... [T]he one thing I always had trouble with were the Winchester's. I don't feel comfortable pouring these, 'cause I know that the narcotic inspector is going to go "How could you spill the whole bottle every week?" (both laughing) So I'd have to get help for that...and then it's so stiff when you're doing something like Visa and you're doing fine work--it's quite obvious. Where, if you're just standing and counting, nobody notices.... I think if I had a busy pharmacy and I had somebody totally healthy apply for the job and a handicapped person...it's only human--you want to do the best for your business--so I don't hold it against him in any way, 'cause I DID get the job, finally, and I DID prove myself!

But Dale also found that her visible disability made it easier to develop relationships with her clients (in contrast to Fran, who thought such sharing was a burden on her customers).

As she expressed it:

[A]ctually, it was better, with customers.... I found people were more open to me than they were to some of the other pharmacists, especially cancer patients, 'cause they would say "Well, what happened to your hand?" (At first, they'd think it was broken, you know, they'd think it WAS my hand.) Then I would tell them and they would always want to see me because they knew--they'd cry on my shoulder and they'd feel really comfortable--so I think it helps other people that way.... So I used it to my advantage, I guess! [laughing]

Like most other pharmacists dealing with cancer, Dale found it easier to develop relationships with her clients after she had

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21 A Winchester was a large glass bottle which contained 80 fluid ounces (half an Imperial gallon); narcotic liquids were often packaged in Winchesters.
become a cancer patient. She became less automated in her dispensing function and made time for those who needed support. When asked to think of any way in which her cancer experience changed her practice as a pharmacist, Dale replied,

I've felt more sympathetic about people with problems.... Before it [was] churning out the prescriptions, and you didn't think of them really as people with problems and then you see them come in and you'd be busy and you'd say "Twenty minutes to half an hour" and they'd get that look on their face. And before this happened, I would think "Oh, come on; you'd line up for groceries that long!" But then I go into a pharmacy and, if you've just come from the doctor, you might have had some bad news, you just want to get home and you don't want to stop, and so it made me a more generous person, more sympathetic. If I saw somebody like that, I would offer "You want us to bring it over to you?" I was turning into a nicer person, because I think I was more of a machine before.... I think it was after it metastasized I got most sympathetic.... I had a harder time dealing with the ones complaining about nothing. But the ones that had the most serious illnesses were the ones that complained the least. They're the ones looking hang-dog and they wouldn't be pushy and you just want to hug them and say it will be all right! And then I just got so much sympathy, in return, from them.

Q: So you really developed some relationships with your patients up there.
Yeah, that was the biggest place that happened because twice I was seriously ill up there...and it was quite nice to have that kind of support from virtually total strangers.

The second pharmacist in the study experiencing cancer personally was Gail, whose reaction to the cancer diagnosis was very different than that of Dale. Gail's breast cancer story began when she was 37 and requested a second mammogram but was refused by her family physician, following data-based
guidelines. He had agreed to order the "baseline" radiograph when she was 35 but told her two years later, saying, "It's not indicated for somebody who doesn't have any risk factors and isn't 40 years of age." (Vis-à-vis risk factors, Gail pointed out that her father had lost nine of 12 siblings to cancer.) Just as in the situation of Fran's husband, Gail's concern for her body was dismissed by the physician. Six months later, Gail found a lump in her breast. Like Fran, her immediate reaction was anger ("I had done all the things you're supposed to"). This was followed by panic, accompanied by fear (cf. Sontag, 1979). But in contrast to Dale, Gail sought meaning in her cancer diagnosis and gave it a social context. Dale had regarded the amputation of her left hand as 'curing' her cancer: the 'cure' lasted 11 years. For Gail, the cancer diagnosis came just one month after she had left her stressful marriage. As she explained,

> it took me 20 years to walk out--a long time--but adding the cancer said "Yeah, I'm entitled to live some of my life the way I want to." It validated it and it kept me from going back.... Actually, a girlfriend of mine put it really well; she said, the way she views it, [my husband] was the cancer. When I got rid of [him], I got rid of the cancer, and it won't come back!

Support for Gail came from two friends, one of whom was a breast cancer survivor. Gail also received special concessions as an 'insider', being cared for by her co-workers in the hospital where she was employed. She found the lump

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Gail's first mammogram was done before she had any symptoms, when her breasts were healthy. Such baselines are taken to provide an early view for comparison with later views.
Tuesday and had the lumpectomy Friday, giving her little time to adapt; her fearful vision of "a cavernous hole with all this raw tissue just hanging there" was allayed by a laboratory technologist who had herself experienced two lumpectomies. She told Gail, "All you end up with is this little white scar." Gail had been "through all the medical stuff but they don't tell you about the superficial stuff," or the everyday, practical information about the surgical scar. Thus Gail felt that she was empowered by her cancer experience and capable of "empathetic advocacy" for others with cancer. As she reflected on that experience, she became more aware of how difficult it was for persons on the 'outside' to navigate through the health care system. As she expressed it,

Now, I know what to say, because I'm on the other side of the fence and most people [including pharmacists] don't know what to say unless they've been through it. I mean, I've [also] been through illness when [my daughter] was so sick, and it certainly helped, being in the profession then, because I wasn't the patient. I was going through it but she was the patient.... I could treat it as a learning experience; I didn't have to deal quite as much with the emotions being out of control. They let me read her charts every night I went in [because of being a pharmacist]; it took a while to get them to give that privilege to me.

Gail thought that her experience of caring for her daughter in the neonatal ICU years earlier had enabled her to develop a "caring for" response to other parents whose children were dealing with life-threatening illness; in her words,
It helped a lot in terms of dealing with pediatrics at work, 'cause you know what the parents feel; I mean, you can only imagine before that, but once you've faced the "I wonder if this kid is going to live or die," you know what those other parents are feeling.

When asked about her pharmacy education, Gail recalled a list of "eye-openers," or consciousness-raising experiences during her clinical placements that had all contributed to her current enlightenment. During that time, Gail had travelled with a nurse from the Victorian Order of Nursing into people's homes, worked in a busy Emergency Department, observed elder care in a nursing home and saw a man "stage" a seizure in order to gain access to shelter. Perhaps these experiences as an undergraduate as well as the support she received at work made the transition to a "caring for" response easier.

Gail was a four-year breast cancer survivor at the time of the interview. She acknowledged that although cancer is not often curable, advocacy in the form of support is possible. As she expressed it,

[cancer caregivers] get different training than the rest of us. I didn't deal much with pharmacists [at the cancer centre] but the rest of them seem to look at the patient and then everything related to that. Whether it's because their cure rate is so low, so they have to deal with everything else around it and the realities of the situation.... So much with cancer is just support therapy.

Recognizing what she had learned about herself through her cancer experience, Gail said,

I'd go through it again. It was worth it. Because you're on the other side now and you can communicate better; now you understand, you've got something to offer. You just become a more complete person because of it.
Because she had experienced being a cancer patient, Gail believed that she was a more credible, empathetic caregiver; her understanding was based on her new knowledge, not just on "science." Having faced existential questions herself, she thought she had the energy to help other patients and their families do the same. Like Lynn, she incorporated her experience into her patient care role.

4.4.2 Pharmacists with Gynecological and Obstetrical Experiences

Just as those experiencing cancer were critical of medical responses to their problems, but reacted in a variety of ways in dealing with these problems, the four women in this study with obstetrical or gynecological problems illustrate different ways of dealing with their own episodes and subsequent relationships with patients. While in their accounts, Helen's experiences of multiple surgeries and Kate's story of her hysterectomy did not have a profound effect on their view of the "informed consumer," Jane and Eve's obstetrical emergencies, on the other hand, did lead to profound changes in how they dealt with patients and physicians.

Like most participants in this study, reflecting on her interaction with the health care system around her four surgical experiences (which related to her fertility and reproduction), Helen was critical of what she perceived as the uncaring manner of most caregivers, particularly in large, teaching hospitals. Her first surgery for an ectopic pregnancy
signalled a crisis in her personal relationship. As Helen recalled,

I guess it was really the beginning of the end of our marriage because [my husband] just didn't understand [how much I wanted children] and he wouldn't adopt because he said that he couldn't love a child that wasn't his. (voice dropping low)

In her second marriage, Helen experienced another ectopic pregnancy; she finished working her shift as a pharmacist, then signed herself into the hospital. Because the pregnancy had ruptured the fallopian tube, causing hemorrhaging internally, the surgeon had indicated that she was lucky to survive. Six months later, she underwent a third surgery to reconstruct her tube during five hours of microsurgery. Her husband "wouldn't go for [a test-tube pregnancy]--he had had enough!" They adopted two children, each of whom subsequently had physical problems requiring medical intervention. Helen refused to allow medical residents to care for herself or her children, blaming them for missed diagnoses. About the long wait to see a specialist, she said:

You go in and you sit and wait and nobody is helpful. Nobody tells you how long; it's just sit and wait and you'll be lucky if he ever sees you.

How did her experiences with illness affect her relationships with patients? Being a pharmacist, Helen was in a position to facilitate referrals for others and herself but she did not describe herself as an advocate; according to her own account, her experiences had little impact on her relationships with patients in her practice.
Kate had also undergone gynecological surgery. Before I met her, I knew of Kate's activism in the profession, educating pharmacy students and practising pharmacists about pharmaceutical care. About one year prior to our interview, Kate had undergone a hysterectomy, which she planned in careful detail, much as I had done mine a few months later. She had taken a straightforward approach to her problem by exercising to get into excellent physical shape before her surgery. As Kate described it,

I went and worked out, did step aerobics two days in a row [and] figured I got my endorphin level built up. I'm not going to need pain medication [I thought], maybe past a day--and I'm going to respond a lot quicker. I had a hysterectomy and I was back to [part-time] work two weeks later!

Like me, she took charge of her body, "did all the research" and decided "I've had enough of this nonsense. I want to move on and enjoy my life!" Also like me, Kate went home on the third day, although the average length of stay after an abdominal hysterectomy is five days. Kate was proud of this, expressing her lack of empathy for the "difficult patient" who might not be as motivated as herself:

You have to be a self-motivated person to do something like this...[and] you are going to run into very many people who can't...they just want to be cuddled. They want to take advantage of all the care that's out there. I know [someone] who had the same thing done for the same reason and it took her MONTHS! I'm sure close to six months and she just wouldn't do anything for herself.... But I guess we're all different!
Kate shared Helen's criticism of large teaching hospitals. In her words:

I DO NOT like teaching hospitals. I had an intern and a fourth year medical student and I KNEW MORE THAN THEY DID! It's so impersonal! And I think about women who don't have any kind of medical background! Am I just a number around here or what?

Although she felt that she was well cared for in her community hospital, she continued:

I only took Tylenol #2 because the [hospital] bed was SO BAD (I sleep on a hard mattress) and my back was just killing me from the bed, not the surgery.

After she went home, Kate went to the chiropractor about her back pain. Because of this positive experience seeking care outside the medical system, Kate has recommended chiropractic to those with back pain in her pharmacy practice, giving them testimonials about her personal experience. Indicating that she had moved some way away from a total commitment to the medical model, Kate summarized her attitude towards "alternative medicine" in this way:

I believe that if you've tried conventional medicine and it hasn't done you any good and, as another choice, you tried something else, and you have positive results from it, then that's all that matters.

Unlike Helen, Kate's account suggested that her orientation towards patients and physicians was actively evolving: she considered herself to be open to acquiring new perspectives: "I have an open mind; I have gone through this." She also wondered "Why did it have to take 25 years for me to get so smart?"
Jane was the third of the four professional activists who had experienced "women's problems." Even before her own obstetrical emergency, she had developed an orientation of "empathetic advocacy" towards patients. She had been a career pharmacist before becoming a mother, active in professional associations. She described herself as "an activist," marching on Hart House as a female student denied access to that once all-male club at the University of Toronto. She also demonstrated activism later in her career by working for safe disposal of hazardous chemicals and drugs, as a hospital pharmacist. However, it was only following her involvement in her parents' illnesses that she recalled becoming more empathetic to the situation of those with chronic illnesses. She had been involved in caring for her father and then, upon his death, she became primary caregiver to her elderly diabetic mother. This made Jane a full-time mother of three young children as well as caregiver to her mother until she died a year prior to our interview.

Consistent with her activism in other areas, Jane had intervened when her father was over-medicated in hospital; by behaving like a staff member, she gained access to his chart and then confronted the nursing staff about his treatment. However, she recalled that she became particularly sensitized to the needs of the elderly during her mother's hospital stays. More than once, her mother, who was paying for private accommodation, had her need for privacy threatened when nursing staff attempted to move her into a four-bed room so
that a male patient could occupy the private room. Jane, however, intervened on her mother's behalf. Jane also recounted an episode when her mother was punished by the nurses for being a "bad patient;" as Jane recalled,

[My mother] had a broken right arm. She needed to call [a nurse for help] to go to pee. Well, she would call and call and call and no one, at night, would come. So, I finally said to her "Mum, if it happens, let go in the bed, and that will show them that they need to come." Well, she did.... [So the nurses] made my mother stand beside the bed--freezing cold--while they changed it before they would change her! I tell you, I had those two nurses up! "How dare you treat anybody like that! Is your coffee break more important than taking a lady to the bathroom?" Those people [the elderly] really need an advocate, someone to stand up for them. Otherwise, that [incident] would have just gone by the board.

As Jane talked, she reflected on her new attitude towards other patients, explaining:

you know what I see my role is, now that I think about it, and maybe it's because I'm aging, having worked with Mum and the geriatrics there--the older people (I hate [the term] 'geriatrics')--they really need advocates!

Combining empathy and activism, Jane planned to become involved in seniors' issues once her children were all attending school. Her own brush with illness, however, had been accompanied by a transformation in the way that she considered her self, a transformation that followed her original development of an empathetic response to patients.

As pointed out in Belenky et al. (1986), becoming involved in a caring relationship with a child may be the trigger that allows a woman to see herself as a being separate
from her work. Jane's first obstetrical experience occurred just prior to her fortieth birthday. Her labour lasted 42 hours:

The first 18 [went] very well; then, as soon as we got to the hospital, it stopped and I got every single intervention known to man there, short of a Caesarean!

Dissatisfied with this medical management of childbirth, Jane and her husband sought the services of a midwife. During two subsequent pregnancies, with much shorter labours, Jane gave birth to two more healthy children, the second child arriving in their station wagon in the hospital driveway. But following the birth of her third child, Jane hemorrhaged. As she said:

[T]hat was probably the scariest thing that's ever happened to me.... I had big blood clots at the back of the uterus, which they had to MANUALLY extract. Talk about a terrible experience! Anyway, they kept working on me; I only had two midwives--the doctor never got there. He was out horseback riding and he didn't hear his beeper go off until he got back to the stables.... [My husband] was there, playing with the baby and I remember saying, as I was feeling myself flow away, "Take care of me! Please take care of me! Don't let me die!" So they called the OBS-GYN and he had to manually extract not once, but twice.

Twenty-four hours later, Jane went home with her third child, feeling exhausted after her ordeal. To build up her blood, she purchased an herbal product, since she couldn't tolerate [pharmaceutical] iron tablets. As she stated:

I'm thinking more of homeopathic and natural remedies than anything else, these days.

OBS-GYN is an abbreviation of obstetrician-gynecologist, a medical specialist in childbirth and disorders of the female reproductive tract.
Jane had also chosen to become a full-time mother. In the past, she had taken her career very seriously and brought her work home with her first-born son, so that work and care of her child were mixed together:

I ended up doing the budget at home! I was breast feeding and writing the budget at the same time!

But through her mothering experience, Jane had changed her self-identity such that she focused exclusively on caring for her children. She became a certified fitness instructor just before the birth of her second child and started attending a mother's support group soon after that birth. At the time of our interview, Jane had not worked as a pharmacist for 10 years.

In a similar process to that described by Jane, Eve's account of her obstetrical emergency described an awakening of her caring response through a recognition of the responsibility she had for an other different from self. Her entry into the alienating medical environment of the hospital was abrupt. While she critiqued this, she also credited a nurse with raising her consciousness both about her self as separate from her work as a pharmacist and her potentially harmful effect on her unborn baby. Early in her third trimester, Eve noticed some vaginal bleeding. Approaching hospital staff for information, she was treated roughly, reprimanded and abandoned. As she explained, her husband drove her downtown to the hospital:
And the first thing they said was "Where are your bags?" and I said "Well, I didn't bring any bags."... It was 10 o'clock at night and [the nurse] says "Well, you're going to be here until you deliver, so you're going to be a while. Your husband might as well go home."... So really, within the span of two hours, I went from being healthy to feeling fine still and yet being told that there was a minor crisis, you're not going anywhere... I think it was just the way we entered the system [that] was a bit of a shock. I was crying for hours it seemed, my husband was only in for a couple of minutes... there's no nurses... you're hooked up to a monitor, you can feel the fetal heartbeat and the contractions occurring and yet you are completely by yourself... And I found that very, very disturbing and you just felt lonely and scared, probably more scared than anything else.

Although she was aware of her baby's heartbeat, Eve didn't realize her connection to her son until a nurse intervened while Eve worked by telephone from her hospital bed, saying, "I've sat here for the last half hour and listened to your conversation and watched your [fetal] monitor... You are now beginning to affect your child's well-being here; you have to stop." I think that was probably the first time I realized that this wasn't just me anymore, that I was in a situation where I was actually going to affect things by my behaviour.

Eve needed to be shown the objective change in her baby's heart rate before she became conscious of her effect on her child and learned to take care of him by taking care of herself. This is in contrast to the feminist critique of the fetal monitor which "estranges us, disrupts a bond that existed between persons" (Lashley et al., 1994:24); for this pharmacist, the fetal monitor enabled her to connect to her child, once she realized that changes on the monitor were evidence of the impact of her activity on her baby. Relying on
technology to monitor our bodies plays a large role in scientific health care, and perhaps Eve's strong identification with the "medical model" before this emergency played a part in her faith in this technology.

During her hospital stays, Eve experienced being a patient. On one occasion, she was informed of two contradictory plans for her treatment by two specialists; in order to clarify the situation, Eve called in her family physician. After that, she became aware that the remaining specialist and the nurses were careful to exclude her from discussions about her care; "as if I had caused trouble." Eve felt she was being punished. Further, after the medically-managed birth of her son, Eve was quite helpless. As she stated,

I had no care and yet, wasn't able even to get out of bed myself.... I was continuously in pain and my husband finally just moved into my room, set up a couch and looked after the two of us, 24 hours a day, and that was really the only way to get the care that both of us needed.

Eve's husband, in the sales and marketing business, saw what his wife and son needed and took over caring for them, even though he had no previous caregiving experience. Her account of her emergency clearly attributed being cared for by her husband as the enabling factor in allowing Eve to care for her self and her baby.

How did Eve's experience as a patient change her and the way she viewed patients subsequently in her pharmacy practice? In her words, when she became a mother,
it was a lot easier to say "No" to people that asked for things and...I left work when I was supposed to leave work and I was home when I was supposed to be home.

In her approach to patient care, Eve practised "empathetic advocacy"—that is, she became more assertive and collegial with physicians. In addition, she felt that she was more able to "say things from the patient perspective." She felt empowered, sharing her power with community groups, advising them to be selective about pharmacy services. Her view was, "if they're really too busy behind the counter, then you don't want to go to that pharmacy." Eve noticed that her teaching also changed; "I really notice the students are explaining things from a patient perspective." Her overall assessment of the effect of her life-threatening illness and the experience of "caring for" her child was that it enabled her to "make a difference" both in her teaching and her professional practice.

4.5 Summary

The stories of all participant pharmacists have been summarized, categorized and analyzed in this chapter, in order to give an overview of the commonalities in themes as well as the variety of responses to illness by pharmacists. Grouping their illness stories in the three categories minor/acute, chronic, and life-threatening illnesses, revealed the
differences in the concepts that pharmacists in these three categories tended to hold about pharmacist-patient relationships.

In the first category, four pharmacists told of managing brief family illnesses. All described their view of patients as having responsibilities to inform themselves as consumers, while it was the responsibility of the pharmacist to inform the patient. By way of contrast, in the six stories of chronic illness, the pharmacists described themselves as sympathetic or more empathetic towards their patients as a result of this exposure to illness. There was a great deal of variation though, with one transforming into an active advocate for the Deaf, while another was so isolated, oppressed and so lacking in energy that she had not been able to change her way of practice, despite feeling that she was more empathetic towards her patients. The experience of life-threatening illnesses similarly sparked changes in orientation to patients according to most pharmacists in this category, and, in about half, what might be called "empathetic advocacy" developed. Themes varied somewhat depending upon whether the problem involved self, family members and infants, and whether the experiences were with cancer or gynecological or obstetrical emergencies.

A common theme in the accounts was a critique of the medical profession and the health care system. However, while those with social support and prior experience dealing proactively with physicians seemed, by their own accounts, to
be able to learn from their experiences in such a way as to pursue patient advocacy more effectively, a few were "stuck" with their anger and insistence that patients merely needed to "inform" themselves and be forewarned about the system.

This analysis has speculated about the relationship between working conditions and illness, identifying barriers to personal growth and changes in empathy and in interacting with patients. These factors, which can be conceptualized as either externally- or internally-driven, will be further explored in Chapter Five, in order to explain why some pharmacists underwent changes in self-identity and their relationships with patients following an illness experience.
CHAPTER 5
DISCUSSION: ANTECEDENTS OF CHANGE
IN PHARMACIST-PATIENT RELATIONSHIPS

There are three phases of suffering:
(1) mute, during which loss takes over personal self;
(2) expressive, which allows for change as voice is regained and narrative begins;
(3) transforming or achieving a new identity

5.0 Overview

In the first part of this chapter, the original criterion for choosing pharmacists who were active in the profession (versus those who were inactive) is briefly revisited. Table 3 (page 103) summarizes antecedents to change in patient relationships for professional activists and inactive pharmacists. In the course of this research, in the process of selecting on this dimension, it became clear that professional activism and patient advocacy differed. Thus, in the first section of this chapter, the theoretical inter-relationship of these two phenomena is questioned. Their relationship remains to be determined, but the point is made that they are clearly not the same phenomenon.

In the second part of the chapter, the antecedents of illness and of perceived changes in patient-pharmacist relationships are reviewed; conditions experienced as "external" (such as working conditions, location and position) and "internal" to the pharmacist (such as family
responsibilities and reported changes in self-identity) may precede or follow illness and relational change. These are considered in this chapter in an attempt to contextualize the analysis presented in the previous chapter and to generate explanations for observed change or lack of change towards empathetic and advocacy relationships with patients. After briefly exploring the contexts within which these pharmacists practised, the impact of identity-threatening illnesses, which preceded personal transformation, is examined in more detail, as well as how such an illness might influence the pharmacist's professional or existential self. What seems to be common in cases where no change is observed is briefly summarized. The chapter closes with speculation about how the pharmacist's "world view" might be related to her relationships with patients.
## 5.1 Professional Activism and Patient Advocacy

### TABLE 3: External and Internal Antecedents to Perceived Change or Barriers to Change in Patient Relationships

<table>
<thead>
<tr>
<th>Name</th>
<th>External Considerations (e.g. Working Conditions, Setting)</th>
<th>Internal Considerations (e.g. Changes in Self-Identity)</th>
<th>Patient Relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Professional Activists</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sam</td>
<td>hospital, no patient contact</td>
<td>scientific world view</td>
<td>detached</td>
</tr>
<tr>
<td>Mark</td>
<td>hospital, no patient contact</td>
<td>scientific world view</td>
<td>detached</td>
</tr>
<tr>
<td>Nan</td>
<td>hospital, some patient contact</td>
<td>low energy due to disease; self-reflexive</td>
<td>empathetic</td>
</tr>
<tr>
<td>Kate</td>
<td>community, some patient contact</td>
<td>scientific world view but &quot;open&quot;</td>
<td>empathetic</td>
</tr>
<tr>
<td>Jane</td>
<td>no patient contact</td>
<td>&quot;connected&quot; with others</td>
<td>empathetic</td>
</tr>
<tr>
<td>Rose</td>
<td>hospital setting</td>
<td>&quot;connected&quot; and self-reflexive</td>
<td>&quot;empathetic advocate&quot;</td>
</tr>
<tr>
<td>Gail</td>
<td>hospital setting</td>
<td>&quot;connected&quot; and self-reflexive</td>
<td>&quot;empathetic advocate&quot;</td>
</tr>
<tr>
<td>Eve</td>
<td>hospital setting</td>
<td>&quot;connected&quot; and self-reflexive</td>
<td>&quot;empathetic advocate&quot;</td>
</tr>
<tr>
<td>Helen</td>
<td>hospital setting</td>
<td>no support; low energy</td>
<td>detached</td>
</tr>
<tr>
<td><strong>Professionally Inactive</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opal</td>
<td>community pharmacy</td>
<td>low energy due to disease; isolated</td>
<td>detached-empathetic</td>
</tr>
<tr>
<td>Fran</td>
<td>community pharmacy</td>
<td>no support; isolated</td>
<td>detached</td>
</tr>
<tr>
<td>Penny</td>
<td>community pharmacy</td>
<td>not &quot;connected&quot;</td>
<td>sympathetic</td>
</tr>
<tr>
<td>Chris</td>
<td>student</td>
<td>low energy due to disease</td>
<td>empathetic</td>
</tr>
<tr>
<td>Dale</td>
<td>no patient contact</td>
<td>&quot;new self&quot;</td>
<td>empathetic</td>
</tr>
<tr>
<td>Irene</td>
<td>hospital setting</td>
<td>&quot;new self&quot;</td>
<td>&quot;empathetic advocate&quot;</td>
</tr>
<tr>
<td>Lynn</td>
<td>hospital setting</td>
<td>&quot;connected&quot; and self-reflexive</td>
<td>empathetic</td>
</tr>
<tr>
<td>Belle</td>
<td>hospital setting</td>
<td>scientific world view</td>
<td>detached</td>
</tr>
<tr>
<td>Ann</td>
<td>hospital setting</td>
<td>scientific world view</td>
<td>detached</td>
</tr>
</tbody>
</table>
Pharmacists were categorized as "active" in Table 1 (on page 30) because they belonged to one of the following categories: pharmacy educator; college committee member; association committee member; or practice innovator, meaning a pharmacist in the forefront of implementing practice change. In other words, they were people who had "made a difference" in the professional practice of pharmacy. Those who were listed as "inactive", on the other hand, had no ongoing activity on behalf of the profession of pharmacy at the time of the interview. They were dispensing accurately and counselling when they could. Some had "buckled under" (Lai, 1996), admitting that they had compromised their professional ideals within the practical constraints of their workplaces.

Before I began this research, I speculated that those who were actively involved in promoting the profession and its ideals might be more likely to be patient advocates or to become patient advocates. As leaders in the profession, I reasoned that they would embrace pharmaceutical care as a practice model and "make it happen." However, my view of pharmaceutical care as caring for patients in a relational way and intervening with physicians on their behalf did not describe what was happening in every case. As shown in Table 3 (page 103), Sam, Mark, Kate and Jane were no longer involved in direct patient care; Sam was employed in the pharmaceutical industry and Jane had become a full-time mother. Mark and Kate were managers who supported the need for pharmaceutical care, educated their staff about it and expected it to be utilized
as a practice model. Because they were not involved in direct patient care, they were unable to "model" pharmaceutical care to their staff pharmacists.

Three of the pharmacists, Gail, Eve and Helen, however, were both active in their profession as well as being direct patient care providers in hospital settings, as shown in Table 3 (page 103). Perhaps caring for patients is more readily actualized in institutions, where the pharmacist is a member of the "team" providing patient care. The fact that Gail and Eve reported caring for their patients in the hospital setting supports this idea. Helen, however, also employed in a hospital setting, seemed isolated in her work and "stuck" in her personal life.

The symbolic image of the white-coated pharmacist counselling patients in a private booth and providing printed drug information from a computerized data base has been widely promoted by corporate pharmacy as necessary to maintain health. Similarly in hospitals, the services of pharmacists-as-consultants have been promoted as necessary for patient care. But critical examination of these services might lead one to ask whether these activities really support patient care or fiscal restraint. I would argue that only by interacting with patients and developing relationships with them as individuals, can pharmacists become patient advocates. Experiencing an illness may be one means of becoming sensitized to patients as people. However, since not all professional activists are oriented towards patient care but
rather, to advocacy on behalf of the profession, it is clear that professional activism is not a sufficient antecedent of patient advocacy; one must have the opportunity as well. In fact, only four of nine "active" pharmacists (Rose, Gail, Jane and Eve) underwent significant self-reported change, while three of nine "inactive" pharmacists (Irene, Lynn and Dale) reported similar changes in patient relationships.

Why did not all professional activists become patient advocates? This research cannot answer this question, but a number of questions can be generated to guide further research on the issue. For example, could it be that corporate-professional agendas (in the sense that John Ralston Saul [1995] uses the term "corporate\(^{24}\)) were internalized by these pharmacists to such an extent that patient advocacy became less of a priority? Or could it be that the corporate-professional agenda prevented these pharmacists from being sensitized to the plight of other patients, even after going through an illness experience? Does the illness itself influence the response of the pharmacist (e.g. in the case of those with "low energy")? Do pharmacists use their experiential knowledge in their professional practice or do they compartmentalize it? Are these pharmacists empowered to act only within the confines of the corporate-professional

\(^{24}\) Saul defines corporatism as the transfer of legitimacy from the individual to the group; each group or "corporation" has its own "ideology" which it presents as a slogan, to be accepted by the members of the group. This acceptance of corporate ideology/ slogans and fear of thinking critically makes us passive, obedient and "unconscious."
direction, not as individual professionals? These are some of the questions that could prompt future research.

5.2 Antecedents of Illness and Practice Change

5.2.1 The Social Context of Pharmacy Practice

Antecedents of illness include factors which can be thought of as personal to individual pharmacists or external to them. Many participants in this study did not talk about the social context of their illness, nor did they talk about the psychological impact of being sick. Instead they described diseases and their bodies in scientific terms—the language they learned during their education as pharmacists. Perhaps because they were telling their stories to me, as one pharmacist to another, they were more inclined to use medical terminology than if they were speaking to a lay person. However, social context was implied as causal in stories of job-related stress. Another external antecedent to illness that was identified in their accounts was poor working conditions which add to occupational stress (Baker, Israel and Shurman, 1996). The combination of low energy due to chronic and/or life-threatening illness and lack of control over their work seemed to explain the fatalistic\textsuperscript{25} outlook of pharmacists such as Opal and Fran.

\textsuperscript{25} As an opportunity for change, illness provides us with one of life's "fateful moments," to use Giddens' term (1991). That is, the consequences of decisions made in reaction to the circumstances of the moment are significant in a person's destiny. This should not be confused with fatalism which signifies passive acceptance allowing events to run their course. It is argued that those pharmacists who reported that they became "connected" to others, empowered and self-reflexive were more likely to become advocates; those who remained "unconnected" after their illness were often depressed and fatalistic in their outlook.
It is clear from pharmacist accounts that their working conditions may predispose them to becoming ill. As described by the "inactive" pharmacists, Opal, Fran and Penny, pharmacists in community practice work 12-hours shifts during which they may dispense 200 or more prescriptions with no breaks and inadequate staffing. Employee pharmacists have little control over their work and can easily be replaced if they complain. In a study by Ortmeier and Wolfgang (1991), pharmacists were stressed by workload, dealing with the public and staffing problems; as stress increased, so did job dissatisfaction. Every day these pharmacists deal with patients who do not want to be counselled and with physicians who do not want to speak with them. In Marxian terms, pharmacists are at risk of becoming alienated from themselves and their work (Archibald, 1978), perhaps making them more vulnerable to stress/illness. Larson (1980) defines alienation as loss of autonomy, having three dimensions: (1) economic--many pharmacists sell their labour as employees rather than operate their own pharmacy; (2) organizational--the division of tasks meets the needs of the employer, not the staff pharmacist; and (3) technical--pharmacists lose control of how they do their work. Pressure from their licensing bodies and professional associations to enact pharmaceutical care, which employers may neither value nor support, may further distress pharmacists in such a role-conflict situation. In their study of stress among pharmacists, Lahoz and Mason (1990:28) found that "burnout" (defined as a
syndrome of emotional exhaustion and cynicism among individuals who do "people work") among pharmacists was most likely to occur in women under 40 years of age in practice less than 10 years.

Simultaneous with the influx of women into pharmacy since World War II, the work of the pharmacist has been devalued and degraded, especially the caring aspect (Muzzin, 1996). That work has changed considerably in the last century and particularly during the last decade. Patient care by pharmacists was negotiated away to physicians in 1871 with the proclamation of the Pharmacy Act in Ontario in which pharmacists were granted the monopoly on compounding and dispensing and physicians achieved a monopoly on prescribing. With the development of "clinical pharmacy" in the late 1960s, followed by the advent of the pharmaceutical care practice model, the "count, pour, lick and stick" dispensing functions are now performed by technicians or have been assumed by the multi-national pharmaceutical industry. Pharmaceuticals are being marketed directly to consumers by the industry in media advertising with toll-free information lines and drugs ready-packaged for consumers, including patient information. Even the "drug use control" (Brodie, 1967) role of the pharmacist is being superseded by computer data bases developed by insurance companies to monitor prescribing by physicians. For example, automated vending machines which dispense prescriptions are available in maritime Canada.
In addition to dealing with change in their workplaces, pharmacists who are working women may also be running households and caring for families in a "double shift." As Fran, an "inactive" pharmacist, stated:

I'm working more hours than I'm used to working and suddenly, there's no groceries in the house! That kind of thing and you just don't feel like your life is running in an orderly manner. And I've been finding myself a little bit stretched.

Seven participants had experienced marital separation or divorce; in addition to the emotional impact of these life events, they also had financial and parenting concerns to manage. One participant disclosed incidents of spousal violence during her marriage to another pharmacist. Lack of a supportive home environment may affect the pharmacist's health, practice and professional relationships.

Pharmacy is a "feminized" profession in Canada. Although about two-thirds of practitioners are women, men continue to occupy the positions of power. "Relational thinkers" and "caring for others" are feminine concepts which clash with concepts of ostensibly objective, value-free molecular science, which form the basis of pharmacy education and practice. The hierarchy of the professions with medicine dominant places pharmacists in a subservient role. An example

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26 The entry of women into professions which were previously male domains has the effect of reducing the status and salaries of female participants (Faludi, 1991:366).
27 In 1984, 1,245 of 3,110 practitioners on the Ontario College of Pharmacists' register were women (DesRoches, 1984). An unpublished analysis of licensing board records by Muzzin (personal communication, 1997) suggests that the national proportion of women pharmacists is now over 60 per cent.
of this phenomenon in Ann's account described how she contacted the physician to request a change in the antibiotic prescribed for her child. She avoided a "clash" because she "could detect some sort of sensitivity" although she stated her request "in a nice way." Many women pharmacists told me that they also try to "be nice" by controlling their thoughts, feelings and behaviour (Brown and Gilligan, 1992:52). As such incidents show, the interaction between pharmacist and physician involves both gender and other power relations. Those without power may be oppressed without knowing it. Perhaps lack of awareness of oppression, besides preventing the development of self-awareness, may also manifest itself in clinical depression or a fatalistic outlook. This may explain why several of these women talked about being depressed when interviewed.

Given all these stressful aspects of professional and personal life, I should not have been surprised to find disempowered pharmacists. Previous research shows alienation with pharmacy work among young graduates (Lai,1996), women who work part-time (Dunn,1993) and those working in discount corporate settings (Muzzin,1995). I did not expect to find that their profession made them ill, but this seemed to be the case for some of them. How, I wondered, could I have expected that pharmacists would become strong advocates for patients? Yet, a few do. How does this happen?
5.2.2 Antecedents of Personal Transformation

Fourteen pharmacists in this study experienced a serious illness, either themselves or in their immediate family. According to their accounts, 11 pharmacists reported becoming more empathetic towards patients in their practice and more conscious of patient needs following their illness experiences (See Tables 2 and 3). Two of them, Irene and Dale, underwent a significant transformation of self. What preceded this renewal of self?

Prior to being abruptly diagnosed as "deaf" by an uncaring specialist, Irene was employed in hospital pharmacy. Upon being told she was deaf, Irene was angry and upset; she had lost her self-identity as a hearing person and feared that she could no longer practice as a pharmacist. As she recalled,

I remember asking someone who was speaking about human rights and discrimination: "You know, I am a licensed professional who just lost my hearing. Can the licensing body refuse to renew my license, because I can't hear and communication is such a big part of my profession?" [But the counsellor had replied.] "No. If you can show that you are gainfully employed and doing your job competently, nobody can tell you otherwise. If you go and do your job and start making dreadful errors, then you are incompetent. You are not incompetent because you are deaf; you are incompetent because you are making all these errors, bad choices, whatever."

As is clear in her account, Irene's deafness threatened her identity. By extension, she felt that her competence as a professional might be questioned. Her construction of a new identity began as she attempted to cope with her own
disability; in this, she was supported by her husband and children. Then she became conscious of how other Deaf were treated in the workplace.

A similar process of learning to care for herself by becoming aware of and caring for others (Noddings, 1984) was experienced by Dale. She reflected that the recurrence of her cancer two years prior to our interview helped her to be even more empathetic; it also gave her the opportunity to re-evaluate her life. In order to spend more time with her family, she had moved in with her parents, who were her primary caregivers. But she had not sold her house, because, as she explained,

I'm not ready to give up my independence of my house, because to me that's giving up and I've been on my own for so long...[and] if I do get better, and I can do something, I haven't gotten rid of my place. But I gave up the pharmacy license...

Dale was developing a new identity apart from her profession but was not willing to sell her house, which symbolized her independence--it was "a room of one's own" (Woolf, 1929). Dale's choice to spend the remainder of her life painting and being with her family met with disapproval from other pharmacists, she said. Dale theorized that pharmacists cannot support each other because of their "objective/ lack of empathy" approach. In preparing to die, it could be argued that Dale was developing a "relational" world view.28

28 A "relational" world view values women's sense of relationships and refers to being conscious of interdependence with others and our environment (Gordon, 1996:261).
Irene and Dale had both been living with disability before the event which sparked their reported change in self-identity. Perhaps "being different" because of being hard-of-hearing or having a prosthetic hand, as well as dealing with their differences reflexively over a period of years enabled Irene and Dale to change more than then others. They also received strong family support.

Two other pharmacists, Gail and Eve, also underwent a change of self, but this came as a result of a threat to their children. After her daughter underwent the surgical repair of a congenital heart defect, Gail was able to care for other children and their parents in her practice as a hospital pharmacist. Perhaps this caring experience also raised Gail's consciousness so that her self-transformation upon hearing her own cancer diagnosis was easier. At any rate, in Chapter Four, Gail described her illness experience as transforming her into a "whole" person, much like the women in Clarke's (1985) study, describing a new sense of self and purpose in life or the mother with polio in Goffman's (1963) account, who learned about life and people through her suffering.

Eve also underwent a consciousness-raising experience which opened her eyes to the relationship with her son, for whom she was responsible. As described in the previous chapter, Eve learned to care for her unborn son when she was chastized by a nurse who pointed at the fetal monitor, explaining that by working over the telephone from her hospital bed, Eve was affecting her son's heart. This example
is so close to the example used by Belenky and colleagues (1986) in their identification of caring for one's child as an antecedent to birth of the self, that one must question whether Eve, despite her professional activism before illness, was really aware of her self, in relational terms.

5.2.3 Antecedents of/ Barriers to Change in Patient Relationships

As suggested in Chapter Four, pharmacists who had not been challenged by an illness threatening to their self-identity viewed their relationships with patients in a more detached way. Perhaps they had never faced the existential questions involving uncertainties about time, space, continuity of life and self-identity. Maybe they separated mind from body more so than those whose body has suffered—who know their self is "embodied". By way of contrast, pharmacists who had suffered chronic illnesses who had not become advocates for others tended to report a change in the sense of becoming aware of being "connected" to others. For example, Nan could relate to another person suffering from depression, Jane could relate to elderly patients, Chris could relate to other people with degenerative disease and Penny was more sympathetic towards people suffering from mental illness. Perhaps Opal, Chris and Nan were limited by their lack of physical stamina as a consequence of their chronic illness; this may have reduced their energy and vitality for engaging

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29 "The self, of course, is embodied" (Giddens 1991:56). As children, we learn about our bodies by relating to others before we explore the world around us. "Reality is grasped through day-to-day praxis."
with others beyond the offer of empathy in their practice as pharmacists. Penny, Opal and Fran were also working 12-hour days in community pharmacy; lack of social support and fatigue were problems they managed continuously.

5.3 Change in Patient Orientation, "World View" and Discrimination

Participant accounts suggested a connection between the experience of illness, orientation to patients and a general way of seeing the world, which might be summarized by the term, "world view" (Boon, 1996). As discussed in Chapter Two, Boon and Muzzin (1996) have argued that students adopt a "scientific" world view during their pharmacy education. Most pharmacists in this study reported that they entered the profession because they did well in high school mathematics and sciences and saw pharmacy as a respectable occupation which provided a reasonable income and professional status. During professional socialization, these students developed a professional image and a new view of self (Haas and Shaffir, 1988).
1981). Upon departing the lay world and entering the world of their chosen occupation, they tried to assimilate what they had been taught as budding professionals.

Pharmacy education is similar to medical education in terms of its focus on molecular science. Pharmacy students experience anxiety as they become alienated from their previous identity and undergo conversion to competent professionals. Haas and Shaffir's (1987:408) description of becoming a physician applies just as well to pharmacy students:

Becoming professional, then, involves a symbolic and a psychological transformation. A symbolic distancing and control over construction of reality is accompanied by psychological and interpersonal distancing.

Symbols which represent the pharmacy profession include: medical terminology; white coat; mortar and pestle; counting tray; and confident manner. Students learn "impression management" (Goffman, 1959) and identify with pharmacy by working with other pharmacists, whom they model; they become separated or compartmentalized from the lay world. They turn off their feelings and objectify their patients, much like physicians. As pharmacists, most will have confirmed the "scientific" world view with which they began their training (Boon and Muzzin, 1996).

As the examples given in this analysis suggest, in order to undergo another transformation of self, some "breaching" experience (Garfinkel, 1970) or "disidentification and identification" (Strauss, 1969) may have to occur which cannot be incorporated into the acquired professional
identity. For Irene, this conversion point (or "epiphany", in Denzin's [1994:510] terms) was identified by her as the day she was labelled "deaf"; for Dale, it was the day she learned that her cancer had recurred. Cancer patients report a period of up to 100 days between the "time of rupture" and "time of epiphany" (Muzzin et al., 1990). This may correspond to the shock of loss and the regaining of voice followed by the renewal of identity. (See the quotation at the beginning of this chapter.)

Although the relationships among changes in world views, awareness of discrimination, reported changes in self and changes in relationships with patients remain to be teased apart, it is worth mentioning that, in the stories of Irene and Dale, there is a connection between raised consciousness and what Freire (1997[1970]) would call consciousness of "oppression" (discrimination). For example, after experiencing discrimination in the workplace, Irene overcame what Freire would call the "limit-situation" of her deafness by joining with other Deaf and becoming an advocate for them. In addition, perhaps it was the "necessity of managing the body" (Giddens, 1991) by coping with her hearing loss that provoked Irene's transformation, not becoming deaf. When Dale's forearm was amputated 11 years earlier, she had thought that the loss of her hand meant the end of her cancer. The shock of recurrence threatened her existential self; she risked dying without having experienced all that she wished to be and do. At the time of the interview, Dale told me, "I don't feel
close to death now." In fact, she lived another 18 months, attending live concerts, appearing on a TV talk show, meeting and corresponding with celebrities and learning to do folk art painting, as well as enjoying her family. Because she interpreted the recurrence of her cancer (correctly) as a death sentence, Dale chose to leave her profession and invest her remaining time in new activities while she developed her new self. She abandoned her objective, "scientific" world view and related to all those whom she met as well as seeing herself in a more "holistic" context.

5.4 Summary

In this discussion about the reported antecedents of change in pharmacist-patient relationships, various factors have been considered in an attempt to generate a better understanding of the patterns described in Chapter Four. First, the phenomena of professional activism and patient advocacy and their theoretical interrelationship were reconsidered. It was argued that professional activism is not necessarily a predictor of patient advocacy. It may be that professional advocacy appeals to those seeking peer recognition and professional support whereas advocating for patients is less visible and less likely to provide tangible benefit to the pharmacist. This differentiation between professional activism and patient advocacy has not been made in previous sociological literature on patient-professional relationships. Second, the relationships among work, personal
circumstances, illness and reported changes in orientations towards patients was considered. Antecedents to illness may include: poor working conditions; power and gender relations; and devaluation of work.

In the third section of this chapter, situations of personal transformation were then considered in more detail by reviewing the accounts of Irene, who was threatened with the loss of her professional identity, and of Dale, who eventually lost her life, as well as those of Gail and Eve, who learned to care for others by caring for their own children. Some final comments and suggestions were made about the development of identity and world view through pharmacy education and professionalization. The opportunity for transformation provided by illness appears to be twofold: change in identity may be triggered by a threat to self but advocacy is stimulated by becoming conscious of others who are similarly oppressed.
CHAPTER 6
SUMMARY AND IMPLICATIONS

6.0 Introduction

In this chapter, I will summarize the findings of this research and suggest their theoretical implications as well as their significance for the profession of pharmacy. After briefly reviewing the changing historical context of pharmacist-patient relationships, I will comment on how this study of pharmacists and their experience of illness adds to our understanding of what being a patient means and also how pharmacists feel that experience impacts on their subsequent relationships with patients. I will also suggest how some of these pharmacists became more "connected" with their patients and how others became "empathetic advocates" for them. Areas for future research will also be indicated.

6.1 Summary and Theoretical Interpretation of Findings

In qualitative research, "competing" paradigms are not often used together. In a single work, researchers most often use one theoretical perspective or another. This research benefited from sensitizing concepts found in the literature of symbolic interactionism, where identity and illness have been examined, supplemented with critical perspectives from the feminist literature as well as empowerment theory and education theory.
While symbolic interactionism is useful as a framework for examining professional identities, it does not address the issues of gender and power that emerged in the illness stories that were collected here. The pharmacist-patient relationship may be viewed through these alternative lenses in order to develop a more elaborated view of the complex relationships of health care workers and their clients in an hierarchical division of medical labour.

In the literature, the almost exclusive focus on physicians and their patients rather than other health care workers and their clients, I think, has obfuscated these aspects of relationships within the health care system. The film, The Doctor, popularizes the idea that experiencing illness can transform patient-practitioner relationships. My thesis, which focuses on pharmacists, rather than physicians, shows that many women practitioners who experience depersonalized "health care" at the hands of physicians and others in our health care system grow to question not only their own experience but the system itself. Their personal illness experiences indeed lead most to feel more empathetic towards their patients. However, the transformation of their relationships is more problematic than the Hollywood film would suggest. It requires that women reconstruct their views of how to address physician relationships with their patients as well as their own. In addition, in commercial workplaces, the women must deal with their bosses, and the constraints that contemporary businesses place on their practices. The two
male pharmacists is this study had no direct experience of being or caring for a patient; hence, they were unable to describe changes in their patient relationships related to illness experience.

Methodologically, I chose to analyze the narratives presented by the participants in as holistic a form as possible, comparing them for similarities and differences in themes, rather than isolating generic processes for examination, as is often done in scientific analyses. This approach is consistent with my concern for hearing the women's voices, a point made emphatically in the feminist critique of science (cf. Bleier, 1986).

6.1.1 Recovering the Pharmacist's Relationship with the Patient

A century ago, in Canada, pharmacists provided direct patient care when they functioned as "the poor man's doctor," since only the wealthy could afford the services of a medical practitioner (Muzzin and Hornosty, 1996). Most medicaments were compounded from botanicals once the pharmacist had listened to the patient's description of his complaint and chosen a formulation for the appropriate remedy. In the twentieth century, co-incident with the scientization of medical education supported by American industrialists, the relationship between pharmacists and their patients changed. Physicians assessed the patient (objectively, versus the more subjective assessment of the pharmacist of old), diagnosed the malady and prescribed the cure. Pharmacists continued to
compound and dispense, but were largely limited to filling the prescriptions of the medical man and controlling public access to patent medicines. Professional dominance by medicine in the hierarchy of the professions had begun.

Drugs continue to be a common treatment for many diseases. The growth and development of multi-national pharmaceutical companies, which have largely assumed the pharmacist's compounding function, accelerated following World War II. At that time, the need for more pharmacists rose dramatically and women began to enter the profession in greater numbers.

Over the last three decades, many changes in the profession of pharmacy have taken place. The "corner drugstore" in which I first apprenticed was part of the neighbourhood; I worked there part-time through high school, as did my two younger sisters. The owner lived across the street from us with his pharmacist-wife and I baby-sat their children. That style of small independent store is now a thing of the past, replaced across Canada by large, corporate chain operations, most often staffed by pharmacists who live in other communities. Personal relationships between pharmacists and patients are more difficult to establish and maintain in these impersonal settings in urban locations.

In addition to changes in the business side of pharmacy, there have been changes in practice models over those decades. Pharmacists are now being told by their licensing boards and academic leaders that they must
"dialogue" with patients and become responsible for the outcomes of the patient's drug therapy in the practice model called "pharmaceutical care." Noddings cites Freire's (1970) description of dialogue as open-ended conversation--a search for understanding or a quest. The benefits of dialogue include: informing decisions; encouraging the habit of seeking information; and providing knowledge on which to base an appropriate response in caring (Noddings, 1992:23). At the most recent world pharmacy congress, one session focused on pharmacist-physician-patient relationships and the problems faced by pharmacists including lack of access to clinical information about patients in their care. Those pharmacists employed in health care institutions are better able to practice pharmaceutical care since they have better access to clinical data, although it is difficult to develop relationships with patients whose lengths of stay are becoming ever shorter. (However, my research suggests that the hospital practice of pharmacy, mostly pursued by women, may provide opportunities for more empathetic relationships than the contemporary commercial pharmacy environment allows.)

With all the barriers they face in relating to patients, I wondered if an illness event might be a sensitizing factor which would help pharmacists to initiate more empathetic relationships with their patients. Since I did

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not do a systematic comparison between men's and women's reactions to illness in pharmacy, it is not possible for me to say that the female members of this feminized profession are more successful in developing empathy than men after exposure to illness. However, I focused on women pharmacists because I believed that I heard them telling me about their struggles to "care" in their direct relationships with patients, based on their experiences with their other caregiving roles for children, parents, family members, and ultimately, themselves. The two male pharmacists in this study were neither directly involved in patient care nor caring for their families at the time of the interviews. The exploration of the role of gender in patient-practitioner relationships where the patient is a knowledgeable professional is a promising focus for future research in this area. Perhaps "[feminist reformulation...can help recapture the meaning and nature of caregiving" (Abel and Nelson, 1990:5).

6.1.2 Self-Identity and Relationships

The pervasiveness of science in our society is challenged by the critical feminist literature. Feminists have critiqued the medicalization of normal body functions (especially of women's bodies particularly childbirth and menopause). Relational feminists such as Carol Gilligan (1982), and Mary Belenky and colleagues (1986), have argued that women perceive the world in ways different from the way it is viewed in the currently-dominant science paradigm, which
is identified with a masculinist perspective (see Bleier, 1986). Being socialized to nurture and care, women often become caregivers in their homes.

Women pharmacists may experience a disjunction between their scientific education and their ways of caring in their personal lives. Caring for her child may be a consciousness-raising event for a woman, as it was for Eve, helping her to realize that she must care for herself before she can care for another (cf. Belenky et al., 1986). That consciousness may also be sparked as the result of an illness experience. In contrast to this orientation to caring, health care in our society is often provided in a detached, apparently uncaring way. The caregiver makes little attempt to engage the patient, also preventing real "caring," which is a reciprocal relationship between the "one-caring" and the "cared-for," in Noddings terms (1984). The indignation at this detachment was quite clear in the accounts of Nan and Irene, when speaking about the medical care that they received.

"Knowing the patient" is a prerequisite of advocacy by the caregiver and of empowering patients and families, according to Tanner and colleagues (1996), writing in the nursing literature. Yet the problem of physicians maintaining "social distance" was identified by several pharmacists who became patients; both Jane and Kate found it necessary to intervene as protectors for their mothers. When they were able to generalize this "empathetic advocacy" to those outside
their own families, they were able to transform their self-identity and their practice as well as their own personal view of what they were accomplishing in their work.

6.1.3 Pharmacists Narrate their Illness Experiences: Summary

During 18 semi-structured interviews, pharmacists of all ages, working in various sites, shared their stories of their illness experiences. From these accounts, transcripts were prepared and thematic analysis began. Three types of illness experience emerged. The first group comprised four pharmacists in whose families brief, acute illness events occurred (from which recovery was complete). As might be expected, they reported minimal impact on their patient relationships as a result of these exposures. In the next group were four pharmacists with chronic medical conditions and one whose brothers were diagnosed with mental illness. The four with chronic illness reported being more empathetic with their patients after the onset of the chronic condition; the pharmacist whose brothers were affected became more sympathetic to others suffering from mental illness. One pharmacist who became deaf also transformed herself, with the support of her family, into an "empathetic advocate" for other Deaf. The third group of illness stories was composed by pharmacists who faced life-threatening crises, either cancer or reproductive, in themselves, a spouse or parents. Several of these pharmacists reported a change in self-identity as well as changes in relationships with patients.
The grouping of illness narratives thus suggests an association between lack of personal exposure to illness and adherence to a detached attitude based on scientific principles of pharmacy practice vs. personal involvement and the growth of empathetic relationships after exposure to illness. The transformation to what is called here "empathetic advocacy" is rare, even after illness. In the clearest cases in this study, there were elements of social support, exposure to discrimination at work and opportunities to relate to patients in similar situations.

6.1.4 Antecedents to Change in Pharmacist-Patient Relationships

Various contextual and personal factors were considered as predecessors of change in the self-identity or patient relationships of pharmacists who became ill.

Professional activism did not prove to be a useful indicator. Four of nine pharmacists selected because of their involvement in professional education and association work underwent changes related to their illness experience. However, three of nine pharmacists who were not active in professional endeavours also reported changes as a result of their illness experiences.

External factors such as working conditions were considered as describing the context within which change or lack of change was possible. In some cases, attitudes towards patients after exposure to illness changed, although the participants felt that they had not yet realized these changes.
in practice. In an unanticipated twist, I found that participant accounts suggested that workplace stresses in combination with power and gender relations plus the degradation of work suffered by pharmacists during recent years may have contributed to their own illnesses. For example, those with musculo-skeletal complaints exacerbated by their working conditions were lacking in energy and motivation, and unable to pursue their professional practice as vigorously as they might have wished.

The personal acuity of the illness event was also considered. The most striking stories, in terms of personal transformation, are those of Irene, who lost her identity as a pharmacist when she became deaf; and Dale, who eventually lost her life to cancer. Gail's daughter's hospitalization and Eve's obstetrical emergency were similarly significant. They said that they had learned to care for others by caring for their children. This required them to care for themselves, thus changing the "objective" view that they had of themselves, and treating themselves as separate from their children. The opportunity for transformation provided by illness appears to be twofold: change in identity may be triggered by a threat to self but advocacy appears to be stimulated by becoming conscious of others who are similarly oppressed and taking active steps to address these problems in the workplace. These hypotheses about advocacy, in view of the
central importance of this concept in academic health promotion and health work generally, are worthy of further investigation.

6.2 A Model of Transformation

The narratives in this research suggest an outline of a model for transformation of self-identity stimulated by response to an illness event. The illness event must be one which directly affects or threatens the identity or life of the sufferer. Minor illness episodes do not trigger this response to threat when recovery is quick and complete. Time is required for the ill person to reflect upon the turn of events or bodily change; the presence of supportive others with whom reflection can be shared is an important contributor to transformation. Empathy begins with identification of self as like others who have been similarly labelled by the health care system. Recognition of the disempowerment inherent in this naming may surface or be subsumed, becoming denial, anger or resentment, in isolation. Identifying with similar others by a reflective pharmacist is the beginning of the transformation into "empathetic advocacy." The advocate rejects the "sick role" (if physically capable), assumes an autonomous, active role and becomes a champion, caring for and empowering those others who are less energized. By dialoguing with similar others, the empathetic advocate may avoid the risk of paternalism which accompanies the "informed consumer"
model. Only by caring for others in a relational manner, I believe, can pharmacists become effective patient advocates.

6.3 Implications for Pharmacists and Recommendations for Pharmacy Educators

When I began this research, I was motivated by a concern for both the patient and the pharmacist in the pharmaceutical care practice model. Legislating pharmaceutical care as a practice model does a disservice to both parties in what should be a caring relation, in my opinion. Encouraging pharmacy students to be more inclusive in their approaches to health (Muzzin, 1996) is a beginning of the development of a more holistic approach to patient care by pharmacists.

Caring in the sense of "taking care of", that is directed toward unknown recipients is already pervasive in health care today (Code, 1996). This approach to patient care values the objective information over the person, who becomes the object of care. Counselling patients to take their medication as directed, in compliance with physician instructions, is directed at patients as objects. If pharmacists are to re-gain their role in primary care, I believe they will have to become what Gilligan would call "relational" caregivers (cf. Gilligan and Pollak, 1988), respecting the person in his or her social context. I suggest that this can be accomplished by teaching pharmacists about pharmaceutical care in a relational way by modelling it to them.
Caring in education posits a reciprocal relationship between the "one-caring" and the "cared-for" (Noddings, 1984). This is a relational interaction such as that which I believe should occur in the pharmaceutical care practice model. I think that matching pharmacists with mentors is one way to develop this caring relation for ongoing educational purposes, since relational knowledge cannot be completely formalized (Tanner et al., 1996).

Another consideration that emerged from my interviews with pharmacists is the importance of sharing narrative experiences. As Charon states, "Listeners enable the narrative to be told" (1996:303) and telling reduces the chaos of events. Since the ability to reflect on one's experience appears so important in developing empathy with patients, I believe that accounts of their lived illness experiences as presented by actual patients should be part of the undergraduate pharmacy curriculum and also a component of continuing education programs for practising pharmacists. Such an approach would not replace the experience of choosing to care for an ill loved one or self, but it could serve as an enrichment to drug use knowledge in people's lives.

I hope to encourage other pharmacists to publish their own accounts of their illness experiences so that we all might share and learn. Through these 18 interviews, I met many compassionate pharmacists who are managing their afflictions and are still able to care for others, including this researcher. They could teach us all.
6.4 Pharmaceutical "Care" as an Area for Future Research

In this section, I go beyond the findings in the thesis to consider what a pharmacy education that encouraged relational caring would look like. This speculation follows from my personal experience of feeling helpless as a pharmacist at the time of my father's death.

This is an exploratory study of the meaning of illness to pharmacists and subsequent changes in their ways of relating to patients in their practice. Additional studies involving larger numbers may be required to research some of the ideas generated here.

As Lorraine Code points out, "[c]aring is fashionable these days, it's "in" (1996:1). According to alternative practitioners (Boon, 1996), one of the attractions of alternative medicine is the caring response that many practitioners provide, in addition to the time they spend with their patients. As pharmacists, if we are to avoid being paternalistic, we must cultivate relationships with the patients to whom we are providing pharmaceutical "care." How do patients perceive being cared for by the pharmacist in this practice model? If we are truly concerned about caring for patients, we must ask them how they value that care.
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APPENDIX A

Interview Questions for Key Informants

Have you or a family member experienced an illness recently?
How did you manage that illness?
How did you decide when to seek help from a physician?
How did you choose that physician?
Have you ever changed physicians because of something you've observed? What might provoke your concern?
How does the physician respond to your dual role as patient/patient advocate and pharmacist?
How do you respond if you do not agree with the physician's treatment? How do you decide when to intervene?
Has this experience affected your professional interaction with patients and physicians?

August 1995

What attracted you to pharmacy? When did you graduate?
How do you feel about pharmacy now?
What does being ill mean to you? Can you give me an example from your experience?
How does being a pharmacist affect your experience?
Can you describe your interaction with the health care system? Examples?
What you think about alternative medicine? Examples?
Disclosure - menopause/ hormone replacement therapy.
Are you practising pharmaceutical care? How would you describe your relationship with your patients?
How would you change your practice? Is this achievable?
What changes would you like to see in the profession of pharmacy? How would you bring these about?

February 1996
Approval by Review Committee on the Use of Human Subjects

Protocol Reference #451/95

Principal Investigator : Dr. L. Muzzin, Pharmacy
                      Ms. P. Sinnott, Student, Pharmacy

Title : Taking Their Own Medicine: How Pharmacists Experience Illness

Review Committee : Dr. S. Bowles, Pharmacy
                   Prof. B. Schlesinger, Social Work
                   Dr. A. Robertson, Behavioural Science

Documents Submitted to Review Committee : A protocol a consent form, a letter dated August 13, 1995 from Ms. Sinnott and a revised consent form.

Subjects : Pharmacists

Procedures : Approximately 20 tape-recorded interviews

Method for Obtaining Consent : Consent form, revised as attached.

Remarks :

Date of Approval : August 28, 1995

*During the course of the research, any significant deviations from the approved protocol and/or any unanticipated developments within the research should be brought to the attention of the Office of Research Services.

*A copy of this approval form is available to Review Committee members upon request.

SP/pp  

cc: Dean D. Perrier

Susan Pilon, Executive Officer
Human Subjects Review Committee
PHARMACISTS' EXPERIENCE OF ILLNESS

The purpose of the study is to learn more about how pharmacists manage personal or family illness, interact with physicians and how the experience of illness affects their professional practice.

The interview should last about an hour. It will be tape-recorded in order to preserve the accuracy of the information; however, you may refuse to be taped or request that certain portions of the interview not be taped. Tapes will be erased at the completion of the research. All information obtained in the course of the interview will be kept confidential vis-a-vis your identity and your location. Data will be stored securely. In final reports, information will not be attributable to you unless you wish certain quotes to be attributed to you. You are free to terminate the session at anytime or refuse to answer specific questions. Neither should you feel under any obligation to participate. Questions about the study and relevancy of the questions are welcome. If you wish, a summary of study results can be made available to you by calling Patricia A. Sinnott at (905) 985-3935.

(CONSENT FORM)

I have read the above study description and give my permission to be interviewed.

Name and Signature of Interviewee ________________________________

Date ________________________________

Thank you for participating in this study.

Patricia A. Sinnott, B.Sc.Phm.
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