UNDERSTANDINGS OF CANCER GENETICS: THE CASE OF COLON CANCER

by

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We accept this thesis as conforming
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Date 14 April, 2005
ABSTRACT

More men and women die every year from colorectal cancer (CRC) in Canada than from any other cancer with the exception of lung cancer (Canada 1997). The focus of this study is on the most common form of hereditary cancer in both men and women: hereditary nonpolyposis colorectal cancer (HNPCC) (Kinney, et al. 2000). The fundamental thesis of this study is that individuals who are genetically at risk for HNPCC employ healing emplotment, a narrative strategy, for constructing their autobiography and managing the lifelong threats to themselves posed by this unique cancer. This concept builds on other work in medical anthropology on illness narratives and therapeutic emplotment that focuses on the ways that patients and practitioners utilize narrative to interpret illness and therapies (DelVecchio-Good, et al. 1994; Good and Good 1994; Gordon and Paci 1997; Kleinman 1988; Mattingly 1989; 1994; 1998; Saris 1994; 1995; 1996). I argue that personhood is at the very heart of the healing process. Personhood is as a process for describing the ongoing negotiation between the self as the centre of experience and the cultural forces that surround it. Furthermore, just as Bourdieu (1990; 1995; 1999) discusses forms of symbolic capital in society, I have expanded upon the notion by recognizing the role of psychological and emotional resources in the concept of emotional capital. Emotional capital flows from personal connections with others: lovers, family, friends and it holds absolute value relative to all other forms of capital during fateful moments. The interviews in this study indicate that emotional capital is a fundamental part of individuals’ interpretations of their experience of genetic risk. Using ethnography and open-ended interviews with 33 individuals from 15 families at risk for HNPCC, this study examines the unique aspects of hereditary colon cancer and investigates the dynamic process people engage in to address the social and clinical threats posed by HNPCC. As well, 18 medical practitioners, primarily specialists in oncology, were also interviewed in order to obtain insight into clinician understandings of HNPCC and the relationship between medicine and clinical genetics.
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I would like to say another special thank you to all the members of my committee: Dr. William McKellin, Dr. Julie Cruikshank, Dr. Doug Horsman and Dr. Nancy Waxler-Morrison for their patience, guidance and support as I met them at the busy intersection of their disciplines. I have been fortunate to benefit from multidisciplinary feedback from the vantage points of a medical anthropologist, an anthropologist with expertise in oral tradition, a sociologist with expertise in the sociology of medicine and a physician with specialization in pathology and medical genetics. I would like to express my gratitude to my supervisor, Dr. William McKellin, who has provided me with many opportunities, expanded my thinking in many areas of anthropology and kept me on track all the way.

I would like to acknowledge Professor Ian Whitaker who was the teacher for my first anthropology course. His narratives about anthropology in the field and at home inspired me to read for my M.Phil. at the University of Cambridge and I remain thankful for his kind guidance on both sides of the Atlantic. I am eternally grateful for his mentorship, encouragement and friendship.

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Thanks to my son, Cole for his patience while his father burns the candle at both ends. And, now, we can finally learn to play guitar together.

Finally, thank you to my other self: Jenny Kwan for her support and love through the writing of this dissertation. It is she who has taught me about emotional capital and pure relationships.
CHAPTER ONE: INTRODUCTION TO UNDERSTANDINGS OF CANCER GENETICS: THE CASE OF COLON CANCER

Introduction

More men and women die every year from colorectal cancer (CRC) in Canada than from any other cancer with the exception of lung cancer (Canada 1997). The focus of this research is on the most frequent form of hereditary cancer in both men and women: hereditary nonpolyposis colorectal cancer (HNPCC) (Kinney, et al. 2000). This study suggests that HNPCC is unique among hereditary illnesses in terms of its social and clinical dynamics and that people at risk for it actively manage the impact of this illness in their lives before they themselves are actually diagnosed with the disease. The fundamental thesis of this study is that people at risk for HNPCC knowingly engage in healing emplotment: a narrative strategy for constructing their autobiography and managing the lifelong threats to themselves as persons in society posed by this unique cancer. This concept is developed from work on therapeutic emplotment in medical anthropology that focuses on the process by which practitioners and patients actively make use of narrative, with a plot-like structure, to help them guide and interpret therapies, treatments and clinical approaches to serious illness (Mattingly 1989; 1994). I argue that personhood is at the very heart of the healing process and that healing emplotment describes the ways that individuals manage the risks posed by HNPCC. Personhood is as a process for describing the ongoing negotiation between the self as the centre of experience and the cultural forces that surround it. For the people interviewed in this study, the significance of the risk for HNPCC is immense, and it does not present itself in their lives simply as a discrete disease experience. This study looks at the unique aspects of hereditary colon cancer and examines the dynamic process people engage in to
address the social and clinical threats posed by HNPCC using ethnography and open-ended interview techniques with 33 individuals from 15 families at risk for HNPCC. As well, 18 medical practitioners, primarily specialists in oncology, were also interviewed in order to obtain insight into clinician understandings of HNPCC and the relationship between medicine and genetics.

Another concept, emotional capital, is also introduced to interpret the results of this study. Emotional capital is derived from personal connections with important others: lovers, family, friends and it holds absolute value relative to all other forms of capital during fateful moments. It is a form of symbolic capital that holds absolute value relative to other forms of social capital developed elsewhere (Bourdieu 1990; 1995; 1999). Emotional capital provides the foundation for individuals’ interpretations of experience and the clinical narratives. This concept will be developed in Chapter Two.

**Analogous Qualitative Research**

This study grows out of a body of research into the social and personal impacts analogous to late onset conditions such as Huntington disease (Bloch, et al. 1992; Chapman 1992; Cox 1999; Huggins, et al. 1992; Kessler and Bloch 1989; McKellin and Burgess 1995; Tibben, et al. 1992), Alzheimer’s disease (McKellin and Burgess 1995; Smith 2000) and Breast and Ovarian Cancer (Gilbar and Florian 1991; McKellin and Burgess 1995; Hallowell 1999; Parker 1995; Richards, et al. 1995; Waxler-Morrison, et al. 1991) that examine the psychosocial aspects of illness. Its methods are taken from medical anthropology and it is influenced by research on illness narratives in this field (DelVecchio-Good, et al. 1994; Good and Good 1994; Gordon and Paci 1997; Kleinman 1988; Mattingly 1989; 1994; 1998; Saris 1994; 1995; 1996). The theoretical framework
for the study has been developed from writings about the relationship between illness experience, biology and suffering (Cassel 1982; Goffman 1986 (1963)) as well as some key theoretical debates about the relationship between individuals and culture (Bourdieu 1990; Bourdieu 1995; 1999; Giddens 1997).

**Background**

This is a very interesting time for research into hereditary colon cancer in this province in that the early genetic detection available in some regions of Canada is not available in British Columbia. This research examines people's experiences with HNPCC, how they cope with this disease in their families and how clinicians treat them before genetic testing is available. At present, families at risk for HNPCC in BC cannot access genetic testing services that could confirm their risk status unless they are willing to pay for this service privately in the United States. Some families know this and some do not.

**British Columbia Cancer Agency (BCCA)**

All of the individuals at risk for HNPCC and the oncologists interviewed in this study had some connection with the BCCA. The BCCA provides care for people faced with cancer through four regional cancer centres located in Victoria, Vancouver, Kelowna and Surrey (BCCA 1999). In partnership with regional hospitals, each centre provides diagnostic and assessment services, radiation, chemotherapy and follow-up care. Surgery for cancer occurs at hospitals throughout the province. The treatment of patients through the BCCA is broken into key areas of specialization called tumor groups. These tumor groups focus on specific types of cancer such as the Gastrointestinal Tumor Group (GI Tumor Group). The GI Tumor Group focuses on cancers that occur in the
gastrointestinal tract such as hereditary colorectal cancer. Within these groups, key specialists (radiation oncologists, medical oncologists, radiation oncologists) provide treatment. Referrals to the Cancer agency are made by a physician.

**Hereditary Cancer Program**

This study was launched under the umbrella of the Hereditary Cancer Program (HCP). The HCP is a joint initiative of the BCCA and the BC Provincial Medical Genetics Program (BCCA 1999). The HCP provides information and counseling regarding hereditary cancers to people and families with strong histories of cancer. During the course of this study, they provided genetic testing for hereditary breast cancer but not for HNPCC. People are referred to the HCP by their physician.

As part of the field research, I participated as a member of the Hereditary Cancer Program Case Conference Committee for four years. The HCP provided clinical background for the study as well as a glimpse into the interplay between clinical genetics and medicine. The HCP is a multidisciplinary team of professionals made up of oncologists, surgeons, nurses, laboratory technicians, genetic counselors, a medical anthropologist, a philosopher bio-ethicist and graduate students from various disciplines. The HCP reviews the cases of individuals with family cancer syndromes and often makes decisions about who receives genetic services and how such services are to be delivered. My analysis of the interviews with oncologists and family members has been informed by the contextual research that I conducted at the HCP.¹

¹ Fluency in the language of the groups under study increases my access to and understanding of important data (Bernard 1995). In this case, medical practitioners applied the languages of genetics and medicine to construct their conceptual world about HNPCC. The process, by which the reality of genetic illness and medicine is assembled, served as a point for analysis in this research project. I attempted to familiarize myself with much of the terminology associated with the genetics of HNPCC through background reading (and by attending clinical conferences) and by being immersed in the field itself, as a participant observer, to observe language as it is being used in a clinical context.
The Research Setting

Upon receiving ethical approval for the study at both the BCCA and the University of British Columbia, attempts were made to recruit participants for the study from three key areas:

- The Hereditary Cancer Genetics Counseling Programs in Vancouver and Victoria
- The Colon Cancer Support Group
- The GI Tumor Group

GI Tumor Group

The GI Tumor Group is a group of clinicians, mostly oncologists, at the BCCA that specialize in treating diseases of the gastrointestinal tract. The group meets weekly in order to discuss problematic or unusual cases. The group seeks input from key specialties of oncology on the treatment, management and prognosis of diseases in particular patients. HNPCC is one of the unusual diseases that occurs in the gastrointestinal tract that would be discussed by the GI group.

I observed many of the GI Tumor meetings over the course of two years. These meetings provided some insight into the institutional arrangements of the BCCA in terms of tumor groups. It also provided a look at the clinical specialties of oncology. In the end, some of the participants in the GI Tumor Group were interviewed for the study. A discussion of the interviews with clinicians from the GI Tumor Group as well as an analysis of their weekly meetings is provided in the chapters on the Institution and Clinical Narratives of this thesis.

Initially, it was hoped that some of the oncologists interviewed for the study, especially those from the GI Tumor Group, would refer some of their patients to the study for interviews. This did not happen for several reasons. Firstly, many oncologists
do not distinguish between HNPCC and sporadic colon cancer with regard to treatment. Most do not track HNPCC and some are not sure whether they have ever treated a patient with HNPCC. When questioned in interview, many interview participants pause to think about the epidemiological likelihood that they have treated someone with HNPCC and then conclude that they probably have, but many are not sure. Therefore, it became clear that most oncologists could not refer patients with HNPCC because they do not track them. Genetics was not seen as relevant to the everyday practice of medicine for these clinicians. It was understood to be the responsibility of another program or of someone else. More particularly, addressing it was seen as the duty of the HCP. This appeared to be a part of the institutional arrangement of the BCCA and health care services. These arrangements will be examined in Chapters Three and Six. In the end, no referrals came from GI Tumor Group or from any of the physicians interviewed. A basic question emerged in the early research: ‘where are all the HNPCC families?’ This question was directly asked of clinical participants in the interviews and their responses are examined in chapter six.

Colon Cancer Support Group

I also gathered information from the individuals who tried to form a support group. The Colon Cancer Support Group had its first meeting as this research project officially began after my comprehensive examinations. I attended the first few meetings that were sparsely attended by less than half a dozen people each time. The group was typically comprised of between two and four people who had been diagnosed with colon cancer in addition to myself and an oncology nurse. After only four meetings the group ceased to meet after the main initiator of the group, a retired man who had experienced
colon cancer, began to experience some health complications and discontinued his involvement. Recruitment from this area was limited to two participants who were interviewed before the collapse of this fledgling group.

**Regional Hospitals**

The study began in the offices of oncologists who were interviewed in order to gain a sense of the clinical perspective and the impact of clinical genetics on medicine. None of these oncologists referred their patients to my study. In the course of my research I observed two distinct though interrelated cultures\(^2\): the culture of medicine and the culture of clinical genetics. I was particularly interested in the impact of these two cultures on the experiences of patients and families. I interviewed patients and family members in their homes and clinicians in their work environment.

**Other Jurisdictions**

The field research also included travel to other jurisdictions in order to acquire a sense of the national and international context with regard to research and services relating to HNPCC. Within Canada, a trip to the Genetics Counseling Program at Mount Sinai Hospital in Toronto, Ontario, was taken in order to contrast BC with a province that provides genetic testing and counseling services for HNPCC. Outside Canada, a trip to the United Kingdom included visits to the Centre for Family Research at the University of Cambridge and Addenbrooke’s Hospital in Cambridge England\(^3\). Professor Martin

\(^2\) Influenced by interpretive anthropology, I see culture as a collectively understood system of meaning that social actors utilize to symbolically construct their semantic worlds. I do not intend to reify the notion of culture here. There appear to be hot spots of meaning negotiation that occur in medicine and genetics that sometimes overlap (especially in the HCP) but are nevertheless, as a rule, disunited. This issue will be discussed more fully in Chapter 3.

\(^3\) The research trip to England also provided an international comparison point with regard to academic thinking about genetic and clinical services for families at risk for HNPCC. Dr. A. Jamie Saris, Department of Anthropology at St. Patrick’s College in Maynooth, Ireland was also visited in order to
Richards, Head of the Centre and a leader in research into the psychosocial effects of hereditary cancer syndromes, provided an overview of the relevant work in the United Kingdom. Dr. David Huntsman, a pathologist and geneticist, provided an overview of genetic testing and medical research into HNPCC at Addenbrookes Hospital. Local clinics that provide support services for families with hereditary disorders have been in existence in England for fifty years and genetic testing for HNPCC is available throughout all of England without a lengthy waiting period. Ontario has had a colon cancer registry since the 1980’s and offers province wide genetic testing and counseling for HNPCC for Ontario residents.

Recruitment

Initially, it was very difficult to connect with patients and families affected by HNPCC. According to epidemiological estimates there should have been many families with HNPCC but no one seemed to be tracking their existence. The HCP was not providing testing for HNPCC so oncologists did not appear to be consistently referring patients to the program. My interviews with oncologists soon revealed that they were not distinguishing patients with HNPCC from those with sporadic colon cancer. Furthermore, those families who were thought by oncologists to have HNPCC were not being told about this likelihood. Rather, they were more likely told that they had a strong family history or a family cancer syndrome. The question that was ever-present in the early part of the research was where are all the HNPCC families and how do I connect with them?
The study started out by examining the notion of lay-perspectives\(^4\) in comparison with professional perspectives. Ultimately, this turned out to be a problematic dualism in light of the complexity of lay-perspectives. I learned through the course of my research that the lay-perspective is a much larger category under which information from professionals (clinical and genetic) is often incorporated as a part. As well, the families were spread out across the country and it appeared that in most families someone had had direct contact with a specialist with expertise in genetics.

In the end, a total of 51 subjects comprised of 33 family members from 15 families (see Table 1) and 18 clinicians and experts (See Table 3) from a variety of specialties were interviewed for this study (See Table 1 and 3 below). Recruitment of participants for the study was challenging because people at risk for HNPCC are not being consistently tracked in British Columbia. As a result, the recruitment of the subjects for this study was not random. All referrals for patient and family participants came from genetic counselors who are directly associated with the HCP. The people who were referred had had some contact with the HCP and were thought to have a mutation for HNPCC. The pedigree shown below of a family with a mutation for HNPCC illustrates that a lot of people can be affected by the risk for a genetic mutation in a family:

\(^4\) Initially, I was concerned about the fact that some of the participants would have their “lay-perspectives” contaminated by the information that they received in a genetics counseling session. However, it became apparent that all the families had had extensive exposure to genetic knowledge. In fact, it became difficult to imagine such a tabula rasa family existed with respect to genetic knowledge. Families were spread out over the country and over time. All the families had some sort of access to genetic knowledge, genetic testing (in some other part of the country) or genetic counseling. These families had a tremendous amount of experience with colorectal cancer. Before having HNPCC identified as a possible description of their CRC, they had often been labeled as “family cancer syndromes”. Regardless of the diagnostic label, they understood from their experience that their families had a higher risk for colon cancer based on their very real experience over generations. As a result, the notion of the study being based on a “before and after” or “pre and post” exposure to a genetic counseling or testing was abandoned as inappropriate. What became more interesting, was how people understood their family’s experience with cancer, its impact on their personal and family identity and what strategies they employed to accommodate their experience.
Figure 1: Pedigree

(Adapted from Chen et al. 2001: 270)
However, this study tended to be restricted to one part of a family as illustrated by the example pedigree below:

Figure 2: Pedigree

If these people have not had genetic testing, then every one of them needs to have regular clinical surveillance (colonscopy). If they are tested for a mutation for HNPCC and found to be negative, then they (and their children) are spared from having to endure the invasive yearly colonoscopy.

Table 1: Participants: People at Risk for HNPCC

<table>
<thead>
<tr>
<th>SUBJECTS</th>
<th>NUMBER</th>
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<tr>
<td>At Risk</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>9 Female</td>
</tr>
<tr>
<td></td>
<td>0 Male</td>
</tr>
<tr>
<td>Spouses</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>5 Female</td>
</tr>
<tr>
<td></td>
<td>2 Male</td>
</tr>
<tr>
<td>Affected</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>9 Female</td>
</tr>
<tr>
<td></td>
<td>7 Male</td>
</tr>
<tr>
<td>Sporadic</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>0 Female</td>
</tr>
<tr>
<td></td>
<td>1 Male</td>
</tr>
<tr>
<td>TOTAL FAMILY MEMBERS BY GENDER</td>
<td>23 Female 10 Male</td>
</tr>
<tr>
<td>TOTAL FAMILIES</td>
<td>n = 15</td>
</tr>
<tr>
<td>FAMILY MEMBERS</td>
<td>n = 33</td>
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</tbody>
</table>
Family members were interviewed from the Lower Mainland ranging from North Vancouver to White Rock and Aldergrove, Victoria and the surrounding areas, and the interior of BC. Participants were drawn from large urban centres as well as from small towns and rural areas. The geographic range of the interviews gave a sense of some disparities between experiences of families in rural and urban settings especially with regard to access to services. The age range was between 30 and 76 years of age and the group was, on the whole, well-educated (see Table 2). All participants were Euro-Canadian and there were no visible minorities in the interview sample. As a result, this provides the study with some limitations in terms of generalizability.

Table 2: Highest Education Level

<table>
<thead>
<tr>
<th>EDUCATION LEVEL</th>
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<tbody>
<tr>
<td>Grade 11</td>
<td>1</td>
</tr>
<tr>
<td>High School Diploma</td>
<td>5</td>
</tr>
<tr>
<td>Trade Certificate</td>
<td>2</td>
</tr>
<tr>
<td>College Certification (e.g. Medical Office Assistant)</td>
<td>3</td>
</tr>
<tr>
<td>Bachelor Degree</td>
<td>4</td>
</tr>
<tr>
<td>3 Years of University</td>
<td>1</td>
</tr>
<tr>
<td>University Certification (e.g. Chartered Accountant, Engineer)</td>
<td>3</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>3</td>
</tr>
<tr>
<td>Medical Doctor</td>
<td>1</td>
</tr>
<tr>
<td>Lawyer</td>
<td>1</td>
</tr>
<tr>
<td>Ph.D.</td>
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In addition, I interviewed one individual who was affected with sporadic colorectal cancer. This individual was interviewed about his attempts to initiate a colon cancer support group and gave me a sense of the experiences of people with sporadic colon cancer. I learned of the experiences of people with sporadic colon cancer by participating in and observing the short-lived colon cancer support group. In particular, I listened to three women who had been diagnosed with sporadic colon cancer describing their experiences. These conversations were not structured interviews and were not taped (field notes were kept).
Referrals to the study for clinical participants came from the Clinical Director for the HCP. The clinicians who were interviewed were employed within the BCCA as oncology specialists or they worked in regional hospitals where they receive referrals from the Agency. The Clinical Director for the HCP was also interviewed for the study.

Table 3: Participants: Clinicians and Specialists

<table>
<thead>
<tr>
<th>CLINICIANS</th>
<th>NUMBER</th>
<th></th>
<th>gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Oncologists</td>
<td>3</td>
<td>2 Female 1 Male</td>
<td></td>
</tr>
<tr>
<td>Surgical Oncologists</td>
<td>3</td>
<td>0 Female 3 Male</td>
<td></td>
</tr>
<tr>
<td>Radiation Oncologists</td>
<td>4</td>
<td>1 Female 3 Male</td>
<td></td>
</tr>
<tr>
<td>Oncology Nurses</td>
<td>1</td>
<td>1 Female 0 Male</td>
<td></td>
</tr>
<tr>
<td>Genetic Counselors</td>
<td>2</td>
<td>2 Female 0 Male</td>
<td></td>
</tr>
<tr>
<td>Gastroenterologists</td>
<td>1</td>
<td>0 Female 1 Male</td>
<td></td>
</tr>
<tr>
<td>Researchers</td>
<td>2</td>
<td>0 Female 2 Male</td>
<td></td>
</tr>
<tr>
<td>Pathologists</td>
<td>2</td>
<td>1 Female 1 Male</td>
<td></td>
</tr>
<tr>
<td>TOTAL CLINICIANS</td>
<td>7 Female 12 Male</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The clinicians were interviewed in order to develop a fuller understanding of the experiences of the patients and families. It turned out that the interaction with the medical and genetic world was not as large an influence on the lifeworld of the families as I had initially imagined.

Methods

Person-Centred Ethnography

Ethnography⁵ was well suited as a method for studying many of the issues surrounding genetics and genetic susceptibility to illness. For example, an ethnographic

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⁵ Ethnography can be defined as follows: "As a noun, it means a description of culture or a piece of culture. As a verb, it means the collection of data that describe a culture" (Bernard 1995: 16-17). I assume that ethnography is both a "product and a process" (Tedlock 1991: 72). Ultimately, the aim of this research is
approach is useful for examining some of the ethical issues associated with genetic services for HNPCC. There is a distinction between lived and theoretical ethics. Theoretical ethics typically relies upon assumptions of individualism whereby patients and professionals are supposed to enter autonomously into contractual relations voluntarily which are independent of their social context. These assumptions tend to underplay the importance of the social context which, in actuality, has a dramatic effect upon decision making. Bio-ethicists, then, typically discuss which ethical decisions individuals ought to make. For example, medical ethicists analyze theoretical ethical situations and have therefore removed themselves from the lived experience of the patient (Burgess 2001; Conrad 1994; McKellin and Burgess 1995). In contrast, my study relies upon ethnographic methods, that is participant observation and interviewing, in order to see how people make ethical decisions in the context of the BCCA. Ethnographic methods were used for exploring the HCP and the GI Tumor Group at the BCCA.

While this study is concerned with healing narratives, it also focuses on the circumstances of narrative production. For professionals, narratives are inextricably entangled within an institutional topography. The recounting of clinical narratives took to produce a narrative ethnography. In contrast to ethnographic memoirs that centre on the writer, narrative ethnographies combine the experiences of the researcher with rich ethnographic detail, reflexive examination of the fieldwork encounter and an analysis of culture. I attempt here to describe both the qualities and the process of the ethnographic discourse or event so that both the "ethnos in ethnography and the graphia—the process of writing" are included as part of the dissertation (Tedlock 1991: 79).

6 More precisely, this investigation will employ observation of participation rather than participant observation, thereby moving away from the exclusive examination of either of the self or the other towards an analysis of both the self and the other as they engage in an "ethnographic dialogue" (Tedlock 1991: 69). As part of this research, I attempt to attain a level of intersubjectivity or bicultural familiarization with the subjects of my study.

7 I rely upon Saris's (1995: 42) notion of an institution as the working definition before developing this concept further in the discussion. Institutions assist and constrain the production of narratives: "...bundles of technologies, narrative styles, modes of discourse, and, as importantly, erasures and silences. Culturally and historically situated subjects produce and reproduce these knowledges, practices, and silences as a condition of being within the orbit of the institution. This definition of institution focuses our attention on the ability of the institution to define and
place against a complicated landscape at the BCCA. I have tried to be aware of influential ambient factors such as institutionalized arrangements, an awareness of moral tensions, commentaries on suffering and power relations. The data in this study are comprised primarily of narratives collected through in depth one on one interviews. The results of these interviews were transcribed word for word and included, whenever possible, accurate transcriptions of colloquial words, informal utterances such as “uhms” as well as pauses each of which sometimes held important information such as emotional emphasis.

My approach employed person-centred ethnography, an approach aimed at digging deeper at the understandings and experiences of social actors. Approaches based on person-centred ethnography attempt to get nearer to experience in order to describe the interplay between the cultural outer world and the subjective inner world. Person-centred ethnographies allow for the exploration of the phenomenologically and culturally constituted world of social actors by utilizing extensive open-ended interviews. In contrast to a traditional ethnography that produces a larger scale illustration of a community, akin to a cultural satellite picture of the area of interest, person-centred ethnography explores the issues that are most meaningful to the participants. Furthermore, I attempted to explore the important emotional and meaningful cultural forces as they directly impact upon people’s agency and experience with cancer rather than to assume the presence of cultural forces that are presupposed to be present in some abstract form. The exploration of the personally and culturally constructed world of the patients and family members in this study has been investigated through flexible,

constitute as well as on the silences and erasures that provide the persuasive forces for such institutions. [emphasis added]"
open-ended and participant-driven interviews in order to see what is consequential for these individuals in their everyday experience. This method allowed me the opportunity to detect the elaborate and changing experiences of these very real human subjects. With respect to illness, this method allowed me to examine the way that the subjective experience of cancer is embodied and concurrently embellished by the culture into the self and, ultimately, into the ongoing construction of people’s personhood (Hollan 2000).

**Storytelling in Open-ended Interviews**

The majority of studies that analyze the psychosocial aspects of cancer rely upon instruments that yield quantitative data, such as structured interviews, standard scales, and systematic questionnaires, rather than qualitative approaches that might be able to shed light on the issue of validity (Gilbar and Florian 1991; Greendale, et al. 1994; Waxler-Morrison, et al. 1995). These standard instruments are typically aimed at generating quantitative data in order to test hypotheses. In contrast, qualitative studies are especially useful for identifying new areas for investigation and are typically utilized for “discovery, not verification” (Waxler-Morrison, et al. 1995: 180).

The study of stories, individual illness episodes, descriptions of the overall illness experience, and the context within which the illness occurs, that is, in the lives of individual sufferers and their family, provide medical anthropologists with a tremendous scope for examining the ways in which narratives give shape to illness experience. The accounts which people give of their experiences in interview settings typically bear similarity to stories in that they exhibit the essential elements of narratives (Mishler 1996).⁸ By carefully examining people’s narratives, I have attempted to uncover the

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⁸ Traditional surveys and interviews tend to restrain story telling and narrative communication (Mischler 1996). As a result, the amount of narrativity which occurs in standard interviews is not actually known.
“cultural scaffolding” of people’s understandings of hereditary colon cancer (Cruikshank 1998: 27).

**Medical Anthropology**

This investigation is situated within the field of medical anthropology. Medical anthropology is concerned with the complex interactions between individuals, their bodies and social institutions. In medical anthropology, disease is used to refer to biological pathologies, illness describes the unique ways in which disease is brought into individual consciousness, while the concept of sickness applies to the process by which disease and illness are socially constructed to take on culturally appropriate expressions (Robinson 1990; Young 1982). The narratives collected in this study show that while these are useful analytical categories of disease, the phenomenological characteristics of these three aspects of illness events are not experientially separate. Here, the focus of study is the relationship between culture and illness whereby “disease is not an entity but an explanatory model” (Good 1996: 6). Early architects of the meaning-centred approach asserted that the medical system is a distinct part of the cultural landscape and is therefore constructed, just as are other components of social reality, by a collection of symbolic meanings⁹ (Kleinman 1973). Within this socio-cultural setting, the medical complex does not simply identify, categorize and react to illness.¹⁰

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⁹ A further example of this reasoning can be extended to the notion of efficacy as well whereby: “Efficacy, itself, is a cultural construct. The healing dialectic has been considered effective when the bonds between the sick individual and the group, weakened by disease, are strengthened, social values reaffirmed, and the notion of social order no longer threatened by illness and death; or when the individual experience of illness has been made meaningful, personal suffering shared, and the individual leaves the marginal situation of sickness and has been reincorporated in health or even death into the social body. Healing is
Some medical anthropologists have suggested that patients and their family members retain a number of narratives, with rival plots, in order to explain their illness (Good and Good 1994). They may make use of subjunctivizing strategies (strategies that point to a future filled with potential, hope, and multiple possibilities) (Good 1996). In this study, I interviewed clinicians, patients and family members in order to explore the various narrative strategies that they create and to examine the purpose of these techniques. My research design relied upon unstructured interview techniques in an attempt to allow people to take a leadership role in defining the questions and issues, to speak in their voice as much as possible, and to elaborate on their perspectives. Whenever possible, I attempted to let the interviewees maintain control of the direction of the conversation.

**Sporadic**

Colon cancer is a common disease. It is the second leading cause of cancer death in Canada. According to the BCCA (BCCA 1999), six per cent of people will develop colon cancer at one point in their lives. The incidence of colon cancer in men was approximately 54 per 100,000 in British Columbia in 1997 (See Appendix I). The incidence for women was around 34 per 100,000. In Canada, the combined incidence for

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9 The interpretive paradigm, however, does not dispute the importance of biology; instead, it accentuates the interactionist and relativist approach where physiology, social customs and meaning interact in order to organize illness as both a social phenomenon and a lived experience (Good 1996). Rather than simply focusing on illness representations, then, the meaning-centred paradigm centres on the investigation of how various interpretations and understandings of illness interact with social, psychological and biological forces in order to produce unique manifestations of illness. Thus, my research, under this theoretical orientation, is aimed at examining the many ways in which social relations, clinical constructions of medical objects and cultural interpretations interact and ultimately influence individual perceptions of the clinical services and the experience of hereditary colon cancer itself.

10 Sporadic refers to the non-genetic form of cancer that occurs in the general population and for which there is no known genetic mutation.
men and women was approximately 50 per 100,000 in 1997 (Canada 1997). There were an estimated 1,950 new cases of colon cancer in British Columbia in 1997. Roughly 6,000 people died of colon cancer in Canada 1997. The mortality rates for colorectal cancer are estimated at 23 for men and 14 for women per 100,000 in Canada. In British Columbia, the mortality rates are estimated at 18 for men and 11 for women per 100,000.

**Clinical Surveillance**

The most crucial prognostic indicator of colorectal carcinoma is the extent to which the tumor has developed at the time of diagnosis. In general, the cancer is highly treatable by resection, but in 25 to 30 per cent of patients the disease has spread beyond the range of curative surgery at time of discovery (Robbins, et al. 1994). There are several typical types of clinical screening for colon cancer: digital rectal exam, fecal occult blood testing, barium enema, sigmoidoscopy, flexible sigmoidoscopy, colonoscopy and virtual colonoscopy (see Appendix III). The techniques are often combined, such as fecal occult blood testing and sigmoidoscopy. Clinicians vary their use of these tests based on their judgment of the urgency of the case, the effectiveness of the test in detecting the signs of CRC, the invasiveness of the procedure and the availability of equipment (sigmoidoscope or colonoscope).

The colonoscopy is the most effective screening and diagnostic test for CRC. In the case of HNPCC, it has been shown in a 15 year trial to cut the risk of CRC by 50 per cent, to prevent deaths due to colorectal cancer and lower overall mortality in families affected by HNPCC by 65 percent (Jarvinen, et al. 2000). While it is the most effective

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12 Please refer to Appendix 1 for a more detailed illustration of the estimated incidence and mortality rates of colon cancer in comparison with other cancers.

13 The tests are described in more detail in Appendix 2 and give the reader some sense of the types of clinical surveillance techniques that are experienced by people at risk for HNPCC.
surveillance technique, it is very invasive and has to be administered by a highly trained clinician such as a gastroenterologist or a specially trained general practitioner. Individuals who have undergone genetic testing for HNPCC and received a negative test result have their risk reduced to that of the normal population and are spared from having to undergo unsettling procedures and rigorous clinical surveillance. Genetic tests are typically administered as a blood test by a medical geneticist while the clinical surveillance is performed by a medical clinician. Unlike the less effective screening tests such as the fecal occult blood test, the colonoscopy is not covered as a preventative screening test by the provincial health plan. It is only covered when clinically indicated. According to the interviews with people at risk for HNPCC they sometimes encounter problems obtaining a colonoscopy because they do not appear to have any clinical signs of the disease that would warrant it medically. There is a lengthy waiting list for the procedure and many communities do not have a colonoscope.

**Hereditary Forms of Colorectal Cancer**

The BCCA sees approximately 2,200 cases of colorectal cancer each year, of which five to ten per cent are due to hereditary cancer predisposition syndromes (Huntsman 1996). While environmental factors are believed to be significant in the etiology of the majority of colorectal cancers (sporadic colorectal cancer), two forms of hereditary colon cancer, HNPCC and familial adenomatous polyposis (FAP) account for between five and ten per cent of these instances (Blackburn and Giardiello 1992; Hardcastle 1993).

The social and clinical dynamics of hereditary colon cancer appear different from those of other diseases. In contrast to other late onset genetic conditions for which there
is a test available such as Huntington’s disease, breast and ovarian cancer, support groups do not exist for hereditary colon cancer in B.C. and the site of the cancer itself may contribute a dimension of stigma that restricts the development of support groups. Furthermore, unlike other genetically determined cancers for which there are only limited therapies available with unproven effectiveness, genetic testing for proneness to hereditary colon cancer can lead to early detection and effective treatment with surgical intervention (DeCosse 1995). By raising awareness of risk and increasing the vigilance of clinical surveillance, genetic testing for HNPCC could help to prevent people from dying of colorectal cancer. It could also spare some individuals from families with family cancer syndromes the discomfort of invasive surveillance techniques such as the colonscopy.

Colon cancer is usually a disease of the elderly. Forty-five per cent of all new cases of cancer and fifty-six per cent of deaths attributed to colon cancer in Canada occur in individuals who are seventy years of age or older (Canada, 1997). However, familial colon cancer is different. In contrast to sporadic colorectal cancer, which occurs around age 70, HNPCC manifests itself at an earlier stage in a person’s life, typically around 40 to 50 years of age. Individuals with HNPCC are also at a higher risk for ten other cancers: endometrial, ovarian, bladder, breast, kidney, larynx, pancreas, stomach, small bowel, and ureter (Blackburn and Giardiello 1992; Li 1995). As a result, HNPCC is most accurately referred to as a syndrome given that it does not only refer to genetic susceptibility to colorectal cancer but also a number of other cancers.\textsuperscript{14}

\textsuperscript{14} Following this logic, although I recognize that HNPCC is more accurately described a syndrome, I use HNPCC rather than hereditary nonpolyposis colorectal cancer syndrome throughout the dissertation for brevity.
In the case of HNPCC, inherited mutations in one of five DNA mismatch repair (MMR) genes (MSH-2, MSH-6, MLH-1, PMS-1, and PMS-2) have been identified that bring about this cancer (Syngal, et al. 2000). Mutations in MSH-2 and MLH-1 account for over 95% of HNPCC families (Burt 2000). The penetrance\(^{15}\) for HNPCC is high; people with these genetic alterations have approximately a 70 per cent chance of developing this colorectal cancer. Some clinicians suggest that the treatment of choice for the prevention and treatment of inherited colorectal cancer should involve a total colectomy (DeCosse 1995; Schofield and Martin 1993). With the advent of genetic testing, one of the difficult issues that emerges for people at risk is to consider the possibility of prophylactic colectomy.

HNPCC is unusual among genetic illnesses in that careful surveillance and early detection can, unlike other diseases such as Huntington’s or hereditary breast cancer, lead to effective medical interventions that are highly effective for people at risk for colon cancer (Jarvinen, et al. 2000). To put it simply, if a genetic mutation and the related cancer are detected early, individuals with mutations for HNPCC are unlikely to die from colon cancer. Despite this optimistic prognosis, colon cancer still remains the second leading cause of cancer death in Canada. Yet, if it is not detected early, people almost certainly die from this disease.

**Qualitative Research on Advances in Genetics**

The research was driven by findings from previous research on analogous genetic conditions that suggested that there may be a fundamental incongruity between the perspectives of genetic service providers and the people who utilize these programs.

\(^{15}\) Penetrance refers to the likelihood that individuals who have inherited the faulty gene will develop the condition.
(Richards 1997). The more precise nature of lay-perspectives on inheritance and on the social dynamics that affect them have not been adequately studied (Richards 1993). Those studies that do exist tend to compare and contrast lay perspectives with medical points of view (Davidson, et al. 1989; Davidson 1996; Richards 1997) or attempt to classify them (Henderson and Maguire 2000). While this study provides direct data on lay-perspectives it also raises some questions about the accuracy of the conception of lay versus expert perspectives.

There are several features of genetic testing which make it culturally unique (Davidson 1996; McKellin and Burgess 1995). Firstly, genetic information about future illness can be provided at an extremely early point in a human’s life. Secondly, genetic aspects of personhood can be transferred inter-generationally. Thirdly, DNA information offers a biographical blueprint of personhood. Finally, there is a shared heritage to genetic material that may have a dramatic effect on kinship and family identity. Advances in genetics have transformed screening technology from an earlier point when it was used for the early detection of disease to the point of identifying a “latent or pre-clinical phase” (susceptibility in people who have not manifested the disease) (Goel 2001: 1176). In the case of HNPCC, this means that a genetic test tells someone well in advance that they have an extremely high likelihood of developing cancer.

Genetic tests offers the potential benefit of identifying high-risk groups by providing them with increased clinical surveillance that can reduce morbidity and mortality (Evans 2001). For example, predictive testing demonstrates certain clinical

\[16 \text{ The possibility for social exclusion (i.e. vocationally or with respect to health insurance due to illnesses that are not yet manifested ) looms in the background with DNA based information (Davidson 1996). In the future, Galton’s eugenics and the related drive for human classification may be re-awakened under the} \]
utility in the case of HNPCC where regular surveillance with colonoscopy of people at risk reduced their development of cancer by 62 per cent (Evans 2001; Jarvinen, et al. 2000). However, in many instances, such as the case of breast or ovarian cancer, the provision of genetic information about an inherited predisposition does not lead to a clear-cut reduction of risk (Evans 2001). Yet, during the course of this study genetic testing was available for breast cancer but not for colon cancer in British Columbia thereby providing support for the suggestion that genetic testing services are sometimes implemented without substantiated clinical benefit (Burgess 2001).

The identification of genetic mutations that confer a high risk for breast, ovarian and colorectal cancer have sparked debate in the medical field about the core of clinical practice with respect to whose responsibility it is to provide services for people at risk for these diseases (Donnai and Elles 2001; Greendale and Pyeritz 2001). This debate is further fueled by the suggestion confirmed in the findings of this study that there do not appear to be enough programs or experts in medical genetics to provide services to those at risk for these diseases. There does not appear to be a large enough “genetic workforce” to cope with the needs of diseases presently massed together under the umbrella of medical genetics as the demands on the primary care physicians and the health care system increase (Greendale and Pyeritz 2001: 224). While it appears that primary care providers are the most logical candidate (family physicians, pediatricians, obstetricians or general internists) to expand their role to include medical genetics serious questions remain about the adequacy of their knowledge base and clinical practice with respect to genetics (Emery, et al. 1999; Pinsky, et al. 2001). In fact, in a recent study it

guise of a bio-technical mandate to improve the human gene pool (and possibly discriminate against people with particular genetic backgrounds) (Rabinow 1993).
was found that a family history of cancer, the primary tool for the assessment of genetic illness, was only taken in 51 per cent of interviews with new patients and only 22 per cent of interviews with longer term patients (Acheson, et al. 2000).

Social scientific research on genetic testing suggests that social variables outside the clinic, such as family dynamics and commitments, profoundly affect whether people seek out genetic services and, if so, how they will ultimately utilize the information provided (Burgess and d'Agincourt-Canning 2001; McKellin 1997). These findings have led ethicists to reconsider the basic tenets of ethics by examining the impact of “relational responsibility” or “commitments to others” in clinical practice and ethical analysis (Burgess and d'Agincourt-Canning 2001: 24).

Provision of information through genetic services does not appear to change people's pre-existing ideas about inheritance. People are more likely to recall information that is consistent with their pre-conceived notions (Shiloh and Berkenstadt 1992). The precise way in which information is communicated to individuals by professionals is important. People tend to have difficulty in understanding information that is presented statistically\(^{17}\). Verbal descriptions tend to have a more powerful impact on people (e.g. ‘the risk is dramatic’ or ‘the results are striking’)\(^{18}\) (Shiloh and Sagi 1989). Pre-existing ideas about inherited illness are a key area for this study.

Changes in a person’s risk status for an inherited disorder, brought about by testing, may have profound implications for the identity of an individual or that

\(^{17}\) It is rare to find people who describe inheritance in scientific terms. This includes people who have undergone genetic testing and counseling. It appears that many individuals who seek genetic counseling do not have any previous knowledge of chromosomes or genes and attempts by counselors to educate them with respect to these terms seems to confuse clients (Richards et al. 1995). Lay accounts do not typically specify how inherited features are passed on (division of genetic material in the formation of eggs and sperm, their union in the zygote with the fusion of two sets of chromosomes).
individual's family (Chapman 1992; Richards 1993; Wilke 1995). However, several issues remain under-examined. How are children prepared for the possibility of genetic susceptibility to illness? What rival models do people have for understanding illness and guiding their behavior with regard to genetic information and treatment? How are various family dynamics affected by genetic susceptibility to illness and genetic information? How are people pressured or prevented from seeking genetic information by family members? Genetic testing and counseling services may necessitate the reconnecting of family members who have not been in contact with one another for a long time. What is the purpose of genetic and clinical information for families and how do they use it? The qualitative methods employed in this study have been useful for exploring these issues and offer some insight into how family members communicate about inherited illness.

Research on analogous diseases such as Huntington’s disease (HD)\(^{19}\) and hereditary breast cancer is useful for demonstrating the differences between the predictions of service providers regarding the utilization of genetic testing and counseling services and the actual practices of service users. Before testing was available for HD, surveys were administered in Britain to people who had a 50% chance of developing the disease. On the basis of these surveys, it was inferred that approximately 75% of these people would come forward for testing once it became available. In 1993 the gene itself was identified. As a result, direct testing was available for individuals without requiring

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\(^{18}\) Counsellors may describe risk in terms of a single figure, a sequential comparison to other genetic risks in the general population or in verbal terms such as: doubtful, high or low.

\(^{19}\) Huntington’s Disease (HD) is an exclusively genetic disorder. It is a degenerative disease which begins in middle age and has no cure. It is fatal. It is a dominant disorder (one faulty gene and one normal one will result in the disease) that is 100% penetrant. It is exclusively genetic in that the disorder never develops in someone who does not have the faulty gene. Approximately 1 in 5000 people develop this disorder.
blood from other family members (linkage analysis). This meant that near certain results were available in contrast to linkage testing which gave probability results. In actuality, only 5% of people came forward for genetic testing. As well, the motivations for seeking testing were different from those anticipated by service providers. For example, in contrast to service provider notions of the usefulness of genetic services for reproductive choices, most of the people who come forward do not have concerns about their children at the forefront of their mind. In fact, the issue of risk for their kids is often first raised by the genetic counselor (Richards 1996).

Counselors and clients appear to have different ideas about the purpose of genetics counseling and testing. For instance, while counselors are mostly concerned with conveying risk assessment and offering scientific information, clients are typically more interested in finding out about disease prognosis, treatment options and strategies for reducing their risk. Clients experience difficulty in understanding scientific genetics and they have elaborate ideas about inheritance that differ from Mendelian genetics. Furthermore, family relations appear to have a significant impact on the information that is provided in the genetics clinic.

There have been some surprising findings with respect to the predicted benefits of genetic testing services, especially for people who have learned that they have a low risk for a disorder. In contrast to the predictions of service providers, some of the individuals who were told that they were not likely to carry a faulty gene still reported high levels of

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20 Genetics counseling has not been proven to be effective in shaping behavior. For instance, the effects of genetics counseling on reproductive decisions are unreliable. Rather, it appears that information about genetic risk interacts with people’s notions about the burden of genetic disorders (such as the consequences of having children who have a serious illness). These already existent ideas may actually influence people’s decision making more than the information that they receive through genetic services Hallowell and Richards (1997).
psychological distress (Huggins, et al. 1992). In fact, some reported that they encountered feelings of grief and depression after their initial experience of relief upon finding that they were unlikely to carry the defective gene. On the other hand, those who found that they were likely to carry the faulty gene appeared to experience psychological and emotional pain initially, but recover rapidly (Tibben, et al. 1992). This study suggests that family members at risk for HNPCC have already developed effective strategies for coping with risk for inherited susceptibility to illness long before they obtain genetic testing. The experience of genetic services fits into a lifetime of experienced lived risk.

Most studies of genetic services have tended to focus on areas of concern for professionals. Chapple et al. (1995a) provide one of the few studies about lay understandings of genetic disease. Although they did not originally set out to explore lay conceptions of genetics, these perspectives emerged during the initial interviews with their subjects. They found that many of the people who were initially referred for genetic counseling had never heard of genetic counseling and were therefore unsure about what to expect from these services. Furthermore, they discovered that genetic disease was perceived as exceptionally stigmatizing and that many people experience a great deal of guilt and shame about genetic conditions.

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21 For example, reviews of the curriculum in graduate programs for genetic counselors in North America are available (Smith 1993). The historical and practical factors that influence the use of non-directiveness in genetic counseling have also been examined (Wolff and Jung 1995). As well, numerous scholars have discussed the ethics of genetic testing (Shapiro 1994), and the need for the development of professional protocols (Greendale et al. 1994; Lernman and Croyle 1995; Reilly 1995) in addition to cost-benefit utilitarian analyses in relation to the advantages of such technologies for society (Rothstein 1995; Shickle and Chadwick 1994). Studies that offer a discussion of the hazards of genetic counseling, such as the potential for suicide as a result of testing, usually represent these issues from the point of view of the service provider (Peters 1994). Moreover, some scholars, who purport to describe the initial experiences of genetic counseling, strangely neglect to represent client experiences of these programs (Oosterwijk 1996).
In fact, both health professionals and the general public make judgments about blame and control on the basis of the screening history of a person who carries a genetic disorder (Marteau and Drake 1995). However, further research is required in order to determine the prevalence of iatrogenic guilt that may at times be brought about in the genetic counseling setting (Chapple, et al. 1995b). Some authors suggest that contemporary social emphasis on life style as a causal agent may hinder the acceptance of genetic explanations for disease (Chapple, et al. 1995a). This study offers a different explanation that hinges on the protection of personhood.

Research on Colon Cancer

Very little qualitative research has been completed on HNPCC to date. Unlike sporadic colon cancer, even the precise incidence of HNPCC is not known. Most previous work has been undertaken from the perspective of service providers, clinicians and geneticists. However, studies that document what physicians, patients and family members actually know about this illness are simply not available. The area is so new that ethnographic techniques are essential for identifying potential research questions. Some scholars have suggested that information regarding how families cope with uncertainty in the absence of genetic testing should be investigated before introducing wide-scale genetic testing services (Strong and Marteau 1995). My work addresses this concern by examining HNPCC in the pre-genetic test era. My investigation also attempts to provide a systematic inquiry into patient experiences and understandings of

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22 There is a notable exception of a related psychosocial study of a disorder that takes place at the same site as colorectal cancer: inflammatory bowel disease (Fouldes, 1984). This study makes use of open ended interview techniques with people living inflammatory bowel disease in order to examine how people construct meaning from their illness experience.

23 It is not clear how much clinicians, who receive very little training about genetics and genetic illness, actually know about HNPCC.
inherited colon cancer and genetic information. A number of questions were used as organizing themes in my research (see Appendix II). However, these were used only as rough guidelines for research areas of interest.

Very few researchers have examined attitudes about genetic testing for colon cancer. One exception was a study that surveyed American adults and revealed that most respondents reported that they would be interested in being tested, that people with higher incomes reported a higher interest in being tested, and that 94 per cent of people would share positive results with others. Respondents identified three major concerns that they might have if they were told that they were susceptible to colon cancer. These concerns related to the reduction of risk for colon cancer, the possibility of increased anxiety and the worry about colon cancer risk for relatives. Because the authors used a structured interview technique designed for gathering quantitative data, they missed collecting information in several meaningful areas. For example, the investigators did not ask the subjects whether they would discuss their results with anyone if the results were negative. This research was also limited due to the fact that the individuals who were interviewed had not actually experienced either colon cancer or genetic testing.24

Preliminary research into the experiences of individuals who pursued genetic testing for familial adenomatous polyposis (FAP), reveals that people may have pre-existing notions regarding having colorectal cancer. It appears that family identity is strongly affected by the illness and the presence of a gene mutation in the family

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24 Most research in genetics has tended to examine what people say they will do rather than actual behaviour due to the fact that longitudinal research is too expensive (Hallowell and Richards 1997). In contrast, I will track actual behaviour in my study by completing pre and post test interviewing.
(Petersen and Boyd 1995). However, lay beliefs about inheritance have not been systematically studied, such as the notion of running in the family or ideas about proximity (Chapple, et al. 1995a; Richards 1993). The narratives in this study provide some of the missing data on lay-perspectives about hereditary cancer as well as information about people’s understandings of HNPCC before the advent of genetics testing which have not been studied in the past.

One of the few studies of communication between physicians and patients regarding colorectal cancer reveals that there are significant misunderstandings between doctors and patients with respect to treatment and prognosis (Haidet, et al. 1998). Patients tend to estimate their prognosis more favorably than their doctors. These very basic misunderstandings are not enhanced by further direct communication between medical practitioners and patients. These findings suggest that there may be basic incongruities between patient and clinician ideas about illness.

**Social and Clinical Dynamics of Colon Cancer**

Over the course of several years that I worked on this project many people who were not directly involved as official research subjects asked me questions about the study. Most of the people that I talked to about my research clearly believe that colon cancer is primarily a disease that strikes only men. Most also seemed to believe that it is a relatively uncommon disease that primarily strikes the elderly. As well, nearly all seemed to find my choice of topics odd and somehow humorous and I came to understand their amusement as an innuendo of shame about the site of the disease. The

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25 Although these researchers relied upon open-ended questioning, in conjunction with a predetermined set of research concerns, their research did not appear to draw heavily, at least in its final form, upon the rich qualitative data that must have been collected.
mere mention of the word colon sometimes precipitated utter stillness in the
conversation, nervous laughter or outright inquisitiveness about why I had chosen such
an implicitly scornful topic.

This study shows that HNPCC is unique for several reasons. Firstly, it is different
from many other cancers in that there are effective treatments for it. It can be prevented;
yet it remains as the second leading cause of cancer death in Canada. Secondly, it is
unique socially. Unlike other common cancers in BC, there is no support group for colon
cancer. The narratives of people at risk for HNPCC show that there are three negative
social components associated with the cancer: the shame associated with the site of the
colon cancer, guilt and shame associated the genetic side of the cancer and fear connected
with cancer in general. The narratives of people at risk for HNPCC in this study confirm
the suggestion that genetic disease can be seen as both “amoral and moral”(Finkler 2001:
248). This study will show that genetics is sometimes used by people at risk for
hereditary illness as a way to deflect blame for their illness.

Conclusions

Advances in genetic testing technology hold the potential to shift the focus of
medicine from the patient to the family and to encourage a stronger emphasis on the
management of risk and the prevention of disease. Notwithstanding, this research
suggests the potential brought about by advances in clinical genetics with respect to
HNPCC have not been realized in medicine. The results of interviews with medical
practitioners and observations in clinical settings also suggests that the potential of
genetics has not really penetrated the practice of oncology as it pertains in any real way to

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Proximity refers to the lay belief that an individual can only inherit an illness that has been manifested in
a close relative of the same gender (Richards 1993).
the treatment of patients with HNPCC. It appears that oncologists still address disease, rather than the risk of disease and that their object is still the patient rather than family. This thesis examines some of the institutional arrangements and wider contextual variables that appear to shape clinical roles and configure medical practice.

The narratives of people who actively manage their risk for HNPCC highlight some of the factors that influence individual and cultural constructions of personhood. This study attempts to explore the impact of hereditary illness on personal and family identity and to provide a glimpse of some of the strategies that are employed by people and families as they try to contend with their experiences. The theoretical underpinnings of this dissertation will be discussed in more detail in Chapter Two: Theoretical Underpinnings: Towards an Anthropology of Personhood.

The third chapter of this dissertation examines some of the wider health care context and institutional arrangements as they pertain to the treatment and clinical construction of HNPCC. This chapter is only able to offer a brief overview of a number of overarching societal arrangements of health care that impact on families with colon cancer and the oncologists who treat them. Their impact will be seen in more detail in the family and clinical narratives presented in Chapters Four, Five and Six.

Chapter Four: Introduction to Patient and Family Narratives begins with the assumption that given that there are distant, inconsistent and sometimes nonexistent genetic services for these families, they have had to develop their own understandings of hereditary colon cancer. Their understandings are their own, they are immensely complex, and they are based on personal experience, medical knowledge, genetic knowledge, lay theories, the media, the internet, library research and soul searching.
These personal interpretations are part of a process of intentional self-authoring by people whose very person is under siege as they confront the borderland between the psyche, culture and their own illness. These narratives form the heart of this dissertation and are also discussed in Chapter Five: The Construction Of Personhood.

In Chapter Six, the clinical narratives provide a look at the understandings of medical practitioners, mostly oncologists, with respect to HNPCC. In particular, this chapter reveals that genetics is not very influential in the clinical practice of medicine with respect to HNPCC. It will also demonstrate that medical practitioners concerned with colon cancer, as a rule, do not diagnose HNPCC or recognize the hereditary nature of the disease or the need to follow it in families. I argue that this is related to the unavailability of genetic testing and institutional arrangements of clinical roles (e.g. organization of their oncology roles and disciplinary hierarchies) and the organization of health care (what oncologists are paid for and what they are not).

In the final section of this dissertation, Chapter Seven: Conclusions, I argue that people at risk for HNPCC knowingly create their essential being in the midst of culturally constituting forces (such as the experience of being genetically at risk for illness or the experience of being a cancer patient). People who have been at risk for hereditary illness for their entire lives recognize threats to their status as persons that include guilt, shame, diminished sexuality, job loss, death, portrayal as a cancer patient and the stigma associated with the site of colon cancer. The interviews with family members suggest that the fateful moments brought by illness or the genetic risk for it lead to a heightened awareness of or focus upon the construction of personhood rather than a passive acceptance of culturally constituted identities. People do not want to be defined by their
cancer or the risk for it and they reflexively use healing emplotment to narrate their autobiography in ways that are sustainable. I also suggest that medicine and genetics are distinct cultural spaces with respect to HNPCC. In the clinical world, lay-perspectives are sometimes problematized and seen as a barrier or obstacle to the provision of medical information. Lay-perspectives are the messy things that prevent the transmission of medical and genetic knowledge into the preferably empty and therefore receptive vessel of the patient's mind. This study examines the issues in a different way by focusing on the complexity of lay-perspectives that are receptive to genetic and medical understandings, flexible but not subservient. The next chapter outlines the theoretical framework for the study.
CHAPTER TWO: TOWARDS AN ANTHROPOLOGY OF THE PERSON

The theoretical approach introduced in this chapter attempts to go beyond the focus of illness narratives and therapeutic emplotment on *sense making* to a healing emplotment approach that emphasizes the process of *person making*. Each person has many narrative selves that cumulatively highlight their life narrative (Ochs and Capps 1996). A life narrative connects a constructed past with an imagined and hoped for future (Brock 1995). The importance of life narrative is central to the process of healing emplotment. People use healing emplotment to organize the many segments of their cumulative experience with genetic susceptibility to illness. The interviews with people genetically at risk for HNPCC will show that the variables that they draw on to make themselves may include but are not limited to their experiences with illness and therapies. At the heart of healing emplotment is the need to fortify a protective cocoon around a coherent life story about personhood. Personhood is a crucial part of healing emplotment and it involves the construction of a consistent identity:

"Personal identities are narratively constituted. They consist of tissues of stories and fragments of stories, generated from both first- and third-person perspectives, that cluster around what we take to be our own or others' most important acts, experiences, characteristics, roles, relationships, and commitments" (Nelson 2002: 30).

While illness can disrupt peoples' hoped for futures, healing emplotment can fortify the imaginescapes of their personhood.

The people who were at risk for HNPCC in this study were aware of some fundamental existential questions associated with their risk status and the potential for this disease. This chapter presents a conceptual framework that attempts to explore these larger questions raised by the narratives of people at risk for HNPCC. The framework
combines anthropological issues about narratives in medical anthropology with key theoretical discussions on the relationship between the self and society. This chapter begins with a brief discussion of what it is to be a person (Cassel 1982; Geertz 1975; Morris 1994; Shweder and Bourne 1984) and challenges to a person (Goffman 1986 (1963); James 1995). This includes a discussion of several variables that can threaten personhood such as stigma, guilt, shame and fateful moments (Giddens 1997) and examines their applicability to the risks to personhood of people with HNPCC. This is followed by a description of how people manage the ever present risk in their lives by attempting to colonize their future, to search for life politics and to develop pure relationships (Giddens 1997).

**Therapeutic Emplotment and Healing Emplotment**

These risk management strategies are part of a process of healing emplotment. My concept of healing emplotment is a process that foregrounds the perspective of the person actually managing the risks of HNPCC in the context of their entire life: past, present and future. Healing emplotment grows out of work on therapeutic emplotment in medical anthropology that focuses on the process by which practitioners and patients actively make use of a narrative or story framework, with a plot-like structure, that

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27 This term is not my own. I have adapted it from Nuttall (1992).

28 I do not intend to use the notions of society and culture synonymously but instead to look at them as two important and related topics of study for anthropology. On this issue, I have adopted the interactionist position of Hannerz (1992). A full discussion of this position does not fall within the bounds of this study and has been covered extensively in the original work of (Hannerz 1992).

29 While I will use the terms story and narrative interchangeably, it should be noted that literary theorists make a sharp distinction between the two concepts (Mattingly 1994). The term story refers to a series of events or experiences, whereas the notion of narrative refers to a specific discussion that describes events or experiences. According to this reasoning, actual experience lacks the guiding shape provided by a plot, whereas plot always provides the structure for literary narrative. This investigation will focus on the process of narrativity. Here, narrative is conceptualized as a social action, rather than as a simple manifestation of experience which can be captured in text. In keeping with the assertions of contemporary investigators of narrative, I do not claim that narrative is a direct reflection of experience. This is clearly
helps them to guide and interpret therapies, treatments and clinical approaches to serious illness such as: planning treatment schedules, determining which therapies are undertaken initially, and ascertaining which side-effects may be manifested (Mattingly 1989; 1994). While therapeutic emplotment has focused on therapeutic and illness-centred narratives, I employ the concept **healing emplotment** in order to shift the focus to the non-clinical aspects of illness such as the management of risk, the construction of meaning and the way that people knowingly work to construct themselves as persons. The approach espoused in this study is a patient centred approach that looks at the larger life strategies employed by people to successfully live with the risk of HNPCC and in so doing to grapple with the essentiality of what it is to be a person.

In the latter section of this chapter, I introduce another concept, emotional capital which emanates from the social support networks that individuals are able to mobilize during the course of their healing. It is a form of symbolic capital that builds upon various forms of social capital (Bourdieu 1990; 1995; 1999). Emotional capital is gained from more personal connections with others: lovers, family, friends and it holds absolute value relative to all other forms of capital during fateful moments. Emotional capital provides the underpinning for individuals' interpretations of experience and the clinical narratives and the relations they develop with medical practitioners with respect to HNPCC. In many instances, this desire to contribute to the wider human community through research and to share what they had learned appeared to be the explanation behind many of the subjects' participation in my research. The supreme value of emotional capital made it clear that not only institutions and individuals define persons

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distinct from the simple analysis of stories. As well, an illness narrative is but a smaller part of the overall life story of an individual.
but that significant others also make us who we are. People knowingly shared the narrative of their self with important others in their social world. The narratives provide instances where personhood appears to be collectively narrated by couples, if only for a fateful moment.

**Narratives in Medical Anthropology**

This thesis takes a phenomenological approach to individual's experience and its representation in illness narratives about personal experience of illness. It is unusual for individuals, who are essentially social beings, to experience their self-definition abruptly somatocized by serious illness (Good, 1996). Individuals' experiences are socially legitimated and mediated by clinicians. Illness narratives help individuals to re-constitute themselves in the face of illnesses such as cancer. The clinical realm reveals a battlefield where all the stakeholders—clinicians, patients and family members—struggle to achieve understanding of the illness, to find meaning in the situation, and to choose a therapeutic direction. Clinical or therapeutic narratives tend to unfold the medical plan for the patient and refer to the meaning for the disease experience constructed from the point of view of the clinician or therapist. The perception of medicine as a narrative activity itself has permitted me to move beyond the issue of disease diagnosis in order to include an analysis of the complex personal and social experiences of patients, their families and clinicians as they encounter hereditary colon cancer (Hunter 1991).

In this study I will show that people make use of a similar narrative strategy, **healing emplotment**, to organize their experiences with cancer in order to take more control over the protection and direct authorship of their personhood. Healing emplotment foregrounds the perspectives of people directly affected by illness rather than
the joint construction, led by the clinician, of therapeutic emplotment. Healing narratives go beyond the confines of the clinic and the clinical relationships but include family members and others who provide emotional capital and social support as well as those who are also at risk. They are a larger enterprise and can incorporate both therapeutic and illness narratives. In this case, they refer to a larger process of managing the personal, experienced risk of HNPCC.

Situating ourselves within an understandable narrative told as a story is essential to the process by which individuals make their lives meaningful (Mattingly 1994). Humans create sense and meaningfulness from their experiences by generating a plot while actually experiencing their lives. Social actors have a narrative stake invested in making stories as they live through life events. The narratives collected in this study show that family members affected by HNPCC create a narrative response to their family’s illness experiences early in life. They actively emplot a healing strategy that shapes their ongoing experience into a congruous form where narrative order gives birth to a recognizable beginning, middle and end. The narrative production of a whole from a number of occurrences permits the discovery of or creation of a meaning, a moral, and a purpose of a story (Mattingly 1994). The interviews in this study show how people narratively construct their many experiences and understandings in order to sustain their personhood as part of healing emplotment.

Narrative strategies are employed by both clinicians and patients in order to structure time so that it is either abbreviated or lacking in distinct limits in order to focus attention on the moment, thereby attempting to facilitate hope for the future. Medical professionals who cautiously attempt to direct the pace at which information is shared
carefully regulate discussions with respect to treatment and prognosis. For example, the interviews with oncologists reveal that most do not, as a rule, discuss death with patients even though the oncologists recognize that this is a very important issue for their patients. The development of an optimistic therapeutic story is a crucial element for the medical practitioner in the treatment of cancer (DelVecchio-Good, et al. 1994). The potential for a tragic ending to an illness story is especially unsettling in the treatment of cancer and, as a result, oncologists may address the issue of endings by actively working to guide the perception of time by their patients (DelVecchio-Good 1991). The narratives of people genetically at risk for HNPCC suggest that the development of a healing story is more important for people who have been at risk for hereditary cancer for a lifetime and that their illness and treatment story is only a small part of this overall narrative. The examination of the healing narratives of people affected by HNPCC has provided an "especially fine mesh for catching such ideas" (Good 1996: 165).

Healing narratives emerge from the interaction of individual life experiences and agency with the preexisting social institutions and cultural models. I employ both a psychogenic and sociogenic notion of human agency in order to build a bridge between the two ends of this theoretical continuum (Ortner 1997; Veroff and Goldberger 1995). While agency is culturally constructed in specific times and places, it is arguably also a strategy employed by people to engage the contextual forces that constrain them. This study attempts to show that the construction of agency is part of the way that family members affected by cancer actively manage their personhood as an essential part of healing.
The interviews in this research have emphasized the importance of examining subjects as “contextualized persons” (Geertz 1975: 36). Patients receiving treatment are also part of a social context where they are mothers, fathers, sisters, grandmothers, daughters, spouses, nurses and professors. Neither the genetic nor the clinical world appeared to have much bearing on the construction of their person or their illness experience. HNPCC has a different meaning to families than it does to clinicians, epidemiologists or geneticists. It has a much more real presence in their lives. All the people interviewed in this study had been dramatically impacted in some way by the presence of many instances of cancer, likely to be HNPCC, in their family. The participants in the study had either experienced colon cancer personally, were themselves at high risk for colon cancer or were the spouse of someone in one of these two categories. In order to be classified as a family likely to have HNPCC, families had to have multiple occurrences with cancer over the period of several generations.

The narratives in chapters four and five about peoples’ experience with HNPCC are a complex intertwining between their health experiences, their social world and their cosmology. Individuals who enjoy full personhood may have this status jeopardized by an illness experience or, as sometimes the case with HNPCC, the risk of illness. Their narratives reflect a concern about the status of their personhood. For example, when a parent realizes that they may die before their children grow to adulthood or even adolescence, this fateful awareness has a dramatic impact on the construction of their personhood. In some cases, people dramatically altered their way of understanding themselves as persons (e.g. regarding their work career, their marriage relationship, their children, the meaning or direction of their life).
In practical terms, these families have a tremendous amount of experience with cancer. They live their lives with an elevated sense of risk. They have all lost family members, often including parents or siblings, at an early age. Hereditary cancer has become a large part of their family’s experience. They were not strangers to cancer or the cultural ideas normally associated with cancer such as death, uncertainty and loss of life potential. They were very aware of the stigmatizing aspects of this particular cancer, in particular due to its site and potential for highly stigmatizing surgical interventions. The question with which many of these people struggle is the extent to which they allow cancer to define who they are in their social and personal world, that is, the role it takes in personhood.

Research on people’s decisions about their genetic risk and health are often affected more by considerations about social relationships than they are by the medical information that is provided by medical or genetic practitioners in clinical settings (Burgess and d’Agincourt-Canning 2001; McKellin 1997; McKellin and Burgess 1995). While the field of bio-ethics uses a framework for understanding based on autonomous decision-making, this framework has been challenged by anthropological orientations that identify social relationships as one of the most influential variables in decision-making about health (Burgess and d’Agincourt-Canning 2001; Frank, et al. 1998). The disclosure of illness status by medical practitioners and the way that this information is handled by patients is affected by relationships which range beyond those established between clinician and client inside the medical environment. In fact, some patients choose to avoid information about a possible health condition and, instead, elect to have their families manage the rate and flow of disclosure information about their disorder.
(DelVecchio-Good, et al. 1993; Gordon and Paci 1997). Anthropologists have further challenged bio-ethical conceptions of autonomous patient decision-making by demonstrating that in most situations, it is the family rather than the individual that makes serious decisions about health such as whether or not to employ life-support technology (Frank, et al. 1998).

It appears that one of the most important factors for patients when making decisions about their health relates to their sense of personal obligation to maintain family relationships and responsibilities. Decisions about health care are not really made in clinics; they are made within a network of family relations. In foregrounding the healing narratives of families directly affected by HNPCC, this study examines the purpose of genetic and medical information in people's ongoing autobiography of their person and life plan.

The theoretical framework for this dissertation draws upon the work of Pierre Bourdieu and Anthony Giddens each with a different treatment of the relationship between self and society. The qualitative data gathered in this study supports a move towards a theoretical vision "of structurally embedded agency and intention-filled structures, to recognize the ways in which the subject is part of larger social and cultural webs, and in which social and cultural 'systems' are predicated upon human desires and projects" (Ortner 1996:12). The interviews provide evidence for the argument that people at risk for and affected by HNPCC are knowingly at the centre of a number of culturally constructed and constructing spheres that influence personhood. These spheres of mutual influence include the culture of genetics, the culture of medicine, institutional arrangements and narratives about cancer in the wider society. Before turning to the
work of Bourdieu and Giddens it may be useful to review some of the important ideas about what it is to be a person.

**Personhood**

In the context of this study, personhood is understood as a process where the subjective and social worlds engage one another. The field of cultural psychology has made some important contributions to theoretical ideas about personhood. The subject matter of this field is useful for developing a fuller definition of personhood:

"the study of the way cultural traditions and social practices regulate, express, and transform the human psyche, resulting less in psychic unity for humankind than in ethnic divergences in mind, self, and emotion. Cultural psychology is the study of the ways subject and object, self and other, psyche and culture, person and context, figure and ground, practitioner and practice, live together, require each other, and dynamically, dialectically, and jointly make each other up" (Shweder 1995: 41).

Building on this definition, then, I define the person as a process by which the interconnections between human beings as perceiving selves and culture relate mutually with one another. The assumption being made here is that culture does not have autonomy from the process of meaning-production by humans and likewise the sentience and perception of humans is affected by their engagement with a meaning-laden social world. The identity of persons and their culture are interconnected and are indivisible with respect to the production of understanding and meaning.

A convincing examination of the relationship of the individual to cultural context needs to address the perception of individuals who they exhibit agency in their social and clinical lives, that is, it should contain an underlying current of intentionality in both the person and the social world (Ortner 1997; Shweder and Bourne 1984). In this study, I analyze the way that people narratively construct agency and simultaneously give
meaning to their personhood and social world. This dialectical territory of cultural and personal agency is an ongoing process:

"by which culturally constituted realities (intentional worlds) and reality-constituting psyches (intentional persons) continually and continuously make each other up, perturbing and disturbing one another, interpenetrating each other’s identity, reciprocally conditioning each other’s existence" (Shweder and Bourne 1984: 71)

Culture in this sense is particular rather than universal and is, along with human identity, ever changing rather than fixed. The two phenomena mutually make up one another. The narratives of patients, people at risk for HNPCC, their family members and attending medical practitioners gave a window on cultural “zones of friction” where different meanings, identities and levels of power encountered one another (Ortner 1997: 8).

Personhood provides information about the status of an individual’s membership in society while stigmatizing illnesses challenge personhood. Full membership carries with it dignity, power and privilege. Attributes that are intensely socially compromising can degrade an individual from a full person to a tarnished, diminished one (Goffman 1986 (1963)). People with this diminished value are considered to be “not quite human” (Goffman 1986 (1963): 5). The ascription of full personhood is value laden in that it comments on key issues of morality with respect to behaviour, and in the case of illness, in terms of the root cause of an illness. Those without full membership as a person have reduced “life chances” (Goffman 1986 (1963): 5). The people living with HNPCC in their families interviewed in this study were aware of threats to their person brought by the risk of the disease and their healing narratives addressed this peril. The concept of healing employment accounts for more than the illness or therapeutic experience itself. It
encompasses larger variables about people’s standing as persons as well as the potential for suffering brought about by the risk of disease.

Given that suffering is a challenge to personhood, it is not restricted to physical pain (Cassel 1982). This is particularly clear in the case of genetic mutations for colorectal cancer where people who have not yet manifested the disease may still suffer due to the risk of illness and past experience with it in their families. Suffering is a complex personal experience that can come about due to innumerable variables such as the anguish of a loved one, physical agony, powerlessness, hopelessness, homelessness, memory failure, loss of friends, lack of validation, lack of meaning, isolation, the loss of a secret dream, the inability to work and fear of the destruction of an individual as a person (Cassel 1982: 640-641). A person contains many components such as: life experiences, a past (e.g. cancer and death of loved ones), a family with obligations, work history, a culture, physical characteristics (how we look to ourselves and others), relationships, emotions, consciousness, sexuality, a political side, a body, perceptions about the future, secrets, fantasies, hopes and dreams as well as roles such as: father, mother, brother, sister, anthropologist, teacher or orphaned son (Cassel 1982: 642-643). Illness and the risk for it in the case of HNPCC threaten to damage not only people’s bodies but also their public and private selves. Therapeutic or illness experience is only a small part of the person. Medicine focuses on the alleviation of the suffering associated with physical injury or disease where a person is chiefly looked upon as a body or in the case of oncology: a tumor. Genetic services offer a risk assessment for the presence of a genetic mutation but do not address the manifold components of suffering described above. Healing and struggling not to be overwhelmed by the suffering brought about by
the risk of HNPCC is a part of a larger and more personal enterprise. I argue by focusing on the healing emplotment illustrated in the narratives of those at risk for HNPCC we can more fully understand how people manage the manifold facets of possible suffering brought about by the presence of a cancer in their families. This is a cancer that has already taken many lives in each family studied, that can take the life of a person before their children are grown and a can ultimately be a source of suffering for the children themselves.

**Reflexive Protection of the Person**

In modern life\(^3\), the self is a reflexive project that is regularly remade as part of an ongoing process of connecting individual and social change. People are consciously aware of their actions and reflexive consciousness is an essential part of human activity:

"...to be a human being is to know, virtually all the time, in terms of some description or another, both what one is doing and why one is doing it... The social conventions produced and reproduced in our day-to-day activities are reflexively monitored by the agent as part of ‘going on’ in the variegated settings of our lives. Reflexive awareness in this sense is characteristic of all human action.... All human beings continuously monitor the circumstances of their activities as a feature of doing what they do..." (Giddens 1997: 36).

People have a general conception of what it is to be a person that is as applied to their individual self as well as to others. This self-monitoring feature of human action was seen in the narratives of people affected by HNPCC and needs to be included in a complete theory of personhood.

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\(^3\) Giddens (1997: 15) refers to the present period as high or late modernity, a term which corresponds to the industrialised age where industrialism refers to "the social relations implied in the widespread use of material power and machinery in production processes". The period of high modernity also has other dimensions including capitalism (production of consumer goods with labor as purchasable), surveillance of citizenry (primarily with information) and the industrialisation of war where the state controls the means of violence. The state is a social form that is part of a global system of relations based on territoriality, an advanced capacity for surveillance and a principal custody of the means of violence. The state has created the organisation whose essential character is the ability to maintain reliable command of social relations over relatively limitless distances of time and space.
People at risk for hereditary conditions such as HNPCC do not live their lives in a constant state of anxiety and obsession about their risk status. Giddens (1997) describes how practical consciousness creates a sense of security and trust for all people by “bracketing” out the anxieties associated with the potential chaos and risk of everyday life. Trust gives individuals the courage and hope to carry on as participants in everyday life. Practical consciousness is normally developed in the early life of children who develop a basic trust and confidence in their caregivers that acts as an emotional protection against the unpredictability of the social world:

“emotional inoculation against existential anxieties—a protection against future threats and dangers which allows the individual to sustain hope and courage in the face of whatever debilitating circumstances she or he might later confront. Basic trust is a screening-off device in relation to risks and dangers in the surrounding settings of action and interaction. It is the main emotional support of a defensive carapace or protective cocoon which all normal individuals carry around with them as the means whereby they are able to get on with the affairs of day-to-day life” (Giddens 1997: 39-40).

This emotional inoculation is built from a foundation of a trust, a kind of protective system for the self and is essential for overcoming the risks of modern life. This protective system, is developed early in life and is, in Gidden’s view, largely unconscious.

We live in a risk culture (Giddens 1997). The concept of risk here refers to a particular way that the world is socially constructed today:

“...the concept of risk becomes fundamental to the way lay actors and technical specialists organize the social world. Under conditions of modernity, the future is continually drawn into the present by means of the reflexive organisation of knowledge environments. A territory, as it were, is carved out and colonised. Yet such colonisation by its very nature cannot be complete: thinking in terms of risk is vital to assessing how far projects are likely to diverge from anticipated outcomes. Risk assessment invites precision and even quantification [as in the case of genetic risk] but by its very nature is imperfect. Given the mobile character of modern institutions, coupled to the mutable and frequently
controversial nature of abstract systems, most forms of risk assessment, in fact, contain numerous imponderables” (Giddens 1997: 3-4).

Individuals affected by HNPCC have to sort through several different representations of risk: clinical, genetic and bureaucratic, all of which occupy different territories that intersect in the most personal and profound form of risk, lived risk. The imponderables described in the passage above are at the heart of lived risk and it is to these that people affected by HNPCC respond with a number of strategies for minimizing their lived risk.

Individuals retain stability in their identity by maintaining a sense of narrative continuity:

“A person with a reasonably stable sense of self-identity has a feeling of biographical continuity which she is able to grasp reflexively and, to a greater or lesser degree, communicate to other people. That person, also, through early trust relations, has established a protective cocoon which ‘filters out’, in the practical conduct of everyday life, many of the dangers which in principle threaten the integrity of the self... A person’s identity is not to be found in behaviour, nor—important though this is—in the reactions of others, but in the capacity to keep a particular narrative going” (Giddens 1997: 54).

The narrative construction of personhood does not occur in a vacuum. It has to maintain reasonable consistency with the outside world and needs to reconcile between external feedback and the continuing biography of the self. Personhood is sustained through reflexivity about the viability of the chosen story of their self amongst numerous possible stories. The integrity of the self has to be strong enough to withstand social turbulence that challenges the integrity of the story and this is done based on an underlying foundation of trust, courage and hope (emotional inoculation).

Fateful Moments and Security of the Self

Fateful moments are those where occurrences or situations may have important consequences for a person or a group (Giddens 1997) and penetrate the practical
consciousness that keeps risk at bay. These events are very significant for personhood. In the narratives that follow, I will show that fateful moments, such as the diagnosis of colon cancer or a receiving of a positive test for a genetic mutation, undermine the protective cocoon of personhood and during these times external determinants of personhood come into view as powerful. During these occasions, an individual may face decisions (such as choices regarding course of treatment) that may have dramatic consequences.

During fateful moments, the emotional inoculation that permits people to act in the risk filled social universe is undermined and their personhood is jeopardized. The narratives that follow will show that people with HNPCC employ complex strategies to regain this emotional inoculation in order to successfully manage risk and promote certainty about their personhood. Their strategies attempt to minimize the influence of more objectified variables on personhood. People resist representations of themselves as only inert parts of the genetic world. Those interviewed did not see themselves as mutational maps that unfold genetic narratives where the self is a powerless victim of a genetic biography. People worked hard to show that their person was not to be understood in terms of HNPCC and they did not want to be known as cancer survivors. Personhood was distanced from the constraints of cancer. People understood themselves as healthy and vibrant people. They would prefer to be understood by other criteria, as examples from the interviews will later show. For instance, one person describes herself as a hot-blooded lover rather than as a victim of tragedy. People focused on the things that they could control such as the frequency of clinical surveillance of their cancer or access to knowledge such as genetic services. Using these techniques, people reinforced
their “protective cocoon” so that they could get back to the “very business of living” and the “affairs of day-to-day life” (Giddens 1997: 40).

Fateful moments, such as the threat of death or the loss of a close relative seriously undermine the protective cocoon of the person. The intuitive trust in the possibility of proceeding in the inherently risky world is in peril. The strategies employed by people at risk for HNPCC to regain their practical consciousness after facing these fateful moments is a major part of the narratives collected in this study. It appears that the people who have successfully faced these fateful moments emerge with stronger protective cocoons and more secure narratives about their person. As part of this process, they have to overcome the fundamental untrustworthiness of a world that includes HNPCC.

The narratives that follow suggest that there many different types of fateful moments such as those that are social threats that fuel anxiety for people at risk for HNPCC. This was seen when friends distanced themselves from the people with cancer. Family members also communicate disapproval of the “bad genes” brought by one ‘side’ of the family. In these situations, the “ontological security” of the person is seriously threatened (Giddens 1997: 44). Ontological security is important because it is the trust, hope and courage that allow people to carry on. Without this they are disempowered as they stare headlong into an abyss without agency where they suffer with “the pain of helplessness” (Giddens 1997: 46). The security normally brought about by the protective cocoon forms the “very faith in the independent existence of persons and objects” and it is this that makes us human.
The reestablishment of security of the self is an essential part of the grand task of maintaining biographical integrity and "to be ontological secure is to possess, on the level of the unconscious and practical consciousness, 'answers' to fundamental existential questions which all human life in some way addresses" (Giddens 1997: 47). The narratives will show that people encountering HNPCC had done more than confront the anxiety of this fateful moment; they in many instances attempt to change the social rules. Their knowledge of these processes appear to be well above the level of unconsciousness in their narratives and it is on this point that I depart from both Bourdieu and Giddens.

The family narratives will also show that the presence of HNPCC can lead to both shame and guilt to families affected by this disease\(^\text{31}\). They will illustrate that some parents experience genetic guilt about having "passed on" the mutation for HNPCC to their children. Others appear to be confronting the danger of shame associated with cancer, the site of the cancer (colon) and the genetic component of HNPCC. Both shame and guilt appear in the narratives of families affected by HNPCC. Shame is a more fundamental crisis for personhood given that it threatens the currency of personhood and is a menace to the biography of the self in society. The interview segments will show that families respond to the peril of shame with a great deal of narrative resourcefulness.

The underlying mechanisms of personhood are more far reaching than reflexivity (understanding and re-examining oneself). More fundamentally they relate to the development of a valuable sense of self in society (Giddens 1997). The value of the self can be roughly measured against the various forms of capital: cultural, material and

\(^{31}\) Guilt and shame are distinct phenomena. Guilt refers to feelings of transgression based on specific acts that contravene social conventions or in some way violate important others such as family. Shame, in contrast, threatens the integrity of an individual's narrative about their personhood by unveiling negative characteristics (Giddens 1997).
symbolic. However, the most powerful variable influencing people's sense of identity is encompassed by a different market whose currency is emotional capital and whose value trades on social connectedness with significant others in *pure relationships*. Pure relationships take on tremendous importance for people at fateful moments.

A pure relationship is defined in terms of several key variables summarized below:

<table>
<thead>
<tr>
<th>ELEMENTS OF THE HIGHER ORDER RELATIONSHIPS SOUGHT BY PEOPLE AFFECTED BY HNPCC</th>
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<tbody>
<tr>
<td>• It is brought into existence based on intimate emotional connections with others. It is ideally initiated for no other reason than the rewards of the relationship itself.</td>
</tr>
<tr>
<td>• It is only between two people and the commitment is in the first place only between the two partners involved. This is its purity. It is based on balance and reciprocity with respect to the contribution to the relationship by each partner.</td>
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<tr>
<td>• Like personhood, the pure relationship is a reflexive project that is examined by both partners in an ongoing fashion.</td>
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<tr>
<td>• The pure relationship is founded on commitment between the two partners and this commitment replaces traditional external anchors such as religious or familial obligations for maintaining a relationship. Commitment refers to a demonstration of reciprocity by both partners.</td>
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<tr>
<td>• Pure relationships are successful when there are equal power relations between the two partners and they both have a confident perception of the value of their person.</td>
</tr>
<tr>
<td>• The pure relationship relies extensively on intimacy (a close and trusting connection between two people). This intimacy is established by a mutual exchange of trust.</td>
</tr>
<tr>
<td>• The pure relationship involves a substantial amount of collaborative authorship of each partners' life narrative. It involves the building of shared history and the intertwining of life calendars.</td>
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(Adapted from Giddens, 1997: 88-98)

The focus of this dissertation does not allow an extensive examination of the literature on relationships but introduces a reference to the notion of an important personal connection because this was a recurring theme in the narratives. The subjects in this study repeatedly emphasized significant personal relationships with more deeply meaningful qualities.

The process of autobiography is at the very heart of understanding the self in society and it is a fundamental part of the theory of personhood being presented here.
Persons are not passive objects but dynamic "action systems" and "we are, not what we are, but what we make ourselves" (Giddens 1997: 75-77). A lifestyle is defined as a system of generally regular actions that a person endorses and performs in order to give shape to their chosen biographical narrative. Individuals evaluate the integrity of their personhood by assessing the continuity of their system of practice across the various sectors of their lifestyle.

The body is more than a physical object, it is a part of an "action-system", a method of practicing the self as part of the social interactions of everyday life as a part of the process of maintaining a reliable narrative about personhood (Giddens 1997: 99). The function of the body, especially in relation to colorectal cancer, provides feedback with respect to the coherence of narratives about personhood. For example, some people affected with HNPCC were concerned about their ability to engage in sexual activity following their treatment for the disease. Others were concerned about their ability to perform normal physical tasks such as going to the washroom in a conventional fashion (i.e. without a colostomy bag).

Given the trends towards increased specialization, one of the dilemmas of the modern world is that there is no ultimate authority to which individuals facing fateful moments can turn (Giddens 1997). As the social world is more organized into expert sectors the dilemma that there is no final authority emerges. Personhood has to be made amidst a "puzzling diversity of options and possibilities" (Giddens 1997: 3). However, while this can be perplexing, it can be simultaneously empowering in that people at risk for cancer take on the task of developing their own expertise with the disease and its
management. Individuals also develop more fulfilling biographies of their persons by taking on the role of health promoter in their family.

During times of illness, the self becomes even more a reflexive project as the fundamental trust in the health of the body undermines the self (Giddens 1997). People affected by HNPCC attempt to colonize the future by seeking information, controlling clinical surveillance and modifying their diet and exercise. Attempts to colonize the future refer to strategies that people employ in order to manage risks to their person and to guard themselves against worrying about future events that encroach upon and threaten their life situation.

Variables that threaten the security of the protective cocoon of personhood are often hidden or sequestered in modern life. Potentially risky or alarming phenomena that are normally sequestered from public view include mental illness, criminality, drug addiction, illness, sexuality and death (Giddens 1997). The sequestration of these experiences are in some cases formally standardized through institutions such as hospitals, cancer agencies or hospices where variables such as illness, cancer and death that threaten security to personhood are concealed. Hospitals are places where individuals who have had the fullness of their personhood invalidated in some way are sometimes sequestered. Frightening things that bring the possibility of risk to the self, such as cancer, are hidden away to reduce the anxiety that they create.

The colonization of the future reaches its final frontier at sickness and death. People with an increased risk for cancer have an elevated sense of the power of fortune and, as a result, they seek to counter this external power. The danger of death not only

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32 Fortune refers to external factors, such as death, that are out of the control of individuals (Giddens, 1997).
threatens powerlessness for people at risk for HNPCC, it also represents a tremendous loss of control for the professionals that provide medical treatment. Death is the "great extrinsic factor of human existence; it cannot be brought within the internally referential systems of modernity...it is nothing more or less than the moment at which human control over human existence finds an outer limit" (Giddens 1997: 163). Sickness and death eventually touch us all and it becomes impossible to sequester ourselves from these forces. As death becomes an imminent possibility, an existential crisis of personhood comes to pass:

"The frontiers of sequestered experience are fault lines, full of tensions and poorly mastered forces; or, to shift the metaphor, they are battlegrounds, sometimes of a directly social character, but often within the psychological field of the self" (Giddens 1997: 168).

We survive the threat of absolute extrinsic factors by becoming increasingly reflexive and by enhancing the authorship of our biography. Nowhere are we more clearly the authors of ourselves than during fateful moments that threaten to uproot us from our social world. As the interviews illustrate, events that biologize us dramatically affect life planning and make the reflexive aspects of person construction even more prominent.

The introspective process of personhood has to be regularly re-written to accommodate the ever-changing experiences of the self in the course of everyday living (Giddens 1997). People are not victims; they are active and critical of their experiences and they are highly motivated to maintain control of their biographies. The subjects of this study were powerfully motivated to fight the potential oppression of HNPCC. During the fateful moments associated with HNPCC, the balance between the psychogenesis and sociogenesis of people's autobiographical narratives were abruptly tipped towards the ultimate extrinsic variables of disease and death.
Emancipatory politics have as their main objectives the liberation of marginalized groups from their disadvantaged conditions and the eradication of class divisions in opportunity (Giddens 1997). Their main goals are to achieve “justice, equality and participation” (Giddens 1997: 212). Life politics, in contrast, focuses not on social conditions but on “the politics of choice” (Giddens 1997: 214). Here, human beings do not simply originate from the conditions of their existence, but are given ultimate authority. Life politics do not focus on how we live but instead they determine how we should live. This approach assumes that individuals are reflexive participants and that the social world is itself a reflexively organized interdependent community of participants. Life politics do not ignore the power of institutions and social conditions in shaping self-identity but they highlight with hope the possibility for collective authorship in the creation of these “internally referential systems” at the core of modern life (Giddens 1997: 225). At the heart of this political agenda are the “rights of personhood and individuality, which connect back to the existential dimensions of self-identity as such” (Giddens 1997: 226). The people interviewed in this study have shown that they can author themselves at fateful moments in their lives. They have also demonstrated that neither biology nor social conditions are sovereign in defining personhood. The organizing principle at the core of this social process is a fundamental human need to be meaningful, to have hope, and to be valued by significant others.

This research illustrates that everyday people construct and reconstruct their notion of who they are in relation to their health experiences, their goals and understanding in relation to social values about what it is to be a person, a set of understandings that are configured and reconfigured during the process of person-
making. The process by which people sculpt their sense of personhood pertains to a
number of key variables goals and values including those that relate to their vocational
trajectory, their family role, their spouse, or their ability to obtain income. People also
create their sense of themselves with an awareness of key variables that undermine their
protective cocoon (e.g. given that they may have “caused” this illness in their children
brings about a kind of “genetic guilt”). The patient and family narratives will illustrate
the fact that an individual does not in a genetic sense have any control over the cause of
their illness is sometimes positive and sometimes negative. The next section focuses on
the work of Pierre Bourdieu as it pertains to the theoretical framework for this study.

**Institutional Consecration**

Clinical roles, programs and specialties are institutionally consecrated (Bourdieu
1999). This notion will be important later when interpreting the narratives where
oncologists describe their focus on tumors rather than patients or families and for
understanding the reliance of medical practitioners on the Hereditary Cancer Program as
the sole provider of services that are understood to be genetic. An examination of the
various forms of social capital (Bourdieu 1995) is also undertaken below to provide the
groundwork for introducing the concept of emotional capital and for understanding the
relationship between medical, genetic and lay perspectives on HNPCC.

The subjects of this study were well aware of the lower status of lay-perspectives
and they readily acknowledged this difference in social position with various self-
effacing statements when referring to them in interviews. A distinct difference between
lay knowledge and expert knowledge in terms of social position was observed in nearly
every realm of this research. This difference is institutionally constructed as illustrated
by the initial failure for this research project to obtain ethical approval through the
Clinical Investigations Committee of the BC Cancer Agency. The CIC initially rejected
the research on the grounds that a provision had been made to allow participants (family
members affected by HNPCC), upon request and with written consent, to be identified by
name and to be co-authors of publications. There were two reasons stated for this
rejection. Firstly, the importance of protecting the institution and patient with respect to
confidentiality was declared. In this instance, patients are primarily understood as
sources for health information, objects for treatment and variables requiring legal risk
management with respect to breaches of confidentiality. Secondly, patients were
described as lay-people without the necessary expertise to publish research articles.

The language of medicine is technical and clinical and is similar to the official
national language of a country. The language of lay-perspectives is like an unofficial
local dialect in the clinical setting and it is subordinate, problematized and has less value.
The officialization of language in the medical and genetic culture maintains legitimacy,
authority and power. Unofficial languages and ways of understanding are de-valued. As
patients and families are drawn into the clinical setting, professionals see them as vessels
from which lay-perspectives need to be emptied so that medical and genetic knowledge
can be poured into them. Lay-perspectives are rejected as “slang and gibberish” and the
more public manners of describing points of view are decreased in value (Bourdieu 1995:
49).

The linguistic capital of medical professionals is heightened relative to those of
family members and patients. Linguistic capital is a special example of cultural capital.
Cultural capital in this case essentially refers to a person’s credentials (e.g. level of
education: medical doctor, oncologist or genetic counselor). As the interviews with people affected by cancer will show, a deficiency in cultural capital for family members who take on new roles such as health promoter in the family sometimes creates tension in families. Words are moored in particular places in the social space and only certain people are consecrated with the social privilege to employ them (Bourdieu 1995). Just as only a physician can pronounce someone dead, only certain medical professionals are consecrated with the authority to perform certain tasks in genetic and medical culture. The interviews in this research show that both professionals and families pay homage to this social guide. Only a genetics expert can diagnose HNPCC and even the physician who treats someone for cancer will not provide their patient with a precise diagnosis of their condition if they are not consecrated with genetic authority. They will leave this task to someone vested with the power to perform this duty. In many cases, no such person of authority exists and the diagnosis is not made until much later or it is never made at all.

In institutional settings (e.g. schools, churches, hospitals, genetics clinics) certain individuals (e.g. teachers, priests, doctors, genetic counselors) are delegated with the authority to carry out key responsibilities (Bourdieu 1995). For instance, only a designated person can perform the task of christening a yacht. Similarly, at the College of Physicians and Surgeons, only a physician (the President of physicians) can deliver a reprimand to a physician guilty of professional violation. It would be inappropriate if a passerby were to spontaneously break a bottle of champagne on the side of a boat at a christening ceremony or if a public member of the College of Physicians Council reprimanded a physician. In these settings, only the designated representative has been
vested with the social authority required to perform significant tasks. In the genetic and medical cultures, there is a crisis in the social field given that there is no apparent designated expert or program to address families at risk for HNPCC. Just as it would create a social uncertainty for a member of the public to perform a Catholic Mass, there is also a social dilemma when families appear to know more about the disease that they are at risk for than the socially authorized representative, the medical practitioner. This research shows that oncologists do not, as a rule, diagnose HNPCC in patients that they treat for cancer because they think that someone else is vested with the cultural responsibility for performing this task.

**Social Capital**

There are a number of different types of cultural resources or capital that people seek out. Economic or material capital refers to assets in the commodified forms of wealth such as currency, stocks, belongings or property. Cultural capital refers to non-material assets such educational and technical credentials, insight or expertise that have been acquired. Symbolic capital (alluding to reputation, distinction, prominence) refers to honour or prestige that has been amassed. Symbolic capital is seen and understood in the power that is held by individuals “in proportion to the recognition they receive from a group” (Bourdieu 1995: 106). Symbolic power is rooted in the relationship between those who use it and those who surrender to it. Another important form of capital, **emotional capital**, which was not outlined by Bourdieu is also very important as the narratives of people at risk for HNPCC will show.

Medical doctors diagnose and patients are diagnosed. In this instance, symbolic power is more than an issue of the words that are utilized to diagnose. It is a reflection
of the organization of the social space. Patients cannot diagnose disease even if they have the words to do it; the performance of this act is the exclusive social privilege of the physician. A person cannot officially die until a doctor medically pronounces him or her as such. Someone who does not occupy the magical space sanctioning this power, such as a sociologist, cannot accomplish this pronouncement. I hope to show that social actors at least in part strategically negotiate these social assets. They are cultural resources that influence a person's value. The data collected in this study demonstrates that people knowingly engage in strategic actions in order to enhance and maintain the optimum value of their person.

Institutions make differences into legitimized distinctions, that is, they have as their main consequence the effect of "naturalizing" essentially social phenomena:

"One can see in passing that, as the process of institution consists of assigning properties of a social nature in a way that makes them seem like properties of a natural nature...such as man is to women as sun is to moon. Thus sexually differentiated rites consecrate the difference between the sexes; they constitute a simple difference of fact as a legitimate distinction, as an institution" (Bourdieu 1995: 119).

The social purpose of institutions, then, is to consecrate difference:

"To institute, in this case, is to consecrate, that is, to sanction and sanctify a particular state of things, an established order, in exactly the same way that a constitution does in the legal and political sense of the term. An investiture (of a knight, Deputy, President of the Republic, etc.) consists of sanctioning and sanctifying a difference (pre-existent or not) by making it known and recognized; it consists of making it exist as a social difference, known and recognized by the agent invested and everyone else" (Bourdieu 1995: 119).

The accomplishment of the institution is to achieve a kind of social wizardry that creates credentials such as medical or professional qualifications that are repositories of social value. The consecration of credentials accounts for why the complex understandings of people directly affected by disease are referred to as "lay-perspectives". The impact of
the institution accounts for what appear to be problems in communication between
treatment professionals and the people experiencing disease.

Institutions are elaborate performances that characterize and communicate
socially positioned identities for individuals. They can magically create boundaries and
some of these identities, such as that of the cancer patient, can be more than medically
dangerous, they can be socially fatal:

“All social destinies, positive or negative, by consecration or stigma, are equally
fatal—by which I mean mortal—because they enclose those whom they
characterize within the limits that are assigned to them and that they are made to
recognize... That is also the function of all magical boundaries: ... to stop those
who are inside, on the right side of the line, from leaving, demeaning or down­
grading themselves... This is also one of the functions of the act of the institution:
to discourage permanently any attempt to cross the line, to transgress, desert, or
quit” (Bourdieu 1995: 122).

As the narratives of those affected by HNPCC will show, people attempt to avoid
traveling across magical institutional borders into the devalued territory of the cancer
patient, the social space where personhood sometimes takes leave forever.

**Meaningfulness and Meaninglessness**

An implicit question emerges from the narratives of people at risk for HNPCC:
why are the various forms of emotional, social and family support: cultural capital so
valuable to people? Meaningfulness and its opposite, meaninglessness, both appear to
be important components of an explanation:

“... could rites of institution, whichever they may be, exercise their power... if
they were not capable of giving at least the appearance of a meaning, a purpose,
to those beings without a purpose who constitute humanity, of giving them the
feeling of having a role or, quite simply, some importance, and thus tearing them
from the clutches of insignificance?” (Bourdieu 1995: 126).
A notable feature of the conversations with people affected by cancer interviewed in this study was their prevailing contemplation about meaningfulness not so much regarding their illness experience but with respect to life itself.

Meaninglessness is the scorned correlate of meaningfulness. While those with powerful personhood enjoy the privilege of increased cultural capital in its various forms, there is a corresponding category of people without these benefits:

"But, through a kind of curse, because of the essentially diacritical, differential and distinctive nature of symbolic power, the rise of the distinguished class to Being has, as an inevitable counterpart, the slide of the complementary class to Nothingness or the lowest being" (Bourdieu 1995: 126).

The position of lower being means that individuals such as those with hereditary colon cancer are in danger of being placed at a social distance from others. This results in a kind of social death and is due to the three distinct blemishes of HNPCC: the shame associated with the site of the colon cancer, genetic guilt and the dread connected with cancer in general. These three factors came up repeatedly in the narratives of people affected by HNPCC and have a direct impact on the tenure of personhood. Those affected by HNPCC are aware of these social hazards and they work hard to avoid lasting injury to their person from these threats.

People's narratives about HNPCC will show that they do not just describe their understandings of their experiences with illness; they illustrate a social strategy within a system of social strategies in relation to personhood. The strategic fostering of personhood by those affected by HNPCC is part of a wider strategy for maximizing cultural capital. The history of family experience with hereditary cancer is powerful and almost always include influential events such as the death of a close relative from HNPCC. The conditions of family experience with HNPCC lead to such phenomena as
pre-selection, self-selection and ideas about cause that are illustrated in the patient and family narratives. Pre-selection refers to a process where family members identify an individual they believe to be a likely candidate to manifest a disease (Kessler and Bloch 1989). Self-selection is when an individual identifies himself or herself as the most likely candidate to develop a disease.

**Creating Meaningfulness: Emotional Capital**

During transformative periods in their lives, people actively and consciously shape themselves. The various forms of capital: economic, cultural, symbolic coupled with the search for significance and the desire to avoid a sense of nothingness are all useful theoretical contributions to a theory of personhood. At these times, people work hard to create subtly different types of capital from those precisely described by Bourdieu. The most important example is that of emotional capital. Emotional capital is obtained through personal connections with spouse, children, friends or other family members and I suggest is embodied in the pure relationship described by Giddens (1997). The pure relationship provides a tremendous quantity of emotional capital. During the siege of serious illness, people attend to threats on the economic and symbolic value of their person but they also create something more, a sense of power that is related to the very core of who they are. At this point, the self becomes a renovation project and in these instances people's imagination is more powerful than the structures that surround them. For a moment people are able to liberate themselves and make their family more important than their career and the pursuit of knowledge and autonomy more powerful than medical treatment.
In chapters four and five, the interviews with individuals at risk for HNPCC suggest that they actively construct who they are in their narratives. As a result, the process of personhood construction is a central aspect of healing emplotment. Individuals are able to re-define the economy of personhood so that emotional capital becomes more valuable than symbolic, cultural or material capital. This is not to nullify the array of social conditions that typically compel people to “cut their coats according to their cloth” nor is it to relegate the study of personhood into a fairy tale where anything is possible (Bourdieu 1999: 65). It is to assert that a complete account of the self must also include in its analysis an examination of the role of knowing strategic (reflexive) action. An intentional organizing tendency of the self is a central element in the narratives of people at risk for HNPCC collected in this study. The interviews in this study show that people at risk for HNPCC are aware of structures in the social space and that they react to them strategically. In order to further focus on the reflexive component of people’s narratives about their experiences with HNPCC, I have relied upon the work of Anthony Giddens. Ultimately, I plan to use the data collected in this study to advance an understanding of personhood that incorporates both the self in social structure (Bourdieu 1999) as well as the inner world of the self (Giddens 1997) to explain people’s narratives about the perils of HNPCC.

This research has led me to a borderland between several fields that include anthropology, psychology and sociology. The focus here is on the relationship between the self as the site for experience (in this case a serious disruption in health brought on by cancer or the risk of cancer), the network of family and friends (that provides the cultural
capital), and the clinic (in which the self is employed therapeutically but not socially or emotionally). My reconstruction of individuals’ accounts is intended as a composite portrait of a process by which everyday people create and recreate their self in context, a social action that is epitomized by the process by which personhood is produced in the circumstance of everyday life. Personhood is not a fixed or unchangeable thing that is beyond the pale of human relations. It is instead a process and social action that provides social actors with a palate to create a working drawing of themselves that they revise again and again. The very act of writing a thesis and looking for themes is itself an act of social construction and my academic interpretation of the subjects’ narratives is a way of appropriating power. In this process, I hope to avoid superimposing too much orderliness onto elements of experiences that might actually be arranged more intuitively by the subjects themselves.

Person-centred ethnography has been used in this study to examine narratives as a strategy to capture the process by which people make themselves and culture makes them (and vice versa). People’s narratives incorporate information gathered from a myriad of different cultures: genetics, medicine and oncology as well as wider familial experiences and cultural ideas that form their person. The portrayal of personhood here is, after all, only a snap-shot in time. This is admittedly one of the limitations of the research; it is only a series of pictures in time. The narratives that are shared provide a glimpse into the process by which families affected by HNPCC were authors as well as subjects in this portrayal. With the eventual advent of local genetic testing and raised clinical consciousness of the needs of these families, the landscape of issues associated with HNPCC is likely to change in the not too distant future. I am hoping that this research
will have provided an impression of the lived experience of families affected by HNPCC before genetic and clinical services were widely and consistently available for them. This study describes how they survive this illness, how they engage their personhood and how they become the stewards over their own survival through healing emplotment. This dissertation is part of their story.

The theoretical approach for this research is a departure from analyzing narratives about experiences with illness or treatment. While illness narratives highlight patient experiences and therapeutic emplotment focuses on medical plots, they both tend to concentrate on relatively specific experiences that are somewhat separate from larger life narratives. In healing emplotment, the process of person construction is pivotal. The framework proposed in this study begins with the premises that “the self is the narrative centre of gravity” (Dennett 1991: 426) and that the protection of personhood is central to the process of healing. By focusing on the importance of personhood, healing emplotment attempts to develop the discussion beyond illness and therapeutic narratives to a position that will allow physicians and patients to understand one another more effectively:

“All this might help us understand the multitude of daily interactions in which people hurt each other because they ignore what they are unprepared to hear. How does it help us figure out how they could heal each other? What change might enable people to realize what stakes are important to someone else, and then to realize that these stakes also matter to themselves, if only because they matter to someone else?” (DeCosse 1995: 19-20)

The theoretical framework proposed for this study encourages patients and physicians to see themselves as participants in each other’s stories (DeCosse 1995).

This chapter has provided a theoretical framework for examining the experience of people at risk for HNPCC in terms of suffering, healing and personhood. It has
offered a short discussion of what it is to be a person as well a brief overview of some variables such as fateful moments that can compromise a person. It has also reviewed some established theoretical areas about how people attempt to maintain their ontological security and a protective cocoon of their self (Giddens 1997). This study attempts to provide evidence that this is part of an ongoing reflexive process for people at risk for HNPCC. I have also entered into some new territory by introducing the concepts of healing emplotment and emotional capital. I argue that the interviews with people at risk for hereditary cancer show that many are searching for and place value on emotional capital as an important part of what appears to be a healing emplotment process. Pure relationships (Giddens 1997) appear to be one of the sources of emotional capital and the narratives of people at risk for HNPCC appear to show that they seek to nurture this type of relationship. A discussion of the institutional consecration of roles and a number of forms of social capital (Bourdieu 1990; 1995; 1999) was reviewed to aid in the interpretation of the clinical narratives. The importance of cultural capital will become evident in chapters 4 and 5 when it is seen that people at risk for HNPCC who take on key roles of information provider or health care promoter in their families sometimes encounter obstacles because they lack the cultural capital that is enjoyed by clinicians. Underlying the theoretical orientation employed in this study is the position that the self is a reflexive project and that people’s narratives about their experience with hereditary cancer tell us something about how they actively maintain personhood. The coming ethnographic chapters reviewing patient and family narratives attempt to provide evidence for this position. The next chapter provides an overview of the institutional and
systemic context of the study and, in particular, its influence on the delivery of medical and genetic services.
CHAPTER THREE: THE CLINICAL CONTEXT: THE BC CANCER AGENCY, HOSPITALS AND THE WIDER HEALTH CARE ENVIRONMENT

This chapter depicts some of the institutional and systemic arrangements that affect access to clinical and genetic services by patients and the practice of health care by professionals. In this section a definition for institution is developed to illustrate some of the structural arrangements in B.C. and their impact on understandings and experience of illness, sickness and disease pertaining to HNPCC. It is argued that institutional systems affect the ownership of health data (e.g. CT Scans), the roles of various medical specialties, the continuity of clinical care, access to genetic services and the various ways that risk is defined. An additional type of risk, institutional risk, is introduced in this chapter. A distinction is made between the practice of medicine and genetics in relation to HNPCC. Ultimately, an argument is put forward that they have different levels of symbolic capital and that they may represent two distinct cultures.

By describing a culture of oncology and medicine, I do not intend to reify the notion of culture. The definition being relied upon for culture in this study is interpretive and refers to a busy intersection of understandings and an ongoing negotiation of meanings. Certainly, it is not possible to step into the same cultural river twice (Hannerz 1992: 4). However, there do appear to be cultural hot spots of shared meaning that are shared within but not necessarily amongst groups of medical and genetics professionals. They appear like localized networks of negotiations where there are identifiable shared understandings about key topics such as the role of an oncologist in treating cancer and the role of a genetics expert in addressing hereditary cancer. They also result in two different foci: for medicine it is the patient and for genetics it is the family. I am using the idea of a culture of oncology and medicine in order to illustrate two quite different
intersections of understanding and meaning with respect to HNPCC. As well, I wish to acknowledge that genetics and medicine are not entirely distinct from one another and that they intersect in specific areas, such as at the Hereditary Cancer Program and at the point of referral for services. However, this chapter as well as chapter six highlighting clinical narratives will attempt to show that medicine and genetics are, as a rule, relatively distinct systems of meaning and understanding for HNPCC.

Medicine is based on clinical treatment; genetics is a realm that oncologists treating colon cancer believe to be better left to those with genetics expertise such as the professionals of the Hereditary Cancer Program. In fact, it appears that the only place where the cultures of medicine and genetics truly intersect in practical terms and cross-fertilize one another is within the Hereditary Cancer Program itself. In the HCP, family practitioners, pathologists, geneticists, genetic counselors, social workers and oncologists hotly debate and discuss the issues associated with genetics and medicine in the treatment and management of families at high risk for hereditary cancer.

The Hereditary Cancer Program

The Hereditary Cancer Program began as a research initiative and has gradually become an accepted program of the BCCA. It is still considered to be a research program but in many ways, in light of discussions by the HCP steering committee about level of service and standard of care, it is implicitly thought to be a health service. Certainly, family members interviewed in this study believe the HCP to be a service.
The HCP is a program that exists within the BC Cancer Agency pictured below:

Figure 3: BCCA

(Photo courtesy of the BCCA library)

By gaining official status as a program in the BCCA, the HCP has taken on the responsibility for providing expert advice and services to families thought to have family cancer syndromes. That is to say, the oncologists interviewed in this study believe that the HCP was the major referral centre for genetics services, that is, for patients and families in need of special clinical or genetic advice and care for hereditary cancers. Therefore, in practice, by having defined their research initiative as the Hereditary Cancer Program, the BCCA has simultaneously created a perception in the medical community that the HCP are the experts for treatment of most hereditary cancers including HNPCC. In
actuality, without adequate resources, the HCP is unable to fulfill all the needs for services for all hereditary cancers. Its main focus has been on hereditary breast cancer with only recent possible movement towards HNPCC.

In clinical practice, oncologists and physicians do not typically distinguish between HNPCC and sporadic colon cancer in their treatment, plan, and therefore, genetics is not very influential in their practice. Clinically, they perceive HNPCC and sporadic CRC as indistinguishable. The HNPCC factor is at most an interesting academic departure from the real business of treating a presenting disease in an individual patient. Patients are often not told about HNPCC by oncologists; some patients will not have heard the words HNPCC until they meet a genetic counselor more than a year after they have been diagnosed, treated surgically, and recovered from the disease. Addressing genetic risk and overall family experience with this disease is seen by oncologists as almost a frivolity and certainly as the responsibility of someone else with different expertise.

Families who have experienced colon cancer may be told, on the basis of their family history, that they appear to have a family cancer syndrome. However, discussion of genetic illness and family cancer syndromes is usually felt to be the responsibility of someone other than the treating physician, such as the Department of Medical Genetics or the Hereditary Cancer Genetics Counseling Program. Physicians sometimes make referrals to genetics programs but often patients are told about these services and expected to refer themselves. These genetics counseling services that provide specific information about genetic diseases such as HNPCC have long waiting lists (ranging from eight months to eighteen months).
Notwithstanding the HCP's inability to provide overarching genetics services for all hereditary illnesses in the province, they are, unquestionably the experts on genetic cancer in British Columbia. Relative to the oncologists interviewed in this study, their knowledge about HNPCC is superior. They may, in this sense, represent the future level of knowledge for the wider population of clinicians in the province. The HCP is a very small program with approximately 40 multidisciplinary participants including representatives from the social sciences, philosophy and numerous clinical specialties. In contrast, there are over 9,000 medical doctors in the province so the HCP is clearly a highly expert group with respect to hereditary cancer.

**Institutions as Bundles of Services that Consecrate Clinical Roles**

The two cultures, genetics and medicine appear to differ with respect to how they define the object of their professional responsibility. The medical clinicians tend to see the treatment of disease as their object. In the case of the oncologist, this is the treatment of cancer, the attempt to eradicate cancer tumors. The genetic culture, in contrast, focuses on the genetic mutation. However, the genetic culture includes the family as their responsibility. These two cultures are not entirely distinct at the HCP. Many of the participants in the decision-making of the hereditary cancer program are, for example, medical clinicians. However, outside of the HCP, it appears from the interviews conducted in this research that most clinicians are part of a culture that is distinct from that of the genetic culture, that of medicine.

In this sense, HCP is in a borderland but this, I found out, was an unusual group of professionals who had essentially time-traveled to the future where the family truly is the
object of medical attention and where genetics is relevant. Consider the following illustration:

Figure 4: Family

(Photograph of a family with genetic cancer provided courtesy of the HCP)

The picture, provided by genetic counselors, illustrates that they understand that the disease occurs in the family. However, the world where the family is the object of clinical attention is a distant one (it might possibly exist at some point in the future) and it doesn’t really exist in the present BC healthcare system.

Institutions include an assortment of services as well as technologies that directly consecrates the roles of its membership. Furthermore, the institution, using this expanded definition, can determine the focus of attention of its members, in this case, the
object of the clinicians in a hospital. In particular, the BCCA further configures the focus of clinicians towards the treatment of tumors (and disease) rather than whole people or families. If a service is not available for a disease, then the disease for the patient and practitioner, in some senses, does not exist. The services and technologies relevant to HNPCC might include: colonoscopies, support groups, genetics counseling, genetics testing and expert clinical advice for families at risk for this disease. In many ways, HNPCC does not exist in the institutional landscape of medical care in British Columbia. The clinical narratives discussed in chapter five of this dissertation suggest that clinical specialists who treat colon cancer do not readily distinguish HNPCC from sporadic colon cancer. Nor, as the interview with a gastroenterologist in the same chapter illustrates, are they always aware of what services are available for families with HNPCC. Virtually no oncologist could describe any specific stigma pertaining to HNPCC nor did they know whether a support group existed for people at risk for this disease. Some clinicians reported that there is a support group for colorectal cancer (there is not) and some even reported that there is genetic testing for HNPCC at the BCCA (there is not). There is not a formal program for testing (or actually even for counseling) for HNPCC in high-risk families. Families with HNPCC are at best treated as cases of sporadic colon cancer and, at worst, not treated at all. No one really knows how many families are likely to have HNPCC in BC. Estimates of incidence to date have been done almost entirely based on epidemiological calculations. There is not a registry of people with HNPCC (although some oncologists interviewed believe there is).
Types of Risk

Epidemiological and Clinical Risk

Several different types of risk have been described. For instance, Gifford (1986) has noted that there are three types of risk: epidemiological, clinical and lived.

Epidemiological risk is defined as the amount of risk facing a population. It is usually stated in terms of incidence per 100,000 individuals. Clinical risk refers to the chance that a disease is manifested in a particular patient. The following passage from an interview with a medical oncologist illustrates clinical risk:

**Interviewer:** In either of those cases, um, what kinds of things ... or, in both cases, would you discuss with the patient? Would you, for example, would you discuss prognosis with them?

**Medical Oncologist:** Oh, certainly. The first thing I ask a patient is what is their understanding of their, of their diagnosis. And that varies, depending on who the patient ... who has sent the patient to you, and, um, you know, what kind of patient it is. But, so, I’ll ask them, you know, what’s their understanding of the disease. And then I’ll tell them what the surgeon found at the time of, of the OR, and I’ll tell them what the pathology report says. Um, and then I’ll explain to them that they fit into either a higher risk group for the disease coming back, or a lower risk group. And if they fall into a lower risk group, then I’ll explain that they don’t need any additional treatment. Um, but that they need to have close follow-up. And I’ll explain what that follow-up is, and I’ll refer them back to their family physician. **If they’re in a higher risk group, then I explain why they’re in a higher risk group, and I usually give them some estimate of, of their risk of the cancer coming back in the next five years.** And I explain how adjuvant chemotherapy can improve the chance that they will be alive and well without cancer, by twelve to fifteen percent. And I explain the chemotherapy to them, the schedule and the side effects, and [pause] that’s about it. That’s about all we do in the first visit. And then, usually, um, if it’s just the first visit, we won’t dis ... and it’s a patient that going to get chemotherapy, we won’t discuss follow-up and so forth until they’re as ... discharged from the chemotherapy clinic. And if it’s a patient who doesn’t require adjuvant chemotherapy, then we’ll discuss, you know, the risk to the family and so forth, on the first visit. But if it’s a patient who does require chemotherapy, often that will come out in subsequent visits.

**Interviewer:** So, exactly how, how is it that you, you describe risk to them?
Medical Oncologist: Oh, um, heh. Most patients, I’ll explain that, um, currently there’s no evidence or sign of cancer in their body. But if their lymph nodes are involved, because this is where the risk becomes a problem, um, that’s a sign that, um, the cancer, uh, is at increased risk of coming back in the future. And, given that patient’s particular pathology, I’ll give them some indication of what the, what the chance is, statistically speaking, that that cancer could come back. And then I’ll explain that we have no way of knowing for any one individual patient whether the cancer will come back or not. Um, and because we, we don’t know that, we give all patients who have their particular stage of cancer, um, adjuvant chemotherapy.

Interviewer: So you essentially are describing to them, trying to translate to them, about epidemiological risk.

Medical Oncologist: No, not ... I’m not sure you would call it epidemiological risk. I mean, just the results of the studies that have been done in stage three colon cancer. Is that considered epidemiological risk? [emphasis added] (5 July, 2000)

The oncologist describes some of the variables that are used to determine clinical risk including: lymph node involvement and the stage of their cancer. The interview also demonstrates that clinicians are not necessarily comfortable in their knowledge of epidemiological risk. It may also refer to the risk of re-occurrence of a cancer that has been treated or that is considered to be in remission.

Oncologists are not necessarily familiar with epidemiological risk, except in passing. For example, when questioned about the number of HNPCC patients that they would have treated, most oncologists said that they had not ever treated one. When asked about the number of HNPCC patients that exist based on an epidemiological calculation, oncologists seemed puzzled or flustered by such an estimate. This question appeared to create some dissonance for clinicians between their original answer stating that they hadn’t treated someone for HNPCC and the realization based on their spur of the moment epidemiological calculation that it was probably the case that they had encountered someone with this disease in their practice.
Lived Risk

Lived risk refers to an individual patients’ experienced and perceived risk. This type of risk was the focus of my research. Consider the following example from an interview with a woman who had been treated for colon cancer:

Affected Female: Yeah. Yeah. Yeah. And, uh, I, I think, um, my experience, too, has been that, um, because of having this, and, and this isn’t just sort of a, a, a small, sort of, anec, anecdote, that, uh ... Because it’s, you know, having cancer, and because of the whole thing, and because of, you know, you’re at higher risk for uh, uh, other cancers, you know, you know, internal organs.

But I had a mole. A small mole. That, um, was itchy. And it seemed to me to have gotten larger. But it wasn’t ... it didn’t look, um, you know, you know, it wasn’t irregular, or dark, or, you know, anything. But it, it itched, and it bothered me quite often. And uh, I sort of had focussed on it. As, as, uh ... I wanted it removed. And I had a really hard time, um, getting it removed. It took me two years to, to get it removed. Um, because it was, you know, my doctor would say, “No, there’s no, nothing wrong with it.” And, and I, I think I asked three times. It took me ...it was, “No, there’s nothing wrong with it. No, it’s fine.” Uh, and to me, it was, it was, uh, “Okay, fine.” But I just wanted it removed. And it was, it was, um, to me there was a lack of understanding that, that considering the ... my background, that even if this wasn’t, you know, partic ... that it was a, it, uh ...

Interviewer: It was symbolically important.

Affected Female: It was symbolically important. And that every time it itched, I remembered cancer. So it, it was, um, uh, [pause]. That was, I thought that there wasn’t, there wasn’t a whole lot of, um, of understanding of, you know, what my, my mental state might be. Or what, you know, my perceptions of, you know how big this mole can get. [Laugh]

Interviewer: Sure.

Affected Female: I’d already had, uh, uh, cancer. And I knew, and you know, it was, it would be [...] I knew. I still ... what if, you know, what if this [...] Uh, and there it is. Uh, you know. So, so, it was always sort of ... and I didn’t like to be reminded, constantly of, uh, my mortality. [Laugh] So ...

Interviewer: This had more significance to you ...

Affected Female: It had more significan ...

Interviewer: Than it did to them.
Affected Female: Yeah, it had more significance to me than just, you know. And I just, um ... and then it turned out that, um ... I made an appointment, uh, with my dermatologist, uh, myself, um, because they also, they won’t pay for moles unless they’re malignant. And so you have to go through this whole rigmarole. And I said, “I don’t care. I’ll pay for it. I just, I just, I just want it taken off.” You know. Um, and even with, you know, with, with the dermatologist, he said, um, “I can tell you right now [interview subject’s name removed]...”

Interviewer: Deal with it.

Affected Female: Tell me. Tell me. Just ... I know, I realize it’s pretty easy to take it. Just take it away. Just, just take it away, and I’ll be really happy. [Laugh] And, and, uh, uh, I laughed at this point, because he said it would probably leave a scar. I mean, it was a tiny little mole, right? I have this huge hemicolecctomy scar. [Laugh] Like, look, it was right here. And I, I, I don’t think it’s going to make much difference. At this point, it can leave a scar. Leave a scar, charge me $100. Just, just take it away. I know I’m overreacting. So, humour me, just humour me. Um. Uh ...

Yeah. Yeah. Yeah, that was, uh, um [pause] Um, yeah. That was, you know ... um, and that ... it went on for a fairly long time. You know with, you know, I’d go every ... and then I’d feel stupid. You know I’d think, “Oh, that’s just neurotic.” And then I’d go in and I’d ask again. And, uh, there still wasn’t anything wrong with it. I just wanted it off. You know, I just really really wanted, uh the whole ...

Interviewer: It was very significant.

Affected Female: Yeah.

Interviewer: On many levels.

Affected Female: Yeah. Yeah. And, I ... Yeah, and I, I think, too, it’s ... you know, there are, um ... I just thought of this actually, too. Is that, that, you know, at this time ... it was also that, um, like, I’ll be forty in June, right, so this is all been really early. But,uh, like, my grandfather died at forty-eight. My father died at forty-eight. And, so I had this ... there was also this little thing going, “I wonder, uh, if that’s significant.” [Laugh]

Interviewer: And these are real things for you.

Affected Female: And these, these are ... you know, and so, so you have this, coming up to that age, and, uh, and then having, you know a colon cancer. In situ, but still it ... for me that counted. Uh, and, uh, yeah. So, you know. And I
think that was .. [pause] that there wasn’t really a lot of [long pause]. Yeah, a lot of concern as to how that would actually, you know affect [ ... ] And then, like, like, and then, you know, I, I thought maybe, you know, if I kept on about this mole long enough, you know, the doctor would say, “You must be concerned about something.”

(Interview with an Affected Female, 20 March, 2000)

The age of death for her father and grandfather were significant as was the mole in her lived risk. The example shows that lived risk may be at odds with clinical and epidemiological estimates of risk but is still a very large part of the overall cancer experience for patients. Lived risk has very real ramifications within the patient and family lifeworld and it may, for instance, lead a patient to have prophylactic surgeries (e.g. colectomy, oopherectomy or mastectomy).

Lived risk can also affect clinicians. For example, according to one general practitioner from a rural region of BC, some patients choose to have mastectomies rather than travel to the urban centre where less invasive surgeries are available. This occurs partially due to the fact that the main specialist in this area, a surgeon whose mother experienced breast cancer and had to have a double mastectomy has herself had a mastectomy and advises all her patients to follow this same course of treatment. As a result, nearly all the patients with any form of breast cancer have mastectomies regardless of its clinical efficacy. In this regard, lived risk can have clinical ramifications and it might be useful for clinicians to take this type of risk into account when engaging patients about their treatment and considering the patient’s understandings of their cancer risk. The efficacy of mastectomies even in the case of women with breast cancer is far from conclusive. In fact, clinicians are not unanimous in their support for mastectomies even in cases of women with advanced breast cancer. Breast cancer still occurs in women who have had mastectomies and their long-term survival rate is not necessarily
increased by this procedure (Interview with Medical Leader of the Hereditary Cancer Program, Radiation Oncologist, 2000).

Genetic risk is another type of risk that might be described as a special category of risk. This risk is usually described to a patient or family by a genetic counselor or medical doctor with genetics expertise and refers to the likelihood that their family may carry a mutation for a genetic disease. Many participants in genetic counseling have not, themselves, been diagnosed with cancer. Genetic risk may also describe penetrance, that is, the likelihood that disease will be manifested in a particular individual once it has been established that they definitely have a genetic mutation for the disease. This type of risk is normally not discussed by mainstream clinicians and they clearly perceive communication about this type of risk as being the responsibility of a different set of experts such as those working for the Hereditary Cancer Program.

**Institutional Risk**

Finally, there appears to be a type of risk that is defined bureaucratically. I will refer to this as **institutional risk**. This risk is defined by incorporating elements of clinical, epidemiological, genetic and lived risk. This final type of risk takes into account potential legal ramifications of providing genetic services (in terms of risk management for the institution rather than the patient). This final type of risk may have direct implications for a patient. The determination of institutional risk also takes into account the available resources within the Cancer Agency and the health system as a whole (through an assessment of funding availability). They may be denied access to genetic testing because they do not meet the criteria for "high risk" that merit their participation in a genetic testing service. When determining institutionally defined risk, the HCP takes
on the role of advocate for resources within the BCCA, the Government health system and the private funding sector. Perceived risk also impacts the way in which institutional risk is defined. Members of the HCP discuss the impact of "not offering" a particular service to individuals, families or groups of at risk individuals. Institutionally defined risk is mapped out in the formal criteria for allowing individuals and families to access genetic services (testing and counseling). Ultimately, institutionally defined risk is spelled out in a letter that explains to patients and families whether they are considered at risk enough to meet the criteria to receive genetic testing. This type of risk is especially evident when the HCP establishes the confidence limits for results for BRCA1 and BRCA2 testing for families who are found to be in a "gray zone" with respect to their risk of having an as yet undiscovered genetic mutation for breast cancer.

In some cases, an individual's personal assessment of risk appears to be based on a complex estimate that incorporates all these known types of risk. Most people interviewed in this study assessed their risk as high. Peoples' perception of risk may also be influenced by worries about external appraisals of their risk. For example, some individuals with strong family histories mentioned fear that even though they have not yet manifested a disease or been shown to carry a genetic mutation for HNPCC, their level of risk might be defined by insurance companies as high. In my examination of clinical, family and patient narratives it became clear that risk is heavily influenced by contextual and institutional factors. Risk is, in short, culturally constructed and it is created in subtly different ways by genetic counselors, clinicians, epidemiologists and families.
The GI Tumor Group

The GI Tumor Group is part of the medical culture. This group showed me a set of observable symbolic arrangements with "an elaborate repertoire of designations and titles" (Geertz 1975: 32). It was a "theatre of status" (Geertz 1975: 33) and the participants played their roles according to a readily identifiable cultural script. There is a clear culture to the weekly case conference of the GI Tumor Group. When I was first introduced to the Group it was announced by the Chair of the GI Tumor Group that I would be observing indefinitely and that he spoke for all the participants in not only welcoming me but proclaiming their collective support for the advancement of medical science, to which my study would hopefully contribute. Each member wore a tie and many also wore white laboratory coats as well. Others wore nametags that designated their official status as a Cancer Agency employee. I modified my clothing accordingly from a sweater and slacks to a dress shirt and pants with a tie. I also requested an identification badge so that I would fit more seamlessly into the group.

There was clear evidence of status differentiation amongst the different subgroups of participants in the GI Tumor Group. The GI Tumor Group had a number of distinct conventions:

- An attending clinician presents (such as a GP)
- Representatives from several groups: Surgeons, Radiation Oncologists, Medical Oncologists
- Pathologist Role: Images: Slides (microscopic view of tissue samples and discussion of type, degree of cancer and amount of penetration to various body systems)
- Radiologists Role: CT scans
- Remarks from subspecialities: Medical Oncologists, Radiation Oncologists, Surgical Oncologists
- Surgeons had the most cultural capital
- The Chair Summarizes, guides and asks for input from each Clinical sector of the GI Tumor Group
The Surgeon seemed to have the most cultural capital of all the participants. If a surgeon was not present for one of the case conferences, then it was noted and in some instances conclusive recommendations for a particular case were deferred until representation from this group could be obtained. If a medical oncologist or radiation oncologist was not present then the meeting carried on without such postponements of decision making.

The clinical culture is not homogenous and there are different zones of expertise. Their expertise existed in different parts of the clinical planet. Their language was understandable amongst their different cultures in the same way that Inuktitut is understood from Russia to Greenland across the Arctic Circle but only at a rudimentary level. The subtleties and more complex words were not immediately comprehended by all the participants. This became evident when members of one subspecialty would ask for clarification from another with regard to a presentation or analysis of a case.33

**Therapeutic versus Healing Emplotment and the Ownership of Health Data**

In one case presented at the GI Tumor Group a clinician shared a number of clinical cases and image studies including CT scans, x-rays and slides but before opening the floor up for questions he noted that some key CT image studies were missing. He went on to describe how these were actually in the possession of the patient who had refused to return them to the hospital after she had been given them to carry to a specialist for a consultation. Apparently, the woman in question had decided that she owned the images since they were taken of her body and that she concluded that she

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33 The power of technology was clearly present. The Case Conference makes use of multimedia image sharing equipment that has the capability to be linked to several sites throughout the province. This real time discussion of cases allows for interactive discussion and, most importantly, the asking of questions by the clinicians about image studies and the particular expertise of each consultant specialist. It showed that
would not allow them to be shown to anyone without her being present. The clinicians chuckled at the thought of a patient perceiving that the results of image studies could be owned by anyone besides an institution, in this case, a hospital. However, this clashing perspective between patient and doctor left a symbolic hole in the series of sophisticated images shown to the case conference. A clinical picture, typically undivided, was fragmented by this symbolic act of patient power.

**Entering the System as a Patient**

A patient is overloaded with a barrage of clinicians with which they interact. At least 12 different clinical experts will follow a single patient with colorectal cancer. The patient will have face to face interactions with most of these individuals. As part of their treatment experience, a patient with HNPCC may interact with the following medical professionals following their case:

- A Medical Oncologist
- A Radiation Oncologist
- A Surgical Oncologist
- A General Practitioner
- A Gastroenterologist
- A Variety of Nurses
- A Genetic counselor
- A Medical Geneticist
- A Radiologist
- A Pathologist

If patients undergo genetic testing, then other clinicians will be added to their case including:

- A Genetic Laboratory Technician
- A Nurse Educator

the interpretation of image studies was not black and white in the case of cancer. There was a great deal of expert interpretation about the meaning of the disease present, treatment options and prognosis.
The actual autonomy of the clinician is constrained by the institutional definition of their role. While theoretically the role of the oncologist may be autonomously defined by the profession in terms of a responsibility to treat patients living with cancer and not those at risk for cancer, it appears that their responsibilities are institutionally defined within carefully circumscribed limits. In actuality, the oncologists are organized into three groups: radiation oncologists, surgical oncologists and medical oncologists.

**Increased Specialization**

Institutions define the precise role of oncologists in interacting with patients. Essentially, surgical oncologists deal with surgery. Medical oncologists deal with chemotherapy. Radiation oncologists deal with radiation therapy. This is part of the local culture of oncology and is institutionally arranged accordingly at the BCCA:

**Interviewer:** Just a, a few basic questions. What is the role of a radiation oncologist?

**Radiation Oncologist:** [Pause] Uh, you've hit on a sore point. Huh. Having trained in Britain, I trained as an oncologist. Here, we've got a dichotomy between chemotherapy and radiotherapy for, uh, for no good reason, except it's what was done south of the border, I think. If I treat a patient with bowel cancer, um, uh, I have to be able to treat it knowing something of the disease and all the other treatment modalities. I mean, if I'm ignorant of what happens in the operation, then the radiation is not safe. Not ... if I'm ignorant of the chemotherapy, the radiation's not safe. And it's the same the other way round. And I find it quite odd that I look after somebody with bowel cancer, and I send them down the corridor or, well, they'll have to wait for another appointment to see somebody else who's going to give them the chemotherapy.

Um, I feel the hyper-specialization ... I feel very strongly that the hyper-specialization is leading to being technicians. And, and I think it is to the detriment of the patient. Uh, I think there is a lot of, uh, important things, uh, because the, uh, there are several modalities of treatment. I mean, there is surgery, which has to be integrated with, um, other direct, uh, uh, anti-cancer treatments. Um, [throat clear] but, um, uh ... and I, I think there is, uh, ample evidence that if you are a specialist, uh, uh, or you, your patient is treated at a special centre, that your outcome is better. Um, uh, I see a lot of problems here in trying to coordinate between two physicians in a centre where our cooperation
between radiation and, uh, chemotherapy is very good. Uh, I know of other centres where it, uh, can be disastrous.

Um, so, a radiation oncologist treats cancer by, um, giving radiation and giving an opinion as to the, um, natural history and management of the disease.

(Interview with a Radiation Oncologist, 8 June, 2000)

This cultural ordering of the role of oncologists into specialized roles indicates a sore spot in the discipline, especially with respect to the continuity of care for the patient as they are compelled by the institutional arrangements to move patients from one stage along a theoretical continuum to another. Other clinicians also recognized the impact of changing institutional arrangements upon patient care:

**Interviewer:** Um, what’s your evaluation of that, relative to the old way it used to be done?

**Oncology Nurse:** Um, I don’t particularly like it. I don’t like being split. You don’t ... the patients aren’t split. You know, the patients get both radiation and chemotherapy. Um, and, and I, I, I feel that, um, um, I’m I ... I know chemotherapy, but I’m losing some of my knowl ... Not ... Hm. Well, some of my knowledge of radiation. Um, uh, I don’t like, um, as well, basically the patients are, you know, if they’re, if the patients are going to be having both treatments, they’re not split into programs. So, why should their, their care be split into programs? You know, like, if they’re on, if they’re having a combination of chemotherapy and radiation, they’ll see me for chemotherapy, and they’ll see another nurse for radiation.

**Interviewer:** So there’s not as much continuity.

**Oncology Nurse:** There isn’t the continuity. Yeah. yeah. And, so, I don’t, I don’t think it’s as good as it used to be.

**Interviewer:** When did it change?

**Oncology Nurse:** About, um, two, three years ago.

(Interview with Oncology Nurse, 18 October, 2000)

In fact, this continuum appears to be only theoretical in nature and patients sometimes may miss key pieces of information or segments of care along the way.
Perceptions of the Researcher

It appeared that I was perceived by clinicians, patients and families as intertwined in (or at least related to) the clinical world. Families frequently asked about whether my research would impact the quality medical services or whether the research would result in the offering of genetic testing for HNPCC. Most people interviewed asked me to define medical anthropology. Some clinicians appeared to perceive my study as a clinical initiative.

For the professionals, I discovered that there were two distinct though sometimes related cultures: the genetic and the medical (some individuals such as the participants in the HCP straddle both of these cultures). Sometimes, the HCP appears to provide the only bridge between the two cultures but most of the time they are separate, that is to say, most of the time people appear to be members of one or the other but not both.

Like the Balinese described by Geertz (1975), the interviews with the professionals in my study did not allow me many opportunities to break through their unvarying construction of their public identity as medical professionals. When it did occur it appeared unnatural and uncomfortable and it was as though as Geertz describes, we had “happened upon each other’s nakedness” (Geertz 1975: 34). Likewise the professionals appeared to be “contextualized persons” similar to those members of Morrocan society described by Geertz (1975). Their personhood, at least in the context of being interviewed by me, was very much defined by their institutional roles.

Overall, I was surprisingly successful in acquiring interviews with clinicians. Given that their schedules were described as extremely busy, I was not anticipating being able to obtain relatively open access to their time for an interview. This availability of
clinicians was likely related to the generous support of a prestigious clinician who e-mailed each of the clinicians who I wanted to interview about my research. This may have contributed to my being perceived by clinicians, at least initially, as a member of the clinical culture.

It appeared that the clinicians were not sure what to think of the research. It seemed unusual to them to be engaged in an open-ended interview where they were asked a series of what appeared to be non-clinical questions. One clinician, when asked about the interview, was unsure about the purpose of the interview. In short, they didn’t appear to follow a scientific or medical pattern of research.

As the research progressed, it became increasingly clear that a monolithic institution of medicine does not exist. This is certainly the case in oncology. The field of oncology is comprised of a heterogeneous group of clinicians each with a distinct focus. The categories of oncology are not immutable. In Britain, for example, the medical oncologist role encompasses the responsibilities for both chemical and radiation therapy. In Canada, these are separate roles. There are clear cross-cultural differences in the cultures of oncology.

In general, the clinicians were very good at describing HNPCC. So much so, that I began to become suspicious about whether they had reviewed HNPCC before I arrived via the Internet, Medline or the medical consultation database. In this regard, my study in some ways may have artificially raised the level of interest into HNPCC as an issue in the oncology community.

It appears that the individuals who treat cancer have a very specific focus and that their roles are institutionally arranged. No one clinician appears to be responsible for
seeing the overall patient, with the possible exception of the general practitioner who is universally perceived by those interviewed as having the least and most inconsistent knowledge of genetic conditions. This raised some questions about the continuity of care for individual patients and their families.

The institutional arrangement of tumor groups at the cancer agency further exacerbates the problem of narrow focus in cancer. Oncologists treat cancer tumors using different techniques based on their specialty. They deal with the patient when he or she arrives; they already have cancer. Their object is a disease, a cancerous growth, a bit of tissue that needs to be resected, radiated or chemically altered. HNPCC is a side issue, something to refer to another department, the Hereditary Cancer Program. Many of the oncologists see HNPCC as irrelevant to their interaction with the patient. The causality appears almost irrelevant in this clinical institutional world; the disease exists or it does not.

**Patents for Genetic Mutations**

In August of 2001, Myriad Technologies sent a letter to the Province of British Columbia Health Ministry and the BC Cancer Agency informing them that by providing genetic testing for the BRCA1 mutations they were in contravention of patent law (See Figure 5). Myriad Technologies, based in the United States, had patented the majority of the processes associated with genetic testing for the BRCA1 genetic mutation associated with the most common form of hereditary breast cancer. Letters were also sent by Myriad to the similar clinical and government bodies in Ontario and Alberta. The health ministry officials of the Provincial Government of British Columbia immediately complied with the request and ordered the BCCA to instruct the HCP to cease all testing
Ontario ignores patent, pushes ahead with breast cancer test

By APRIL LINDGREN and AMY O'BRIAN

The Ontario government is defiantly forging ahead with a genetic-screening test for breast and ovarian cancer despite legal threats from an American company that says it has a patent on all aspects of the process.

In this province, the B.C. Cancer Agency stopped performing the test in the fall of 2001 after the ministry of health services said it couldn't afford to challenge the patent in court.

Ontario's Health Minister Tony Clement announced Monday the province will ignore legal sabre-rattling by Utah-based Myriad Genetics Inc. and spend $1.2 million on a sophisticated screening test for about 600 women over the next nine months.

"We have been threatened by this company with legal action for over a year now," Clement told reporters. "Their claim is that they own the gene sequence that says it has a patent on all aspects of the process. Their claim is that only they can sequence or test a genetic mutation that increases their risk of developing the diseases. We have said that we don't accept that claim and we are disregarding that claim. We will go to the highest court in the land on this."

Clement added Myriad charges $3,850 per test while Ontario's procedure, which can be done more quickly, costs $1,100.

Ontario's stance means women in B.C. who are deemed high risk and qualify for the test will have an option other than forking over nearly $4,000 to the American company. This year, about 200 blood samples from B.C. will be sent to Ontario for the test.

B.C. Cancer Agency president Simon Sutcliffe said the agency will facilitate the testing, but is taking precautions to avoid breaching the Myriad patent.

"We're going to advise the women that the test is available in Ontario, that we can link them to the lab in Ontario, that we can facilitate how the blood gets there, but we can't do the test," Sutcliffe said.

"We also will not have the lab in Ontario give us the result of the test. We'll tell the lab to give it directly to the woman in question and the woman in question can then ask us what the interpretation means and what should be done with it."

Sutcliffe said that though the process is circuitous, it puts the onus on the woman instead of the agency, meaning the agency is not breaching the patent.

The agency does not agree with the patent and would like to be able to do the testing here, but Sutcliffe said it is willing to comply with the law until the matter is brought to court. "I think B.C. believes the law is the law, even though the law may not be correct, it is still a fault to break the law. Therefore you have to deal with this by changing the law."

"I think the position that Ontario has taken is one of 'We cannot be bound by bad law, therefore we'll break it.'"

Clement said if Myriad's comprehensive claim to patent protection for genes becomes the norm, it would have wide-ranging implications, including restrictions on research and the development of tools to predict and treat other genetic conditions. Researchers say 60 per cent of Canadians will experience diseases with some genetic component during their lifetime.

Vancouver's Andrea Griffin is outraged by Myriad's threats and its claims to exclusive rights to people's genes. "I think it's appalling. My genes belong to God, they don't belong to a private company," she said.

"Would I like my daughter to have the right to that test? Damn straight. Our family has several members who carry the gene here and in Ontario. Some have developed cancer, some have not. In order for her to make a reasonable choice when she's older she needs that information."

The test to be used in Ontario is considered more than 95 per cent accurate in predicting whether women with family histories of breast or ovarian cancer have a genetic mutation that increases their risk of developing the diseases.

Setting it straight

This is the list of winners of the Parvasti Bharatia Sarman Award, which honours Indians abroad:

Ujjal Dosanjh, former premier of B.C.; Sir Anerood Jugnauth, prime minister of Mauritius; Sir S.S. Ramphal, former secretary-general of the Commonwealth; Professor Fatima Meer, associate of Nelson Mandela of South Africa; Dato Seri S. Samy Vellu, cabinet minister of Malaysia; Lord Navnit Dhulakia, a member of Parliament in the United Kingdom; Dr. Hari N. Harilela of Hong Kong; Kanakxi G. Khinjii of Oman, Dr. Manilal Premchand Chandaria of Kenya and Rajat Gupta of the U.S.
for hereditary breast cancer. Alberta and Ontario did not. In what seemed like an instant, the legal interpretation of patent law and the wider business world shot a bolt into the HCP and the lives of the families served by the program.

The Impact of the Pharmaceutical Industry on Local Support

No support group exists for HNPCC families. Similarly, no support group exists in British Columbia for patients and families who have experienced sporadic colon cancer. While there is a national colon cancer support program, its base is in Toronto and does not adequately reach the patients in the local area. The national support group, complete with a web site and executive director, does not have any perceivable local presence for patients and families and it will not endorse an independent local group. It has regional representatives from each province and is influenced largely by the pharmaceutical company that funds the support initiative. This company sells medication for colorectal cancer and has a local delegate for the British Columbia region. This delegate told a small group of patients who were trying to set-up their own support group that a local support group was unnecessary and unwise because it compromised the strength of a national voice for colon cancer patients. This national voice is centred in Toronto at the Drug Company-funded support association head office.

As well, after providing funding for the set-up of a national association for survivors of colon cancer, the company told the participants that they were not allowed to accept donations of any kind from any rival pharmaceutical companies. This essentially creates a monopoly across Canada for patient support groups by this particular company. The company also requested that they be able to advertise their chemotherapy medication for treating colon cancer in the pamphlets, brochures and informational materials for people
diagnosed with colon cancer. After considerable discussion and debate with the company representatives, the participants in the national support group were successful in denying this request. The logo for the sponsor company remains on the back of the information pamphlet.

I attempted to assist people diagnosed with colon cancer with the set-up of a local support group but the national representative who wished to support the vision of the national association actively discouraged this process. This representative was also the clinician for a number of the participants in this fledgling support group. As the national representative for the colon cancer association, she flew to Ontario a few times each year and met with the national participants. Her interest was to share information about the goals and activities of the national group in information sessions with BC patients but she discouraged any attempt by these patients to set up an active or independent local group (in terms of funding or goals). The group ceased to meet after four meetings.

Support groups are not “natural” outcomes of all illness experiences. They become or are made “natural”. One of the central organizing principles of a support group is the creation of what Bourdieu (1995) has called an emblem (the opposite of a stigma). One way that a support group is consecrated is to have it anointed by a spokesperson who possesses a significant amount of symbolic capital (such as a famous person):

“The act of social magic which consists in trying to bring into existence the thing named [in this case a support group] may succeed if the person who performs it is capable of gaining recognition through his speech for the power which that speech is appropriating for itself by a provisional or definitive upsurption, that of imposing a new vision and a new limit on the social world... to consecrate a new limit” (Bourdieu 1995: 223).
This is why individuals with HNPCC and the fledgling support group members recognized the need for a ‘famous spokesperson’ for the ‘movement’. They wanted to transfer the symbolic capital of a well-known figure onto the socially devalued person affected by colon cancer. Someone with a significant amount of symbolic capital could either launch the support group by magically changing stigmata into an emblem. A number of people affected by HNPCC made reference to figures with a lot of symbolic capital such as Pamela Wallen or Katie Couric, either of whom might come to exemplify the cultural messiah for colon cancer:

Figure 6: News Article on Katie Couric and Pamela Wallin
Like changing water into wine, a famous person could transform colon cancer disease into a cause worthy of supporting.

It is an example of cultural alchemy to create a support group by turning the stigma associated with HNPCC into a set of emblems. In a support group, individuals with HNPCC have a lowered symbolic capital that they are engaged in a struggle over classification:

"...struggles over classifications, struggles over monopoly of the power to make people see and believe, to get them to know and recognize, to impose the legitimate definition of the divisions of the social world and, thereby, to make and unmake groups. What is at stake here is the power of imposing a vision of the social world through principles of division which, when they are imposed on a whole group, establish meaning and a consensus about meaning, and in particular about the identity and unity of the group, which creates the reality of the unity and the identity of the group" (Bourdieu 1995: 221).

The power to unmake and make support groups is one that exists within the institutional structure of the medical field. Either the BC Cancer Agency itself or a large
pharmaceutical company has the power to approve the creation of a support group. A support group appears unable to survive without the sanction from legitimate sources of cultural power.

**Differing Time Horizons, Expectations, Strategies and Accountability: Research Studies versus Clinical Services**

During one of the monthly HCP case conferences, the issue of time lines for reporting back to families was discussed. In particular, two cases were reviewed where families waited for a number of years before receiving results from the HCP. In one case, a family at risk for HNPCC waited for over four years before receiving results from Ontario regarding their genetic testing. The HCP was the referring agency to the Ontario program. Ironically, in the course of the four-year wait, the Ontario Hereditary Cancer program sent the family a questionnaire surveying their satisfaction with the services that they had received. No doubt this questionnaire was generated automatically and sent to the family following a set time period after their initial referral. In another case, a woman was referred to the HCP in December of 1996. The results of her genetic testing were presented nearly six years later to the HCP case conference in March of 2002.

When the issue of prolonged time lines was discussed at the HCP, it was suggested that perhaps families might not understand the limitations of research initiatives in providing timely results. The interviews completed in this study suggest that families do not fully understand the difference between a research initiative and a clinical intervention with respect to expectations for timeliness of outcomes. Families appeared to perceive the HCP, regardless of how it is funded or cast internally, as a service. Certainly, family members did not appear to have re-adjusted their expectations with regard to the timeliness of correspondence and results from the HCP as part of an
understanding that research is expected to be dramatically slower than medicine. In contrast, the family’s expectations of the HCP appear the same as those for a clinical service; they do not appear to give the program more leniency due to its official status as a research initiative in terms of their expectations for prompt communications, responses and results.

This is understandable given that in early discussions of the HCP, it was not clear that the clinicians themselves actually perceived the program as primarily research. The HCP, in practice, has the appearance of a clinical service and is discussed by the stakeholders in program in relation to appropriate standards of care and medical outcomes for patients and families. At the very least, it is medically related and an integral part of the decision-making process for clinicians who present cases there. In some ways, the decision to offer genetics counseling and testing as research appears to be more strategic than substantive, especially as the HCP gained more of a profile amongst referring clinicians, an increasingly large “caseload” of families and status as a program. The HCP is in many respects implemented on a day to day basis in a similar fashion to a clinical service rather than a research study. While rigorous research and evaluation is an indivisible part of the HCP, its official placement under the rubric of research appears to be in many ways an issue of a funding and political strategy. Families and clinicians appear to share a vision of research as a means to achieving a potentially clinically efficacious end, much like a clinical trial for a medication that might show some curative promise.

Observations of the discussions at the HCP made it apparent that clinical and research initiatives have different timelines and levels of accountability to their
participants. In essence, researchers appear to have less accountability to participants in studies than do the clinicians to patients receiving medical services. In research, the research objectives are at the root of the program whereas in medical service the patient's interest is at the core of the agenda. This difference in focus flows into an evaluation of what is considered to be an acceptable timeline in the research and the clinical culture.

The HCP, as a research program, appears able to stretch out its timeline for delivery of its outcomes (e.g. an appointment for genetics counseling, genetics test results or correspondence with a participant) much farther than a clinical timeline would allow. In the medical realm, a wait of four to six years for a result would not be as readily explainable to the participants (patients). Researchers do not appear as accountable to the participants in a study as clinicians would be to patients receiving medical care.

The second case discussed at the monthly case conference also brought into the discussion the possibility of genetic testing of children. While this was an issue previously encountered at the HCP, this recent discussion provided an opportunity to observe the authority of the medical narrative. In the case reviewed, the possibility of offering genetic testing for two children at risk for a mutation for a rare cancer was discussed. The potential benefit was described as providing one or both of the children with a negative result that would thereby liberate them from invasive clinical surveillance regimes. It was agreed that early diagnosis and surgery was the only treatment for this disease. A number of strategies for enhanced clinical surveillance were discussed including: PET Scan, MRI, spiral CT Scan and surveillance by a thorough general practitioner.
In the course of the discussion, a bio-ethicist suggested that there were possible negative outcomes as well that included stigmatizing behaviour from the parents towards one of the children if they were found to be positive and the other negative for the genetic mutation. A medical doctor interjected at this point in the discussion and stated that they were aware of studies that showed that siblings who were given a negative result alongside a sibling who received a positive result were susceptible to feelings of guilt. A genetic counselor noted that these would be issues discussed at length with the family in question. A nurse practitioner noted that genetic testing is performed in children at risk for FAP.

A senior pathologist noted that the mission statement for the program contained a provision for the possibility of genetic testing of children. The bio-ethicist countered that the medical benefits did not clearly outweigh the potential negative effects of providing genetic testing to children and cautioned that the issues needed to be examined more carefully before proceeding. A medical doctor then asserted that the disease was potentially a lethal one, that it could be prevented and that “he was not going to apologize for taking a medical perspective in this situation”. The medical doctor played the medical field’s “trump” card in the discussion, that is, to prevent death, by detecting and removing a deadly sarcoma. The heightened cultural capital that is held by the medical doctor was made clear in this situation. The medical doctors have more cultural capital than the other practitioners present (counselors, ethicists, social scientists, nurses) and the ability to prevent death garners them additional symbolic capital. The senior pathologist then brought in a narrative that highlighted the economic climate of health care service today by stating that the health care system could not afford to recommend imaging for
both of the children in this family if it were unnecessary. CT scans, he concluded, were an unnecessary cost to the system if you could eliminate [potentially] the need for them by genetically testing the children. Here the clinician employed an administrative narrative to take on the role of the careful steward of the health care system. The bio-ethicist’s perspective was silenced, and the discussion ended.

Interestingly, the genetic testing does not detect or remove the deadly sarcoma. It is the clinical surveillance (serial PT scan, MRI, spiral CT scan, careful observation by the GP) and intervention that could save the lives of the children, not the genetic testing. The genetic testing provides the possibility for one or both of the children to avoid the clinical surveillance. Here, it appeared as though the medical and genetic cultures commingled into a confusing mixture of narratives.

An unpublished research study was reviewed at the HCP in June of 2000. It examined the understandings of participants in counseling sessions regarding uninformative genetic test results. The original purpose of testing in this situation is to find a genetic mutation, but sometimes one is not found. This does not mean that one does not exist but instead means that the test was unable to locate one. These test results are scientifically uninformative in that they do not locate a genetic mutation for a hereditary cancer. Conversely, they do not indicate that one does not exist. These results do not entirely rule out a genetic cause of the family’s cancer nor do they comment on the family’s risk for sporadic cancer. It appeared in the findings of this questionnaire-based study that individuals receiving uninformative results sometimes interpreted them incorrectly to mean that they had received some reassurance that they were not at risk for genetic cancer. These individuals in many cases went on to spread information
throughout their family that was based on their incorrect interpretation (scientifically and clinically) of their result.

The potential widespread distribution of incorrectly interpreted information from a genetics service was a cause for major concern for the participants of the HCP. The lead investigator for the study highlighted a number of concerns about the accuracy of the interpretations by participants in genetics counseling sessions. She made several suggestions for tools that might help increase the accuracy of the participant’s interpretations of information sessions with genetic counselors including the use of:

- Videos
- Pamphlets
- A clearly written letter for the participant about what the results really mean scientifically
- A clearly written letter to family members about what the results really mean scientifically about their risk
- Face to face discussion of uninformative results with the individual who underwent the testing rather than telephone reports
- Face to face discussion with family members about uninformative results.

The presentation of this study and the discussion that surrounded it highlights the difference between the meaning of genetics counseling for professionals and families. The interviews in my study suggest an alternative interpretation. Rather than misunderstanding uninformative results, people affected by hereditary cancer are sophisticated in their understanding of their disease and its risks. However, while the primary purpose of a genetics counseling session for the professional is to provide a scientifically accurate risk assessment, many family members come for entirely different purposes. They already know that their risk is high or they would not be there. The reason that they come to the session is to seek an authority that might help them in their attempt to colonize their future risk of cancer and to enhance the strength of the
protective cocoon of their person and family in the process. Ultimately, they want to lower their sense of risk so that they can overcome the fateful moments of genetic susceptibility to disease and avoid being engulfed by powerlessness so that they can go on with life. Uncertain results help with this attempt to secure a bit of certainty and hope to the mantle of their trust system that is threatened by cancer. Ironically, both families and genetic counselors share a common goal: the processing of risk but one uses science while the other uses healing emplotment. Uninformative results are useful and they are used by individuals to heal by providing emotional inoculations and to create hope that risk can be overcome in families. No amount of reconfiguring the science or methods for communication will address the fact that they are at cross-purposes and their different understandings about healing are like two ships passing one another silently in the night.

The HCP draws on the perspectives of many disciplines including pathologists, medical anthropologists, bio-ethicists, various oncologists, genetic counselors and nurse educators and is, theoretically, constructed by blending the cultures of both medicine and genetics. For the most part, the discussion at the HCP is a busy intersection of narratives from this diverse group of disciplines but during critical times of decision-making two viewpoints emerge with the most cultural capital: the medical and the administrative. The rich exchange of ideas at the HCP is like a microscope with a series of lens: clinical lens, genetics lens, administrative lens and social scientific lens that are put in place to observe the issues on the hereditary cancer slide. However, the most powerful lens is the medical one, with the administrative lens a close second and when they are slipped over the slide all other lenses are blurred.
This chapter has attempted to illustrate some key areas of the institutional and healthcare landscape that shape the experience of clinicians and patients. A working definition of institution was developed and a new type of risk, institutional risk, was introduced. Institutional risk has particular importance for families with hereditary cancer and the Hereditary Cancer Program in terms of its allocation of resources. Other impacts of institutional structure, such as the existence of tumor groups and the alignment of genetics services under the rubric of research have led to difficulties in continuity of service in addition to problems of resource allocation. For patients, these represent more fundamental problems pertaining to access to services that they feel are important. In some ways, genetic susceptibility to illness had become a commodity as was illustrated by the examples of Myriad technologies stopping genetic testing and the intrusion of the pharmaceutical industry into the support group for colorectal cancer. Finally, the chapter ends with an example of the immense symbolic capital of clinical practice in the HCP. A further aim of this section has been to show the institutional consecration of medical and genetic explanatory models about disease, illness and sickness with lay perspectives occupying a subordinate position in this epistemological social hierarchy. Furthermore, lay understandings are often seen as a territory that requires colonization by medical and genetic understandings. These mysterious and murky lay perspectives are the focus of the next chapter.
CHAPTER FOUR: INTRODUCTION TO PATIENT AND FAMILY NARRATIVES

This chapter begins to present the texture for this study by introducing the narratives of family members at risk for HNPCC. This section provides some ethnographic data for the investigation and, in particular, offers a glimpse into what have been categorized earlier by various authors as lay perspectives. These lay perspectives have been largely ignored in research to date and few studies exist that provide data describing them. This chapter begins to provide some actual data on lay perspectives by drawing on interviews with family members at risk for HNPCC about their understandings of illness, disease and sickness. This part of the dissertation includes a description of the experience of interviewing people with cancer as well as a discussion of how the interviewer was perceived. The narratives themselves offer a complex analysis by family members of the knowledge base of professionals, treatment, prophylactic surgery, public ideas about cancer, perceptions of colon cancer as a male disease, the meaning of counseling and the risks associated with genetic testing (e.g. loss of insurance or mortgage). These interviews point to the peaceful co-existence of lay perspectives, medical knowledge and genetics and they begin to cast doubt on the aptness of the term ‘lay perspective’. The narratives show a deep reflexivity as people knowingly confront the fateful moments brought about by HNPCC such as the possibility of death as they work to develop approaches that will bring about a sense of emotional inoculation.
Background

Given that I had not yet obtained written consent for the interviews until I met the participants face to face, I did not usually know much about them except that their family was likely to have a mutation for HNPCC. Often, I did not know whether an interview subject had had direct experience with cancer or if they were family members of people who had experienced HNPCC. I did not ask for background information from the referral source, usually a genetic counselor, before commencing the information. I wanted to interview people in person and to let the interview unfold unfettered by too many of my own prior expectations. As a result, the precise experience of the interview participant was a surprise for me. The participants were the stewards of their family’s experience and their narrative. This meant that sometimes I would meet patients, sometimes spouses (of people at risk or affected), sometimes people at risk and sometimes other family members. Each interview initially began as some mystery about the connection of the participant to cancer. I found out about the person and how they defined themselves before their experience was revealed in due course. Once the initial contact was made to a potential participant, the participant themselves decided whether they would connect me with further family members. Beyond the first referral from a genetic counselor, it was the participants, therefore, who were the gatekeepers for both information and additional interviews in their families.

Many of the families that I interviewed had had devastating and tragic experiences with cancer. One family in particular had lost their father and a sister to cancer and three of the six daughters in the family have been diagnosed with colon cancer. As I first arrived for the interview I was unexpectedly met with a large
contingent of the family and friends who were all assembled together in the room. Some had come to participate while others were there to observe and to provide support.

Earlier in the day I had interviewed one of the sisters who had also experienced cancer in another town. I interviewed this family with three generations present in the room in addition to a spouse and a family friend as well as a niece and her boyfriend. The entire family sat in a semi-circle around the kitchen table with the husband of the first participant sitting on the counter as a part-time participant in the interview. Each person was interviewed one at a time. I focussed on one person’s narrative but from time to time another person in the room would participate directly. However, overall, the group observed one person’s priority at a time while I asked questions and they shared their individual perspectives.

The first of the participants, Roberta, was the youngest of six daughters. At the time of the interview she was 34 years of age and she had two children of her own. Her father was diagnosed with colon and lung cancer and given eight months to live when he was forty-seven. He died when she had one month left to her eleventh birthday. Early in March nine years ago (1993) she discovered that she also had colon cancer. At that time, she was 25 years old and she believes that she may have been the youngest case of hereditary nonpolyposis colorectal cancer in British Columbia. Her children were three and six years old at the time and it was very difficult for them. Her youngest daughter at that time was having a recurring dream where each night she saw an angel over her mother. One day, she announced to her mother shortly before the discovery of the cancer that “mommy was going to die”. Since that time, her daughter has continued to experience worries about her mother’s fate. Today, after having had surgery, Roberta’s
bowels have never been the same. Each year she has blood work and a colonoscopy but life has become scary as she worries about every little pain that it may signal the return of cancer. Her daughter has since quit having the dream about the angel and so Roberta is reassured about death for the time being. One year after Roberta’s diagnosis, her sister Margaret was diagnosed with colon cancer in 1994. In 1999, on the 13th of December, Roberta’s sister Brigette died of colon cancer. Roberta has coped by using lots of laughter and talking with the whole family about the experience. She has told absolutely everyone she knows and does not keep her experience a secret.

As I began to interview the mother of this family, unease overcame the room. Clearly, this woman had lost a lot as she had seen her husband and three of her daughters struck by colon cancer. She was nervous about being interviewed as she began to talk about her experience with cancer in her family. She lost her husband twenty-four years ago when he was 47 years of age. Her youngest daughter Roberta was the first to experience colorectal cancer after the husband and then one-year later her daughter Margaret was struck with colorectal cancer. Her daughter Brigette died of colon cancer in 1999. She spoke proudly of her family as she described all her daughters but as she tried to summarize the impact of cancer on her family she became overwhelmed with emotion. As she sobbed painfully her daughter Roberta stood behind her and rubbed her shoulder and I turned off the tape. There was an uncomfortable moment as the tragedy of the family’s experiences weighed on the moment and although my inclination was to try to say something soothing I said nothing. Suddenly, the good friend of the mom who had been observing the interaction between the researcher and the family says: “Look at him, he’s sitting there all naively and he just doesn’t know a thing about who he’s
interviewing”. At this moment, I thought that I was about to be held accountable, and perhaps rightfully so, for intruding into the lifeworld of these people who have paid so dearly and experienced so much tragedy. I felt as though I had somehow opened up old wounds filled with so much pain that perhaps no one should have dared mention the experiences, never mind ask for the entire account. The justification for the research project seemed colorless for a moment and I looked down at my feet as sadness overcame us all.

But, much to my surprised relief, the friend continued on in a different direction altogether and finished her point with a brilliant rescue: “he knows absolutely nothing about the incredible sex life of this woman and her daughters; it’s their sex life that I think might have some type of genetic mutation and what I’d really like to have them tell us about”. The mom exclaimed over her tears: “what can I say, I’m hot blooded; so are my daughters. It’s what drew my husband and I together in the first place”. Everyone in the room laughed uncontrollably and I revealed my true purpose, that I’d actually been sent by the cancer agency in order to investigate the genetic roots of their extraordinary sex life. The mom went on to portray herself as more than the victim of tragedy and her family as more than people who had experienced illness. She was an oil painter, a world traveler, a camper, a caregiver, a woman who had proudly raised six children on her own and she was a hot-blooded lover. She was well aware of threats to her protective cocoon and her family by societal ideas about cancer, death and tragedy. She would not let herself be defined by a disease and this was part of her healing narrative.

The initial part of the interviews attempted to take a ‘snapshot’ about the participants’ background: their education, their work experience, their health status, their
family and, in general, attempted to derive a sense of how the person defined themselves. One of the first questions that I always asked the participants, whether they were patients, family members or clinicians, was: ‘tell me about yourself’. This gave people an opportunity to define themselves from their point of view. Often, I followed with more specific rapport-building questions and societally defining variables such as: what do you do, what is a typical week like for you, do you have brothers and sisters, etc. In virtually every interview, this line of questioning never precipitated a comment from people with respect to cancer. Even though people knew that the focus of my research was on their experience with cancer, most of the people interviewed for this study never mentioned cancer until I mentioned it.

**Perceptions of the Researcher**

As a rule, it appeared that most people interviewed tended to see the clinicians as all part of the same clinical world whether they were genetic counselors, surgeons, oncologists or medical doctors. The participants also appeared, at least initially, to invest the same level of cultural capital in me as they would in professionals from the clinical and genetic world. Most people interviewed were very supportive of genetic testing and some people even looked to my study as a potential mechanism for advocating for genetic testing for HNPCC. Generally, people appeared to enjoy telling me about their experiences. The following is an excerpt from an interview with a person who had not experienced HNPCC but was at risk for it and asked me directly whether my research would help to establish genetic testing in BC:

**At Risk Female:** So I’m hoping, I’m hoping, um ... I guess that’s the only thing you can do at this time [for local genetic testing]. As far as another emotion or another experience or another whatever, I’m hoping that, uh, the BC Can, uh, the BC Cancer Agency gets a lab or something here in British Columbia soon. Uh,
the research that you’re doing, okay, finding out from family members, how does it affect them? What are their feelings? Um, how do they feel about having it, how do they feel about not having it, uh, and, and, you know, how does it affect? What do you see? What do you feel? What do you hear? Um. That’s ... it’s, it would be nice to see something like that on paper. It would be nicer to be able to read that on the Internet for what cancer research is doing. Um. Because you don’t always read that. What you do read on the cancer research a lot of times, or what I have read, anyway, is basically, uh, their latest study. Uh, sure, the latest study is nice.

(Interview with At Risk Female, 20 July, 2001)

Many of the family members interviewed hoped that my research would help to establish genetic testing and many reported that their motivation for participating in the study was to improve the system of services available (health and genetic) to people at risk for the disease. This social conscience regarding improving the community of people affected by cancer appeared to offer some evidence for the existence of an orientation towards the life politics described in Chapter Two (Giddens 1997).

Overall, people appeared to be quite comfortable in telling me about their experiences. The following example illustrates that some individuals were even comfortable telling me things that they might not tell others:

**Interviewer:** Yeah. Do you tell friends, or [about HNPCC]?

**At Risk Female:** Um, not ... well, it’s not something that’s in the forefront of my conversation, that’s for sure. But I ... there are some friends that know of my family history. Uh, people that I’ve known forever and a day. Sort of thing. But, uh, there’s lots of friends that don’t, that don’t know. I mean, sort of, my friends that know about my, my dad, would, you know, would have know that he had been in for cancer surgery, sort of idea. But, uh, there’s lots of my friends that don’t, don’t have, uh, any idea. And none of my friends know about my, um, problem with the [specific health difficulty]. The [specific health difficulty]. **My husband doesn’t know, either. I haven’t told him that. I mean, he would be worried sick, constantly. So, there’s no point in telling him unless it actually happens.**

(Interview with At Risk Female, 2000)
She did not want to needlessly introduce a fateful moment into her husband's practical consciousness and threaten the integrity of his emotional inoculation. This ease of sharing information with me was likely due to the fact that I was removed from their immediate social group and that my study protected their anonymity. In a number of instances, people became emotional and in others it appeared that the study provided a forum for open discussion and thought about HNPCC that did not exist elsewhere in the lives of the participants.

**Describing Cancer in the Illness Narratives**

Before interviewing people with cancer I had been told by many people that the interviews were likely to be very emotionally exhausting due to their gloomy and tragic subject matter. Before asking people questions about their cancer experience that really 'reached the heart of the matter' I was somehow imagining that I would be lowered into a frightful and shadowy narrative world. In fact, this was almost never the case at all. Instead, whenever I asked the question “can you tell me about your experiences with cancer”, I was treated to a feast of insights, humor and a generous sharing of people’s vitality and philosophy of life. Consider the following interaction:

**Interviewer:** Can you tell me about your experiences with cancer?

**Affected Male:** Well, the way ... because the reason .. the doctor, like you said, my father had had ...my grandmother had colon cancer in her early seventies. And then my father, about four years ago? Also got diagnosed with colon cancer. And had kind of almost an emergency surgery. I mean, he had a big growth that, uh, um ... he was, what, getting anaemic, and he was bleeding inside, and they found a tumor, and they, they took it out. So [wife] said, “Well, at your age, late forties, you know, with your history, you should get examined.” So I went to my GP. He said, “Oh it’s not a bad idea.” He referred me to a gastroenterologist who said, “We’ll do it, though even with your family history, you’re not at a high risk.” Which I've subsequently learned actually isn't true, from the geneticist here. Um, I'm evidently fifty percent predisposed to cancer. Um, coming from
my grandmother’s side, according to [name of medical practitioner], who is the geneticist at VGH.

So, um, so I went for the test and they found a polyp. And, uh, it was, it was flat, or something, so he couldn’t remove it. Apparently because he was afraid to perforate, uh, the lining. So he took a biopsy and then, um, [wife] called as if she was my doctor, saying she wanted the results of this patient [chuckle]. So when I walked in the day, the door one day, she had this look on her face, saying, “It was malignant.” Right? So, um, so it had to come out. In, right, there’s um ...

So, it, it was a little unreal. [Wife] was more upset than I was. In a way, more concerned than I was, I think. I mean, I’m sure of it. I mean, the whole thing was a bit unreal to me. And, um, I got in, I think fairly quickly, in terms of, nine, ten days or something. From the time they found out till the time they did the surgery. And, so I had the cancer. And to be honest, I found being sick like a vacation. You know. I mean, it was, it was, you know, you got to lay in the bed and you didn’t have to worry about what was happening in the market, and you didn’t have to clean the gutters, and, uh ...

[background chuckling of spouse]
... worry about anything. Your life became reduced to that moment, and the post-op discomfort, and, you know, relieving the pain, and can I sit up by myself, and, you know, when am I going to be able to go to the bathroom, and, just ... I mean, it was just ... kind of quieted down. And in a way, it was a holiday. You know. [Chuckle] I mean, I’m ...

**Interviewer:** Mm hm.

**Affected Male:** And it was interesting. Because, um, the surgeon I had was a, really a [...] here. And he said, uh, he recommended this book, “Love, Medicine and Miracles,” Bernie Siegel. And I know the name. You know, he used to be on the pop shows. It was a best seller. Are you familiar with it?

**Interviewer:** I haven’t read the book.

**Affected Male:** So he recommended, “It’s maybe something you want to think about reading.” So, anyway, I read some of it. And, uh, one part was, uh, where, in ... Siegel’s a traditionally trained surgeon from Yale Medical school, and, uh, then he became kind of mind body, and dot dot dot. But, um, he said in his experience, about fifteen percent of the people, when they get a diagnosis of cancer, kind of feel a sense of relief. Because they think they’re going to die, and they won’t have to hassle life anymore. And I had a little flavour of that, you know. I thought, well, you know, I mean, I wasn’t scared. Um, I thought, well, if it doesn’t work out, I don’t have to worry about what the market’s doing. I don’t have to think about retirement, or, or I’m tired. It’s like a rest, you know? I mean, uh, there’s a up side to it. [Chuckle] And I, I was obviously ...

**Interviewer:** [Laugh]
Affected Male: ... it's just kind of stupid, you know, but, um, you know, I thought, if it wasn't for [wife], I mean, we don't have kids, um, that was, you know, that was okay. You know. And I, and I quite honestly realized, I'm not afraid of dying, I'm afraid of being broke. And I joked about this with a parent at school, in September. And it was in May that I'd had the surgery. And he laughed, and said, "Me too." And then it turned out he went broke. And he, he blew his brains out in January. So. He meant it. Um. [Laugh]

Interviewer: Mm hm.

Affected Male: I mean, he really meant it. You know. Um, but I realized that's actually, I'm more in control of my life. Of, you know, planning for retirement and doing that than the fear of, you know, I may not make it out of the surgery. It may, you know, I mean. But I, I liked the experience. I liked it, um, well, because otherwise, I'm, I was at peace... [emphasis added]

(Interview with Affected Male, 11 December, 2000)

The subject describes cancer as a holiday and he notes that it has an upside. The statement that he used to fear being broke rather than death shows how before he was diagnosed with cancer he had valued material capital over death itself. The couple consciously confronted this concern and reconfigured the social value of emotional capital so that it was more precious than material capital. His spouse was a physician who gave up her practice while he continued to work so that they could focus more on a pure relationship. They changed the themes of their autobiographical narratives by seeking emotional capital from a pure relationship. Rather than feeling drained or consumed by dread, I often found myself leaving my interviews feeling inspired and excited about peoples' insights about their experiences.

The families interviewed all had enormous experience with cancer. They had all lost relatives to HNPCC and many had lost close relatives such as parents, siblings or children to the disease. The following interview extract illustrates this point:

Interviewer: Can you tell me about your experience, uh, your family's experience with cancer?
At Risk Female: [Sigh] Well, um, the first person that we know that had cancer was my grandmother. And she had, um, surgery in Victoria. And she had, um, I think it was a gall bladder operation, at the time. When they discovered the bowel cancer. And she, uh... it metastasized. It was, it was, uh, a little bit late when they discovered it. And it had metastasized to her bones and to her brain. And she died when she was seventy-seven.

My, uh, dad. No, not my dad. My uncle was next. And he got the cancer when he was about forty-eight. And he had radical, um, surgery where they remove the whole, the whole bowel and given them a colostomy, and everything. And he died when he was fifty. Now, that would have been about [pause] mm, twenty-seven years ago. Hm, what year is that? ‘77?

Interviewer: Yes.

At Risk Female: Twenty, yeah. Twenty-seven? No, twen, ’73.

Interviewer: ‘73. Yeah.

At Risk Female: Yeah. Um, so he died, and then my dad got cancer. Now, he’s eighty-five now. Still alive. My mom and dad are both still alive. And he got it about fifteen years ago, so he would have been about age seventy. I’m ... now, this is, would be give or take a few years, because I’m not sure of the exact year. And he got the bowel cancer, and had just not, not a colostomy or anything, he just had a resection. Of the surgery. Or, of the, uh, cancer. And he is, he didn’t have any, uh, chemotherapy, or any radiation. Which surprised me. And he’s, he’s living today.

My ... his other brother, about, approximately the same time, contracted cancer. And had the same surgery. I don’t know if he had, um, chemotherapy or radiation. I don’t know. He lives in Edmonton. And, uh, he’s still alive too.

(Interview with At Risk Female, 13 December, 2000)

Later in the interview, this individual disclosed that her former husband had a sister who died of colon cancer at age 36 and that this dramatically elevated her daughter’s risk of HNPCC. People talked about it quite openly and were capable of listing off all the relatives who had experienced cancer, the age of onset, specific manifestation, treatment and outcome. All the families interviewed are very experienced with cancer, and firmly believe that their cancer is inherited and already have an elevated sense of their risk for HNPCC before they ever encountered clinicians or genetic counselors. Most people are
not looking for information about their risk status when they visit professionals; they are looking ways to fortify the cocoon that protects their person so that they can go on with the business of everyday life.

**Threats to Emotional Inoculation and Prophylactic Surgery**

The clinical literature reviewed in the introductory chapter suggests that one of the issues associated with HNPCC is whether or not to perform prophylactic surgery. In fact, although this is a frequent concern for people with respect to FAP, discussion of its possibility does not appear to be a part of the clinical culture in British Columbia. When clinicians were asked about their perspective on this intervention, it seemed as though this was the first time that many of the oncologists had ever considered this issue. The sparse knowledge that oncologists have about HNPCC may be the underlying point here. Given that it appears that most clinicians do not distinguish between sporadic and hereditary colorectal cancer, it follows that they would not consider prophylactic surgery in HNPCC given that they would not consider it to prevent sporadic colon cancer.

In contrast, families at risk for HNPCC do think about prophylactic surgery. In fact, their examination of surgery in general is very complex. For example, one person at risk for HNPCC noted that if she were to be diagnosed with colon cancer she would not only have to decide whether to remove the cancerous tissue but she would also have to consider the amount of the actual tissue to remove. This is balanced off with a desire to avoid a colostomy, that is, how much to remove to maximize the cancer treatment but to avoid the stigma of a colostomy. When faced with removing some of the intestine, at risk family members wondered: do you instruct the surgeon to remove more of the intestine than the part that actually has growths on it or do you have more removed as a
prophylactic measure? This was one of many instances where family members appeared to be ahead of clinicians in terms of knowledge about HNPCC even though the medical practitioner would have significantly more cultural capital.

The family members interviewed were proactive with respect to their agenda in genetics counseling. Consider the following example where an at risk individual raised questions about her children’s risk in addition to the issue of prophylactic surgery:

At Risk Female: Yeah. They were very informative, actually. That lady doctor, doctor, uh. [Physician’s Name] was very nice. Uh, what did I ... what were my questions, now. I had wanted to know about, uh, my children. You know, what the risks were for them. And it depends on if I, if I test negative, they won’t have to be tested. And if I test positive, there’s a fifty-fifty chance that they will have the gene. And then they will have to be tested, as they get older, if we decide to do that.

And, um, I talked to her a little bit about, you know, removing the, the whole colon. The large intestine, as opposed to just taking out the piece where the polyps are. Because I found out that the, the genetic, um, mutation or whatever that we have ... there’s two different kinds. And apparently one is polyps, like hundreds of them. You ... from ... even when you’re a small child. And the one that, that we have is HNPCC, which is a little different, and which is the occasional polyp or whatever, as you get older. And, um, she really didn’t seem to think that, um, it was really necessary. But, more or less up to a person’s choice. Same thing, you know, that the other doctors say. I guess. It takes a long long time to grow this type of cancer. And, uh, the only reason for taking it all is that you wouldn’t have to worry about it coming back. Because usually it’s just in the large intestine. So that’s why more doctors, she says, sort of push towards having the, the whole, uh, large intestine removed. So. But she didn’t really see that ... that that was that necessary, to take the colon out. That it was still up to, you know, you as a patient, really. [emphasis added]

(Interview with At Risk Female, 7 February, 2000)

Here the individual at risk is proactively asking about prophylaxis with respect to HNPCC and has reached the impasse in that there does not appear to be an ultimate expert for them to consult regarding this question. The example also seems to indicate that protective consciousness extends from parents to children. The at risk individual interviewed above further noted that this is a question that is often left out of discussions.
between the clinician and the patient but that this is a difficult one to make without having some scientific data regarding the effectiveness of prophylactic surgery in colon cancer or clinical guidance to help in decision making. This is an especially relevant issue in colon cancer given the belief of patients that the more intestine that is removed the more likely that the individual may have to make use of a colostomy bag which, in turn, carries with it lifestyle changes and stigma regarding the unusual removal of body waste. In contrast, the issue of phrophylactic surgery for HNPCC was virtually never raised by the oncologists that were interviewed for this study.

This particular individual also drew on examples from the experiences of her friends with other diseases such as an acquaintance that had breast cancer and, as a result, was faced with the choice of having either a lumpectomy or a mastectomy as a treatment. The clinicians involved could not provide any scientific or clinical data to support one or the other course of action and therefore left the decision up to the patient who felt ill equipped to make a decision between these two dramatically different options. The interviewee looked forward to getting some answers from the HCP counseling session regarding these issues in addition to an assessment of genetic risk (does she carry the mutation and what are the chances that her kids will). She was looking for some clear direction (an authority) from the clinicians.

Threats to Personhood from Narratives about Cancer in the Wider Community: The Big “C”: You’re Going to Die

Simply having cancer does not mean that you will die. Many people with HNPCC do not die. Colon cancer, although it is the second leading cause of cancer death in Canada next only to lung cancer, death from this disease is preventable through early
detection (colonoscopies) and treatment. The following individual illustrates that cancer doesn’t necessarily signal someone’s demise:

**Affected Male:** The most significant way this experience. [Pause] I don’t know. I would say, probably the knowledge of what’s going on with what you’ve been told. What’s wrong with you is the best. Finding out and understanding what’s going on is the best thing that you can do for yourself. To … for anything like this. ‘Cause when we, when I … like, when I first, I was told I had cancer, it was like, “Oh, shit.” But, uh, once I got the information on what exactly goes on and what’s, uh, what’s there, and what’s [sigh] what’s really wrong, and what they can do, and stuff like that, really seemed to help. And understanding all that stuff. So I think that’s one of the things about this. Really knowing what’s, uh ——

**Interviewer:** Can I ——

**Affected Male:** —— is going on.

**Interviewer:** Can I ask you, on that note, what did you think about cancer before you experienced it? Like, you, you obviously … you found out some stuff about it.

**Affected Male:** Oh, shit. The big C. You’re gonna die. [Laugh] [emphasis added]

(Interview with Affected Male, 19 July, 2001)

However, while HNPCC does not automatically signal a clinical doom it is a fateful moment that warns of a possible social demise that may require an individual to reinforce their protective cocoon.

Many of the people interviewed suggested that cancer appears to be associated with death in the wider community. As a result, many reported that their friends behaved strangely towards individuals affected with HNPCC:

**Spouse of Affected Male:** …As far as the stigma with just colon cancer? No. Um, the only thing I have noticed is that people don’t want to call you. They, they think about you, and they worry about you, but, ev, eventually they will call, and they’ll say, “How is everything?” You know, they’re frightened. They don’t know what to say, because they know he’s been sick, and they don’t know if he’s still alive, or, um … They’ll say, “I, I don’t like to call, but I, I’ve been, I’ve been thinking about you.” You know. And I’ll say, “Well, do call. It, it’s fine.” So, you get a certain shying away from … of friends and, and, uh, even some relatives.
Who are on the fringes. You know, cousins and that sort of thing. "**Been thinking about you, but we didn’t know what to say. So we didn’t call.**"

And, you know. So, that sort of thing. People are frightened of death. People are frightened of, of, uh, what you’re going through. So they don’t know what to say, so they don’t say anything at all. So they don’t call. Um, when you kind of wish maybe they would. Yeah. That’s the only thing. No stigma, that I can feel. But just that feeling of, “I don’t know what to say to them, so I won’t call.” That’s the only thing. [emphasis added]

(Interview with Spouse of Affected Male, 26 May, 2000)

The observation by the spouse of an individual living with colon cancer that people do not know what to say supports the notion that cancer presents a cultural conundrum for people: they do not have familiar narratives besides those warning of death. For some friends and family members of people affected by colon cancer, the idea that someone might be nearer to death impacted the way that they behaved towards their affected relative or acquaintance:

**Interviewer:** Who, who did you tell about your experiences with colon cancer, once you had this, the test, and you were diagnosed with it?

**Affected Female:** Um, a couple of my closest friends. Um, [pause] ooh, I guess obviously, family. Relatives. I can tell you, out, out of interest, that, um, after I’d had surgery -- I’m saying this now that it’s of interest to you -- but, I began to wish that not as many people did know about it. Because I would have ... certain people would come to me, and they would say -- this would be, like, within a year of surgery, or a year after surgery even -- “Are you okay? How are you doing?” Like, you know, “Is there something more wrong with you?” or, “Are you going to be around here for much longer?” And, uh ... so I don’t talk about that very much, now, with, with people.

**Interviewer:** And these were friends of yours. [Throat clear]

**Affected Female:** No, even relatives. Some relatives. Yeah. Really meaning well.

**Interviewer:** Mm hm.

**Affected Female:** But, uh, I really believe everyone needs to be treated the same. Whether, you know, you have it or you don’t. It’s very important.

(Interview with Affected Female, 12 December, 2000)
The association between doom and cancer in the wider community had a very real impact in the lives of individuals facing HNPCC and the effects of these social dynamics were in many ways worse than the cancer itself. A number of affected individuals reported that friends shrank away from them once they had experienced cancer, that the friends stopped calling and that they appeared to be lost for words in conversation. What is it that they fear about cancer more than cancer itself? It appears to be a loss of the status of full personhood. What could this loss of status really entail: loss of social connection, loss of sexual prowess or loss of vocational aptitude? There appears to be a “cultural blind spot” regarding cancer. People are at a loss for words, they don’t have familiar cultural narratives, besides those that signal tragedy, to guide them.

In many instances, it appears that HNPCC can sometimes be a fairly minimal intrusion into peoples’ lives in terms of physical impediments. The following individual, who was diagnosed and surgically treated for cancer was back at his job as a truck driver in one month:

**Interviewer:** So, how long were you off work? You said you took it easy for about a week. When you got home. How long was it before you were back and at it? In terms of work?

**Affected Male:** Well, I was ... operated March 30th. I think I was back at work on May 1st.

**Interviewer:** So not much time.

**Affected Male:** No.

**Interviewer:** Did you ——

**Affected Male:** Couldn’t afford it. {Chuckle}

**Interviewer:** No. And what about, uh ——
Affected Male: Well, my boss just let me take it real easy. It was no problem with him.

Interviewer: How about, um, chemotherapy? Did you have any chemotherapy?

Affected Male: Yeah, I did chemo. I worked while I did chemo. Chemo, for what they gave me. 5FU? Is that what it was? Yeah. Wasn’t all that bad. Uh, had the, uh, little bit of shitting fire. Uh, I got a nose problem from it. I ... well, that’s where I think it came from, but some of the doctors I’ve talked to figure it just happened to ... I get a crack in the inside of my nose, up here?

Interviewer: Mm hm.

Affected Male: And it used to be in both nostrils. This one is gone. And it, it gets real tender and sore, and it ——

Interviewer: Bleeds?

Affected Male: It bleeds a little. It’s just more irritating and sore than it is anything. It ... almost like it’s, uh, gives off this fluid that kind of crusts in there and kind of pulls on the hairs in your nose, and stuff [chuckling], so. And the crack itself ——

Interviewer: It’s irritating.

Affected Male: Yeah. I have to put polysporin in it every once in a while, or stuff like that. So.

Interviewer: So you had surgery on March 31\textsuperscript{st}?

Affected Male: March 30\textsuperscript{th}.

Interviewer: 30\textsuperscript{th}. And then you were back at work on May?

Affected Male: First.

Interviewer: First.

(Emphasis added, Interview with Affected Male, 19 July, 2001)

Many people were back at their jobs and fulfilling their responsibilities within weeks of their treatment. This is partially because of the fact that diagnosis of colon cancer is not automatically a death sentence but also due to the fact that many people’s lives do not exist within the circumstances required by clinical recommendations for recovery.
periods. Everyday people do not have the ability to be off work without pay, to hire a nanny to look after their infant children or to rest for indefinite periods of time while relatives look after their household chores and responsibilities. Most people who were interviewed in this study had to carry on with their lives as quickly as they could. Many family members had duties in their everyday lives that prevented them from having long recovery periods, including babies to look after, jobs at which to earn pay, and other family responsibilities.

**Gendered Illness: Colon Cancer is a Male Disease and Breast Cancer is a Female Disease**

There appears to be a popular notion within the wider community and also within the community of those who have experienced colon cancer that it is primarily a male disease. In contrast, breast cancer is thought to be a disease that only strikes women. In fact, men can have breast cancer and colon cancer strikes women and men relatively equally. As many women die of colon cancer as men. When men have breast cancer they refuse to talk about it as breast cancer but instead prefer to describe "chest cancer" (Richards 1999). Consider the following excerpt from an interview with a male who has been diagnosed and treated for colorectal cancer and has just been asked why genetic testing exists for genetic breast cancer research but not in genetic colon cancer research:

**Affected Male:** Oh. You want the truth? [Laugh]

**Interviewer:** Yeah.

**Affected Male:** Because I think women talk louder. [Laugh]

**Interviewer:** They’ve got a lot, a louder lobby for breast cancer.

**Affected Male:** Yeah. Yeah. Same as, uh ... because I’ve heard, too, with prostate cancer, every male, if he lived long enough, would have prostate cancer.
It's, you know, and it's a major thing. But they don't seem to ... nobody knows anything about it, hardly. Unless they get tested for it.

(Interview with Affected Male, 19 July, 2001)

There are some implicit points in this passage that suggest that the construction of illness is gendered. This individual is arguing that this lobby for breast cancer, which he assumes is primarily made up of women because it is mostly a female's disease, is “louder” and more assertive than that for those affected by colon cancer, which he in turn assumes consist's of men because it is a mostly male disease.

It was common to believe that hereditary colorectal cancer affected only one gender in a family:

**Interviewer**: So the first time that you became aware of the possibility of an increased family risk was through your Dad’s brother?

**At Risk Female**: Yup. Ya, I guess, actually, it was then. A few years after he had his when his brother went to the hospital and, uh, had cancer and, uhm, then his second brother went and same thing again and then there was talk always of “well, you know, if, because they have a sister and she had lots of polyps but she never had cancer. So then there was talk well if it’s in the males its not gonna be in the females [lay notions of inheritance] and all those stories as the years went by [awareness that these notions may not have the same status as the medical perspective] so, just talk, basically they sometimes talk about, but, really, uh, my family and especially my dad is not very open to discussing anything like that. It was a very dark secret even to the fact that he had cancer.

(Interview with At Risk Female, 21 January, 1999)

The above excerpt shows that lay notions of inheritance sometimes contain notions about HNPCC being confined to one gender and not the other. This may be a part of the process of pre-selection (this process will be described in detail later in this chapter). It also shows that awareness that lay understandings do not have as much cultural capital as the scientific and medical perspective on HNPCC.
Evaluating the System: The Perspective of Families with HNPCC

A number of people who were interviewed described problems with accessing diagnostic services that they believe may have prevented their cancer or caught it sooner. These criticisms often related to the knowledge of general practitioners or the difficulty in accessing surveillance or diagnostic tests, usually in the form of a colonoscopy from a gastroenterologist. Once people visited the gastroenterologist, many were, in hindsight, critical of the recommendations made by these specialists. For example:

Interviewer: ... when did you first become aware of a hereditary component to the cancer? Was it ...

Affected Male: Well, you know, I mean [my wife] made the suggestion. My gastroenterologist, who I like, said, “No, you're actually not at a higher risk.” Now, I assume he’s fairly state of the art and reading the studies, but obviously [a physician member of the Hereditary Cancer Program], who has a higher level of knowledge in that area, said just the opposite. That in fact you are predisposed, and ...[emphasis added]

(Interview with Affected Male, 11 December, 2000)

This individual fulfills the international criteria for hereditary colorectal cancer. His story was not unique. Consider the following excerpt:

At Risk Female: Um, I feel it’s important. Um. What I found that was very frustrating is, although – which was very interesting – uh, although they say that, in this family, scopes begin at 20, uh, in the general public, scopes begin at the age of 40. What I found frustrating in two examples was with, uh, C.’s oldest daughter, T2. When, um, uh, she was trying to get a scope done. In, uh, December of 1999. And the ... her family doctor says, “Ach, you don’t need to get them done till you’re 40.” And she tried to explain to her family doctor, “No, it has to get done sooner. There’s a history of it in our family.” And he was pretty much brushing her off. She got ahold of [genetic counselor], and [genetic counselor] then got ahold of her doctor and explained things, and the doctor had T2 in for an appointment where they discussed it. And he was so, he was so happy that she had educated him. We’re talking about, uh, the information that he got from, uh, [genetic counselor], and the information that the doctor had got from T2. Being that, because there was history in the family, that scoping does begin at the age of 20. Not 40. And, yes, let’s get your scoped. And so, in a sense, that made her feel better. Because, you know, um, he, he thanked her. Thank, thanked, he thanked T2 for having [genetic counselor] educate him. I thought, I
though, “Good.” And yet, T2’s older brother, who is a couple years younger, um, he recently went in to, to, for a scope. I think it was in March.

Affected Sister: Mm hm.

At Risk Female: This year. 2001.

Affected Sister: Mm hm.

At Risk Female: He’s been hesitating for [chuckle] he’s been hesitating for years. He finally just went in for the first time to get a colonoscopy done. He’s, like, he’s 30 years old. Twenty-nine, 30 years old. He just turned 30. Anyway. He, he went in, finally, to get his scope done. The colonoscopy done. And after getting it done and everything else, you know, uh, you know, he says, “Really, there’s really nothing to it. It’s done.” Okay. But, um, um, he was told, because the scope was normal, that he wouldn’t have to come back for another ten years. And yet, according to the information through the BC Cancer Agency as far as researching the material that’s available, it explains that with hereditary colon cancer and scoping, it should be done about every two to three years, or five years? Uh, I think they said, under the age of 40 is, uh, about five years. Uh, depending. Sometimes, uh, every three years. And then, after the age for 40, the information it gives is that you get done every two to three years. If you haven’t had it.

So, uh, you weigh, I weigh all that and I hear this, “Well you don’t have to come back for ten years. You’re clean.” And I’m thinking, somehow that doesn’t go right with the information I read. So I wonder. Is the information that’s being provided by the BC Cancer Agency, you know ... how do you get this information to doctors? How do you get the information to doctors, whether they’re surgeons or whoever they are, that are performing these colonoscopies. How do you get that information to them? They’re, they get the education as, as much as any of us, the public, could get, if we dug in. If the public doesn’t dig in, well, you’re not going to know. I suppose that’s the way it would be with the doctors out there. But I’m, I’m finding, through everything I’ve heard in these past, uh, six years, uh, at least six or seven years? And anyway, [chuckle] and anyway, I’m finding, with the information I’m hearing is that, um, I don’t think the doctors are, uh, um ... doctors haven’t got it. Uh. When, when a doctor says, “Well, you don’t have to come in until you’re 40” and yet other family members say, “No, this has to get done when you’re age 20.” You know. You ... what do you do? A lot of them walk away. Um. Because of that.

(Interview with At Risk Female, 20 July, 2001)

Many people were told that they should come back in five years and no mention was made about the need to screen other family members. Variable suggestions for screening by medical practitioners creates a sense of uncertainty for families.
One individual interviewed who presented to her general practitioner with what later she came to understand as clear symptoms of colon cancer was initially told that she had post-partum depression and later chronic fatigue syndrome. She was put on psychiatric medications for depression. Her spouse describes her initial misdiagnosis:

Spouse of Affected Female ... Um, my wife, uh, was diagnosed, um, with colon cancer ... let's see, it's ... must be almost exactly two years ago now? And, um, she had a fairly advanced case. She was very ill. Um, actually she was ill for a long time. We weren’t sure what it was, and then finally it, it, she got to the point where she really couldn’t eat any more and, and finally went to the hospital and finally was diagnosed with this. Uh, prior to that, it had been diagnosed as, um, uh, [sigh] I don’t know what the proper term is. Um, but a, a, basically a form of depression. Since she had had a child, uh, just a, uh, a little bit before that. Within two years of this all coming on. Was that, you know, this is a fairly common thing for recent mothers, I guess. And so that’s what her doctor thought. That these, uh, symptoms such as lack of energy and so on were due to. Uh, anyway, when they finally did diagnose it, they, um, operated almost immediately. Um, I was actually travelling when she got ill, so I, um, rushed home when she actually had to check herself into the hospital. And, uh, she had the surgery within a few days. And the surgery, uh, went quite well. Um, despite the fact that it was a fairly advanced case.

And, um, so far, um, she seems, uh, quite healthy. Uh, there’s no indication of recurrence. Um, but of course we’re, we’re very concerned about that. And also we’re very concerned about our children, since we now both have, you know, in our family, a history. And my, my wife’s mother, also, uh, had ... uh, cancer. Um, I gue ... yeah. Colon cancer, as well. And so it’s really, uh, um, you know, a major concern for us. Uh, for our children’s health.

(Interview with the Spouse of an Affected Female, 3 August, 2000)

This affected woman, when interviewed, was quick to add that she did not have any resentment towards her physician but that this represented a hole in the knowledge base of the entire profession. Many people were aware, based on their experience, that there were no ultimate experts. Her spouse was not as forgiving.

Numerous people described how their gastroenterologist or a general practitioner told them that they were not at higher risk for colon cancer and that they did not require more frequent screening. Another woman interviewed had her symptoms described as
depression initially and as a result was put on anti-depressants before eventually being diagnosed with very advanced colon cancer. Many reported that their conditions were initially misdiagnosed or were determined to be due to other factors such as stress:

**Affected Female:** Okay. My experiences was really ... for me, it was a nightmare. I mean, um, I had probably been misdiagnosed three or four times over the course of eight months, nine months previous.

**Interviewer:** When was this?

**Affected Female:** Back in uh, '94. So it would have started in ... well, actually it would have started in the fall of '93. When there was, uh, you know, there was some indication that, you know, there was some health issues based around, around the, the bowels, the colon, that sort of thing. But it was all put aside to stress, because I was in a business, doing the business, doing the work I was doing, and I was, you know, financial things. And of course that affects it. And of course women have those kinds of problems anyways, so you put it off to that. There was —

(Interview with Affected Female, 20 July, 2001)

Some carried anger towards a particular clinician that they felt should have diagnosed their condition earlier:

**Affected Female:** So, it was like, "Okay, I'm fine." You know. This is going on and maybe this is a little unusual than the normal, but I didn’t put anything to it, other than stress. It was all stress, to me. And I had actually been in to see a doctor at a clinic in November of that year for something else, and he had ... that was a nightmare in that he was totally off base and I should have actually sued the bastard. Pardon my English, but.

(Interview with Affected Female, 20 July, 2001)

Still others remarked that their gastroenterologist or general practitioner never mentioned the need for screening in their family. The following example illustrates how families reinforce their practical consciousness and address threats to their person by becoming advocates for their own health:

**Affected Female:** Yeah. Yeah. Although I did have a ... I'm, I'm, I'm not so good with, um, always doing that. I know, the last time I saw my gastroenterologist and, uh, she said that, um, I should be every three years for colonoscopies. And, um, I didn’t think was ... like I don’t think that's
right. I think that’s too long. I think that the fact that my sister had, had, uh, within three years had, uh ... went from nothing to, you know, a quartersized tumor, uh, that it’s just a bit too long. But of course, you know, she, she insisted that, that, uh, also that, um, because I’ve had a right hemicolectomy and these things are right sided, that it’s probably that I won’t get anything else. Which of course, also doesn’t fit with, um, the information that I’ve read on recurrences. Uh, where it says that if you’ve had anything less than a subtotal colectomy, you have ... it’s like, a fifty ... I can’t even remember this. It’s a very high percentage, uh, likelihood that you will, within ten years, um, have a recurrence. Um, and case studies of people who’ve, you know, had a resection, um ... although maybe in my case it was a too small resection, a right hemicolectomy, but, uh ... and then had it, uh, you know, within eighteen months have it ... a left, a left sided tumor. Like, in the remaining, uh, bowel.

So, uh, so at this point what I’ve done is, I, I ... she, she’s signed me up for 2002, and I’ve gone, “Yes, okay.” But what I’m going to do is, I’m going to start squeaking. When about ... when I think it’s coming up to two years, then I’ll, I’ll start making my squeaking sounds [laugh] and they’ll ... I think, um, it should be a little, a little bit sooner.

Yeah, because I know that otherwise, you know, for that last year, I’m going to be wondering whether, you know, I’ve made a mistake and should ... So, yeah. [emphasis added]

(Interview with Affected Female, 20 March, 2000)

Many of the people interviewed reported that they had to become strong advocates for clinical surveillance (through colonoscopy) or it simply would not occur. For most people, their connection with the HCP introduced them to a professional that was closer to an ultimate expert. This expert made a more accurate assessment of their family’s risk status and indicated the need for vigilant clinical screening throughout the family.

Even medical practitioners are often lay people in the world of specialization. The data collected in this study suggests that there may be a significant difference between the knowledge base of genetics professionals such as the genetic counselors at the HCP and the wider population of general practitioners. The fact that people at increased risk for HNPCC do not necessarily present symptoms puts the general practitioner in the position of addressing prevention of colorectal cancer rather than treating disease that is present. This is an unusual role that appears to strain the average
clinician who operates in a medical context that gives priority to symptoms that indicate the presence of disease rather than on the prevention of disease that has not yet manifested itself:

**Interviewer:** So what you know about HNPCC primarily comes from the family.

**At Risk Female:** Uh hum. My sister had a leaflet given to her when she went for her genetic counselling and that was in there and she was reading it. That's how I know about it.

**Interviewer:** Have you received any information yourself about genetic testing?

**At Risk Female:** No.

**Interviewer:** And your GP you were saying wasn't terribly supportive or encouraging of you going and having testings?

**At Risk Female:** Uh uh and not even to have colonoscopy. At all. Basically I was told that I should start having this test done and I talked to him about it and he said “well do you have any signs or symptoms?” and I said no I’m healthy and everything’s regular and I feel fine but my father never had any signs, uhm, you know, another friend that I know had no signs or symptoms whatsoever and he has a colostomy bag on his side but he had no actual of you know dark stools or bleeding or anything like that. Nothing. Yet, this can happen. And, uhm, “if you feel that you want to do it then do it but”. I think I have a GP that uh is concerned about the health care system.

**Interviewer:** Cost?

**At Risk Female:** Cost, yeah, testing that isn’t necessary and I totally, I work in a doctor’s office, I totally feel the same way so I was, well, maybe I should just not bother but then, you know, it’s just that I mean I have a 26 year old brother now that has had cancer which is, you know, they thought bizarre--his doctors in Alberta--that he had that, at that young of an age so uhm, I did go last year or this past year and he said I didn’t have to go for another five years. [emphasis added]

(Interview with At Risk Female, 21 January, 1999)

The excerpt shows that clinicians have a hard time treating preventatively. They focus on signs and symptoms and they tend to treat disease that is already present. According to the report from this patient, her general practitioner appears to be either unaware of screening protocols for families at risk for HNPCC or he is taking on the role of
gatekeeper for the health care system resources. Regardless, from a clinical perspective, the patient and her family is at increased risk and require regular colonoscopies.

The above case signals a problem for medical practitioners who have to occupy two competing roles: primary clinical caregiver and resource gatekeeper for the medical system. In fairness to clinicians, the analysis of patients and their families about colonoscopies may be influenced by the accuracy of the “retrospectivescope”. When I discussed this issue with a senior general practitioner from the BC Council of the College of Physicians he reported that he sees rectal bleeding and other symptoms that might justify a colonoscopy in his practice several times per week. He went on to clarify that colonoscopies are not readily available and that they are not covered by Medicare unless signs and symptoms are present. If he feels that it is necessary to advocate for a patient to have this test rapidly, then he has to call up a specialist colleague and negotiate an exception. He further explained that he can only do this so many times, that is, argue that a special case is a crisis and requires being advanced in the queue. If these requests are too frequent, then he worries that he may lose some credibility (and therefore symbolic capital that can be influential for changing positions for patients in serious need) with his colleague. This is the practical reality of the lifeworld of the medical practitioner, that is, the landscape within which medical services are offered (Wilson 2001).

As well, I have learned in my experience as a member of the Council for the College of Physicians and Surgeons of BC, in particular as a participant on the Quality of Medical Performance and Executive Committees, that thorough examinations of medical situations, especially ones where there may be partial or full validity to a complaint regarding a medical intervention, demand rigorous research into the context where the
incident occurred. Medical doctors do not all operate in the same context. For example, a rural physician may not have access to the range of specialists, tests and support services that are readily available for doctors practicing in urban centres. More specifically, gastroenterologists and colonoscopies provided by GPs may not be easily available in some communities. The availability of these services may affect patient choices and physician practice. In BC, the general practitioner is part gatekeeper, part advocate for individual patients, part negotiator and part accountant for a medical system with finite resources.

**The Gold Standard of Medical Care and the Symbol of Life for People at Risk for HNPCC: the Colonoscopy**

A colonoscopy is a test that can save the lives of people at risk for HNPCC through the early detection of polyps that eventually turn into cancer. The test not only saves lives of people at risk for HNPCC, it has been shown to save lives in the general population when it is part of a widespread screening program (Jarvinen, et al. 2000). A move is afoot in the province to provide population screening with colonoscopy to adults over the age of fifty (Thorensteinson 2002). Almost everyone interviewed described his or her ability to obtain a colonoscopy as a measure of the effectiveness of the medical system.

People often provided a commentary on the differences in the United States and Canada, between privately and publicly funded systems, with regard to this test and its ability to save the lives of people at risk for colorectal cancer:

**Affected Male:** Uh, they just bang bang. No problem in the States. He had none, whatsoever. My other brother, he has a friend who’s a doctor, so it wasn’t too bad with him, either. They went in and he had a colonoscopy too. No problem. And I have a brother who’s ... the one that’s younger than me. The first one. He’s mentally challenged. And my mother brought him in, and he’s been checked. As far as I know, my sister hasn’t. Which is ... she, I think, is
Communications by respondents about the availability of colonoscopies not only commented on jurisdictional differences in the US and Canada; they provided a kind of implicit comment on the underlying potential for their lives to have been saved or their illness to have been essentially prevented if this clinical test were to have been widely available.

Individuals interviewed have extremely clear knowledge about tests available for detecting HNPCC. Consider the following example:

At Risk Female: I told my sister when I returned from there, you know, and, uh, all the information, and that she, she'd make sure that she was getting her colonoscopies on a regular basis. Um, he had, uh, just done a, um, a sigmoidoscopy before. And sigmoidoscopies aren't good enough to detect high level cancers. So, uh, I made sure that she knew that she had to get a colonoscopy, and not a sigmoidoscopy. So. She just tells her doctor what she wants. [Laugh]

(Interview with At Risk Female, 13 December, 2000)

This individual, in the role of health promoter in the family, not only outlines the recommended tests for clinical surveillance but also communicates their shortcomings and strengths for detection of HNPCC.

The exact screening protocols for HNPCC with respect to colonoscopy appear to be unclear to clinicians and people at risk for HNPCC. Those interviewed sometimes perceived that genetics testing (and in some cases counseling) could put them in a more powerful position for demanding more frequent colonoscopies. The following example illustrates how an at risk individual not only sees genetic testing as producing more power for acquiring colonoscopy, but implies the difficulty experienced by family
members in acquiring this test and in convincing medical practitioners about applicable
screening protocols:

**Interviewer:** So, just one, uh, just a couple of final questions. Have you [pause]
just to summarize, would you, what would you feel the benefit of genetic testing
would be for the family?

**At Risk Female:** Well, I would think that, uh, if we gained that information
[sniff] that, I mean, you would know that you, what you are doing is the right
thing. And, you know, as I say, we could increase the amount, or the number
of, uh, colonoscopies and have, you know, more regular check ups. Instead of
saying, “Oh, I think that, I think that I should have that colonoscopy pretty soon.”
And then making the appointment, and you know, finally, six months down the
road, you have it. You would make sure that you would do it on a more, on an
extremely regular basis. And then determine what other, uh, um, testing or, uh,
results from the testing, what, **whatever the doctor sort of said you should
have. You should need to be done.** [emphasis added]

(Interview with At Risk Female, 13 December, 2000)

The last statement shows a widespread suspicion, in some cases based on personal
experience, of clinicians’ knowledge base about screening protocols using colonoscopy.
Affected and at risk family members know early detection utilizing colonoscopy is the
most effective way of preventing death from HNPCC and often report frustration when
they are unable to convince a medical doctor that they need this test. Once the doctor is
convinced and the referral is made, the families sometimes have to wait for long periods
to acquire colonoscopy especially if they are not actually presenting with symptoms of
colon cancer. Addressing risk and prevention is not currently the main focus for
clinicians who attempt to allocate scarce resources such as colonoscopies in the medical
system. Few professionals provide colonoscopies and not nearly enough colonoscopes
exist to meet the need for testing of patients on long waiting lists. Some towns do not
have a colonoscope or professionals trained to administer this test.
Enhancing the Security System of Personhood Utilizing Genetics Counseling and Genetics Testing

Overall, the respondents interviewed gave favorable reviews of genetics counseling services. Most of those interviewed were strongly in favor of genetics testing:

At Risk Female: Okay? But, uh, how do you get in on it? Okay? Um. If you want to do the genetic testing and they show you all the studies being done on it, yeah, it’s in Ontario. Okay? Where do you go in BC to get it done? “Well, sorry, we don’t have it.” Okay? You have to be a resident of Ontario? Well, no. So, um, I’m hoping with the research you’re doing, with, if you can begin and find out how people are feeling about this, and, you know, it may be important to some of them. It may not be to others. But I would like to see it here. I would like to have it more available to people and, um, I would, I would like to see more people get interested in – this in only my opinion – uh, more interested in, uh, learning about the family history. Uh, especially hereditary colon cancer. If you first hear that it’s in your family and you’re under the age of 55 or the person that has it and they’re under the age of 55, find out if this is normal, or is there something else that maybe you should know.

(Interview with At Risk Female, 20 July, 2001)

Most of the people interviewed expressed their disappointment that testing was not available:

Interviewer: Have you been for any, um, genetics counselling, or?

At Risk Female: Yes.

Interviewer: You have.

At Risk Female: Yes.

Interviewer: What was that like?

At Risk Female: It was good. Yeah, it was an enjoyable experience. Um, a lady named [name of Genetic counselor] in, in, um, Victoria.

Interviewer: What sorts of information did she tell you, or talk about?

At Risk Female: Um, she, well, told me, of course, that, uh ... took my family history and she, uh, went through all the, um, sort of, um, family tree type things that she did. And she gave me some information on, uh, the, uh, whatever you call it. Hereditary nonpolyposis colorectal cancer. [Chuckle] She, uh, she gave
me some information on that. Which really, um, seeing that I’m a nurse, I, I understood a lot of this ... it, it ... ahead of time, sort of. So, there was some, a little bit of new information, but, uh, I knew a lot beforehand. And I was disappointed that the testing wasn’t available.

Interviewer: The genetic testing?

At Risk Female: Yeah.

(Interview with At Risk Female, 13 December, 2000)

Many people go to genetics counseling believing that they are going to receive genetics testing. When they arrive and realize that testing is not an immediate possibility, they report that this is a source of frustration. The chuckle that is shown in the above demonstrates that most people experience some difficulty in remembering and pronouncing the precise form of cancer in question: hereditary nonpolyposis colorectal cancer and its long complex title is sometimes a source of humor amongst those at risk for it who have to enunciate it.

There were a few critical comments of genetics services that pertained mostly to availability of resources over which genetic counselors have no immediate control. Firstly, the time period that families have to wait (between six months and 18 months) once they had received a referral from their doctor was found to be frustrating. Families sometimes appeared puzzled about the time lines and the “goings on” inside what appears from the outside to be mysteriously unhurried system:

At Risk Female: Yeah. Now, the thing is, is, from May 19th 2000 till February 2001, which is, like, a year, it took all of that time to get the forms for the tissue blocks sent down to the BC Cancer Agency. It only takes, like, a couple weeks or a month.

Interviewer: Mm hm.

At Risk Female: This took, like, a year. So this, this kind of ... this was very frustrating for me. Okay? I felt like, you know, there was a lot of procrastination
going on here. It’s like, you know, although it’s up to the individuals, it, it’s, it’s their right whether or not they want to, um, give that ... sign away, okay, their tissue blocks or information, okay? Because of the form that was being sent, I understand from K. that the only form she got was to release the records or something. I thought, “Well what is this? It’s supposed to be tissue block forms.” But anyway. Um. It took about a year to get that done. Um.

So, seeing the procrastination on that part, I have not had contact since about February 2001, as far as, um, uh, um, with, uh, [Genetic counselor] and [aunt] as far as, they were going to see about genetic counselling in, uh, Hamilton, Ontario. They could go to McMaster, or they could see somebody, get the genetic counselling done first – which is the first step, where everything is explained – and then, um, they would talk to him as far as, if he wanted to give blood to go for the genetic testing. All of us has since been waiting.

Um, the waiting is driving us nuts. We haven’t heard anything from the BC Cancer Agency, what’s the update. We don’t know. Um. K. has even ... what I got from K. months ago, uh, was, she had wanted to even go to a lab in the States. There’s a lab in the States, apparently, you can get this done. It costs, like, $3000.

(Interview with At Risk Female, 20 July, 2001)

This passage illustrates a frustration that many family members experienced with system timelines and also shows an awareness of funding issues in the system. The respondent notes, at the end, that services can be expedited by purchasing them in the United States. This lack of fulfillment with respect to timelines that families reported may reflect a misinterpretation by family members about the status of the HCP as a clinical service rather than a research pilot. Family members appear to evaluate the HCP as a clinical program rather than as a research initiative. While the HCP professionals are clear to explain that their program is a research initiative, the family members do not appear to make the inference that research initiatives have certain weaknesses in terms of infrastructure that affect punctuality of the exchange of letters and results that are not necessarily shared by clinical programs34.

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34 Lengthy waiting periods and waiting lists are often common for families with strong histories of cancer especially those likely to have a mutation for HNPCC in their family. However, these lengthy waiting periods have a big impact on how families perceive and evaluate genetic and medical services. Issues that may be routine for medical professionals such as the period taken for forms to travel between institutions,
Many people were surprised that they could not receive genetics testing for HNPCC. This may be partly due to the fact that there is a long waiting period between the time that they have their initial telephone contact with the genetic counselor and their actual genetics counseling appointment. People did not appear to have a full understanding of the parameters of genetics counseling before the session occurred which could even be longer than a year from the time of initial referral.

Furthermore, people did not always perceive the genetics counseling session as providing counseling, but rather, as a service that provides genetic information. There appears to be a discrepancy between the perspectives family members and those of clinicians:

**Interviewer:** What was your experience of that [genetics counseling]? What did you think about that?

**Affected Female:** Well, we didn’t ... I don’t think we actually sat down and talked about my, talked about my experience like you and I are talking. We basically talked about, again, uh, the clinical view of, you know, this is what we see, this is the pattern we see, this is what we expect the outcome to be. This is why we’re suggesting to you that you take care of it in this way, shape or form, and protect your family. That’s my experience. And I’ve only actually sat with one, uh, with one, uh, in one clinical session. And I sat with, uh, the woman, just one woman, herself, myself, and my daughter. So. And I’ve, I’ve not sat with my family through one of these clinics.

(Interview with Affected Female, 20 July, 2001)

People often mistakenly anticipate that genetics counseling is more like psychotherapeutic counseling. Rather than being given an opportunity to share their story in a supportive environment with a clinician who is a good listener and to receive emotional support, they receive a genetic risk assessment. In the clinical context, limits the time that a letter takes to be written and delivered or the time for a test to become available, figure prominently in the lives of patients and families interviewed for this study (see Chapter 3).
in resources appear to confine genetics counseling mostly to providing genetic
information in an empathetic way in a relatively time-limited and structured format.

The information retained by participants in genetics counseling was varied. It
appeared that people do not always retain exactly what the professionals providing the
information intended. Consider the following example of an individual’s comments on
information about gender, treatment and risk that she received in a genetics counseling
session:

**At Risk Female:** They really didn’t go into any detail, except for the question
that I asked about, you know, taking out the whole intestine, or whatever. They
really didn’t go into any detail whatsoever about treatment. Basically, they were
concerned about the genetics and, the documentation, and stuff like that. But they
really didn’t go into the, the treatment of it, or, or anything of that nature, at all.
They were just, you know, talking about being tested.

**Interviewer:** What did they say your risk level was, in terms of [...]

**At Risk Female:** Oh, I, I believe she said it was quite high. I really, I really
don’t ... uh, but she didn’t say. You know, she was grasping at all of the, the, of
telling about each and every one that had it, and stuff. And and I, I’m sure she
touched on that, but I, I’m not sure what she said, now. I, I, I believe that she
said something like, you know, I don’t know if she said, chances are that, or
there’s a good possibility that it would be positive. Because it has been ... and
I, I remember her saying that, because it’s in both sexes. You know, sometimes
you will see that, that it doesn’t seem to be, you know, gender related, but
sometimes you will see that. That, that the males of the family will have it
but the females won’t. [emphasis added]

(Interview with At Risk Female, 7 February, 2000)

According to this report, the genetics expert providing the counseling did not necessarily
give a precise risk assessment, did not comment on treatment options, and stated that
sometimes HNPCC is manifested in only one gender in a family. This summary of the
information provided in a counseling session would likely be perceived as entirely
antithetical to the information typically provided from the point of view of a genetic
counselor. Regarding HNPCC, genetic counselors would typically endeavor to
communicate a precise estimate of risk, would probably discuss treatment options and would never assert that HNPCC occurs in only males or females in a family. This interview shows that people fit the information that they receive in interactions with medical and genetic practitioners into pre-existing ways of understanding. Furthermore, genetics counseling may have a different purpose for professionals and participants. For professionals, it is a time to provide scientific information while for the participant it is an opportunity to assist them with their survival strategies.

One of the most common reports from family members regarding new information that they had learned in genetics counseling pertained to their increased risk for other cancers associated with HNPCC:

**Interviewer**: So, you went to the Hereditary Cancer Program at the BC Cancer Agency for your interview.

**At Risk Female**: Mm hm.

**Interviewer**: Okay. Did you learn anything new there?

**At Risk Female**: Um, actually I learned more about other cancers than the colon cancer. In terms of, um, links. Uh, uh, genetic links. I sort of already knew there’s, that there was a genetic component, or a suspected genetic component to colon cancer. I didn’t realize that there was also suspected links between some of the other cancers.

(At Risk Female, 20 November, 2000)

While some participants did not remember all the information that they received at genetics counseling, many reported that they had learned that they were at risk for other cancers. In discussing the possibility of sharing genetic risk information with her children a woman at risk for HNPCC responds as follows:

**At Risk Female**: Um, but I do want them to be aware of, of the slight, of the slight risk.
Interviewer: Did they talk at all about risk at the, uh, genetics, uh, counselling session that you had?

At Risk Female: Yes, they did. I, I can't remember exactly what, um, what risk they ... they felt that I should be ... the risk was to the extent that they felt every year I should have, uh, an ultrasound of the pelvis. Every year I should have a mammogram. A colonoscopy every few years, and, uh, I think that was it. I think that that was [pause] yeah, ovarian. To watch for endometrial and ovarian cancers.

(Interview with At Risk Female, 20 November, 2000)

Interestingly, this respondent downplays the risk to her children for a genetic mutation for HNPCC but remembers her own increased risk for other cancers. This may be part of her strategy to extend and enhance the protective cocoon of her family.

It was commonly reported by those affected or at risk for HNPCC that clinicians outside of the HCP had poor knowledge about HNPCC, its detection or the Hereditary Cancer Program. The following excerpt demonstrates how a medical practitioner has sound knowledge of the criteria for diagnosing HNPCC but appears to be under the mistaken assumption that genetic testing is available in the province:

At Risk Female: I talked to the doctor that I go to for the colonoscopy. He's a surgeon in [town]. And, uh, I ... he'd ... I talked to him about it. Or, he talked to me about it, first. He said, he said I ... with the, uh, history that I had, that I would qualify for, uh, genetics counseling. He said, "You have to have, uh, three people, three immediate relatives in your clan, in your, in your uh, family history. And one of them has to have died before the age of fifty." And I, so he, he knew that. And so he said to me, he said, "You, you would qualify." He said. "Would you like to go and have, uh, genetic testing?" He said testing. He didn't say counselling. And, uh, I said, "Yeah, I'd be really interested in that."

And, uh, my sister's GP didn't seem to think that it was necessary. I mean, maybe he knew that there, that it, the testing wasn't available. I don't know for sure. But he, he didn't seem to think it was important. He sort of made light of it when she mentioned genetic, uh, testing to him. But, uh, this fellow, um, [the respondent's doctor], he, uh, seemed to think that it would be alright for me to have this. And I said, "Sure, well I'm quite, completely willing to have, uh, to go, to go and see about it." And so he made the arrangements, and we did that. And, uh, as I say, I was really disappointed to find out that the testing itself wasn't available. But, anyway, I, I was pleased to talk to her. [emphasis added]
Here, the family has two distinct experiences. In one case, the general practitioner advocates for genetic services (that don’t exist actually) while in the other case the family practitioner discourages the patient from seeking out the service. Both patients, sisters, have the same risk and yet they receive antithetical advice. Both family and clinical narratives indicate that there is a lack of harmony in the medical community regarding HNPCC and genetic services.

**The Influence of Living in an Urban versus a Rural Settings**

The different expenses and obstacles facing individuals who live in rural rather than in urban areas was also a large concern for families. The fact that genetic counseling facilities or medical services do not exist within easy access of many rural families was a huge issue for families. The cost of the trips from rural settings to major centres for genetics counseling was, for some individuals and families, prohibitive:

**Interviewer:** Did you see them locally?

**Affected Male:** Yeah, they come to Kelowna. Well, they wanted ... they first, when they, they first told me about it, uh, like, I forget who my doctor [pause] or my cancer doctor gave my name to them, or something. They got hold of me and they wanted me to go to Vancouver. And ... for an hour interview. I says ... and they’re not paying for nothing. [Chuckle] I said, “No, I’m not going there for that. If you’re coming out here.” Which they do, I guess, now that Kelowna has a cancer clinic. They go to Kelowna every six months or so, or. So they scheduled me in. I missed them once before. Um. They phoned and left a message. When I phoned back, they were booked. So. I got back in, and that was in March, I think it was. Or somewhere around there.

(In Interview with Affected Male, 19 July, 2001)

In many instances, if a clinical service was not available locally, then families would not be able to receive it.
Confronting Fateful Moments and the Possibility of Death

As part of the process of fortifying their protective cocoon against threats to their person, some individuals described that they had developed a familiarity and almost a comfort with death. However, while death was a reality for them, it was an issue that friends and family were not necessarily comfortable with:

Spouse: And my feeling is that people hear cancer, and to them it equals death.

Affected Female: Yeah.

Spouse: You know. Or imminent death. And it makes them very anxious. Well, especially the second time. Most people don’t understand that prostate cancer isn’t directly related. It’s not a reoccurrence. Uh, so they seem to think, well, well this is, you know, it’s come back. Uh, he’s done for. And, um, they lack information. They don’t understand that. And they just feel uncomfortable being around you. And ...

Affected Female: And I’m not going to let it get me.

Spouse: No.

Affected Female: I won’t.

Spouse: You end up extending yourself toward them, and comforting them. [Chuckle] You know. [emphasis added]

(Interview with Affected Male and Spouse, 4 December, 2000)

In contrast to their friends without the experience of cancer, though, the interviewees reported that they would accept whatever happens thereby implicitly making reference to the power of fortune and the inherent uncontrollability of the appearance of cancer.

I was met with some surprising information when interviewing the spouse of a woman who had been diagnosed with HNPCC when he revealed that he, too, had direct experience with colon cancer in his family:

Interviewer: Okay. Uh, can you tell me a little bit about, uh, your family’s experiences with, uh, colorectal cancer.
Spouse of Affected Female: Okay. Um, actually my father, uh, died from that when I was four years old. So, that's not related to my wife's cancer, which I think is the relevant one to this study. But, but actually, uh, my own family has a history of this as well. And, um, so, uh, there hasn’t been any other incidents that I’m aware of, uh, in my direct family. You know, my, uh, blood relatives of myself... [emphasis added]

(Interview with the Spouse of an Affected Female, 3 August, 2000)

This interview like many others illustrated the immense experience of families with hereditary cancer. Later in the interview, the same individual comments on the impact of early experience with cancer on his thinking about the realities of death:

Spouse of Affected Female: Um, well again, I think it’s, you know, it, uh, because of that, I’ve always, uh, understood that, um, people can die at any time. Um. Uh, so at least, uh, you know, that’s I guess been part of my, uh, consciousness. In, you know ... but I can’t really say anything further than that. Uh, I don’t think it affected, uh, um, you know, choices I’ve made, or, or that sort of thing. [emphasis added]

(Spouse of Affected Female, 3 August, 2000)

This individual, like many others interviewed, appeared to enter into a complex negotiation between an acceptance of the risks associated with cancer (including death) and the things that he could control with respect to his health.

The Experience of Chemotherapy

People universally reported bad experiences with chemotherapy. People often believe that chemotherapy is the most hazardous part of their experience with the clinical system:

Affected Female: ...But, went through that. Um, you know, dealt with the nausea. I ... actually, I have all my records at home. One of these days, you might be curious to see what the reports were like. But. Went through all of that [sigh] and I probably was at it for a couple months and, like I say, I basically hit a bottom. Just ... there was, like, nothing left. Psychologically, physically, you’re exhausted by it. I remember having moments where I would arrive at the front door to the clinic and just ... I couldn’t go in. Uh, I remember that happening, happening to me specifically at least at one time. And going down the lake, you know, and just getting, you just can’t do it. Um, as a woman, I had to deal with ... when I was around my cycle.
Interviewer: Mm hm.

Affected Female: Okay? With the advent of that, and then, you know, the che, uh, the chemotherapy, I got really, really sick. So there were times where I’d say to them, “I can’t do this.” You know, I just ... I’m in bed for four days when these two things are combined. I am just too sick to get up and go anywhere. So. I would say, probably, you know, with everything that was happening, in about a month’s time, I was probably taking less of the pills during my treatment. I was probably more coming home and closing the blinds and curling up on the couch and sleeping for four days because I didn’t want to deal with it anymore.

Interviewer: Mm hm.

Affected Female: Things like that. Um. You know, at one point, all the sensi ... uh, vaginal tissue, underarm tissue, went absolutely black. My forearm went black. I spoke to the oncologist about that one day and asked him why all this tissue was turning black. And he just said to me, “Well, there’s no reason to quit the treatment.” So I ended up in my car, down in Penticton, talking to the clinic down there to get some answers from a nurse, because I wasn’t getting anything up here. You know. It was just ... it was horrible for me. Absolutely horrible. You know.

Interviewer: Mm hm.

Affected Female: Um, after I’d been through it for a few months, I remember the oncologist asking me into his office, and I thought, “Okay, he’s going to ask me about, you know, I ... obviously you’re having a tough time with this. We see that you’re not making all your appointments. You know, la la la.” And I thought, “Finally I’m going to get some compassion.” And what I got was a lecture for not making those appointments. And that chemo, chemo, the chemical, whatever, is expensive. And it’s like ... and I, again, just sort of thrown back. So.

(Interview with Affected Female, 20 July, 2001)

It is the experience of chemotherapy rather than cancer that people report as an experience that nearly killed them:

Spouse: Yeah. And, uh, he came home, and I was flushed. Like, I can be flushed. He says, “What’s the problem?” That was his question.

Affected Male: You bumped the car.

Spouse: [Laugh]
Interviewer: [Laugh]

Spouse: That’s the face I have, usually. [Laugh] When I bump the car. Huh. And then, uh, [chuckle] no, it wasn’t that. So. And so I was very in, in, uh, interested and involved in getting the best follow up for him. Uh, I am always very involved with my patients, but I was involved emotionally too, and [affected male], um, has his own mind, sometimes. When [chuckle] like, when he was sick, I saw he was sick with the chemotherapy. And he was watching a program, his favourite show on TV was “Millennium.” I don’t know if you watch “Millennium.” It’s not on anymore [chuckle], but ...

Interviewer: What is it? What is it?

Spouse: It’s called, “Millennium.” It’s a, it’s a series, uh, a suspense.

Affected Male: It’s not on anymore, “Millennium.”

Spouse: No, it was ...

Interviewer: Oh, “Millennium.”

Spouse: “Millennium.”

Interviewer: Okay.

Spouse: Yeah.

Interviewer: Yes

Spouse: Yeah. And he was watching that, and he was having chills and he was having fever, and I said, “I have to get you to the hospital. You’re on chemo and, and ...” “I don’t want to go. Why?” [Chuckle] He had to finish “Millennium” [Laugh]

Interviewer: [Laugh]

Spouse: So, “Oh, okay.” [Chuckle] And he was, he ... I knew he was sick, so I brought him to the emergency room after that. And he was kept. Uh, with, with this, uh, [chuckle] I couldn’t believe how stubborn he was. The ... so.

Affected Male: It was the new season.

[Laughter]

(Interview with Spouse of Affected Male, 11 December, 2000)
Although this particular respondent tells the story with humor about the importance of his favorite television show, both he and his spouse believe that he nearly died from the chemotherapy. They immediately removed him from the treatment after this misadventure. Many individuals describe chemotherapy as a complicated utility equation between its deleterious effects and its role in improving health or eradicating disease.

**Reflexivity and Foreshadowing Illness: A Sense of Expectation**

Some people interviewed suggested that they were not shocked that they had cancer. Many knew that something was dramatically wrong with their health. They often had to take on an advocacy role for their health because clinicians were unable to find anything prominently wrong. However, they still *felt* that something was awry:

**Interviewer:** —— you said that ... the scope. You said that they ... you had a sense they wouldn’t find anything.

**Affected Male:** Yeah.

**Interviewer:** Why was that?

**Affected Male:** Uh, because of the ... all my experience, life experience so far with stomach problems, that this wasn’t anything like it.

**Interviewer:** Oh, okay. So it was quite different. It was something different than a stomach problem.

**Affected Male:** Yeah. Yeah. Well, yeah. Because I knew it ... the pain was over here, and I’d known ... all my other pains with my stomach problems, what they were like. So.

**Interviewer:** So, can you tell me a little bit about, um, [pause] ... this was a shock to you.

**Affected Male:** Yeah.

**Interviewer:** Um ——

**Affected Male:** Uh, yeah. In the back of my mind, I’d always kind of wondered, anyway. If something’s going to happen. Like, when they told me it was, you
know, okay. "You’ve got cancer" it’s a bit of a shock, but there was also, in the
back of my mind, I kind of had a feeling that that’s what it was.

**Interviewer:** [obscured by static] just a feeling from the pain, of what it was?

**Affected Male:** The pain, and my father dying from cancer. Around ... he was
probably a couple years older than me. So.

**Interviewer:** How old are you now?

**Affected Male:** Forty-four. He died when he was forty-five. But when I got
cancer, I was a little younger than when he got it.

(Interview with Affected Male, 19 July, 2001)

Even after multiple tests people still had a sense that there was something wrong with
their health. This was possibly due to the fact that, like the individual interviewed above,
these people had already seen a great deal of cancer in their families and they were not
strangers to ill health in their families. Many had lost close relatives and had seen death
from cancer through many generations:

**Affected Male:** W., who is my cousin, I started talking to her. And P. She had
cancer. So I started talking to her. And then that’s where we got into the
research. That’s where I found out L. had done this research. So I got them ... P.
had some of the stuff, so then I got in with them. It was more P. I talked to, then.
They e-mailed me this stuff, so I got in with it, that. And then, G. has died. Uh, I
talked to L. She phoned, and I talked to her. I was supposed to phone her back
here, after I talked to those, um, those two women. I forget their [chuckle] ——

**Interviewer:** [name of genetic counselor] and [name of genetic counselor].

**Affected Male:** Yeah. Uh, I was going to phone her and see what else they had
for update. I’ve talked to W. every once in a while. These two are going for, uh,
genetic, uh, research. They’re going ... they’re just waiting for stuff to get back.
Through London, Ontario. So, through them, I might be able to get tested.
Through Ontario.

**Interviewer:** Oh, I see.

**Affected Male:** So, we’re just kind of, just sitting waiting. Uh, to see what’s
going to happen there.
Interviewer: Now, a couple of, uh, questions. One, did [spouse] go with you to the genetics counseling?

Affected Male: Yep. She's been with me everywhere. With it. And she's better on remembering stuff than I am. [Laugh]

Interviewer: This is amazing. So there's —

Affected Male: That's what everybody says. [Laugh]

Interviewer: Yeah. So there's a str, there's a strong, uh, history of cancer in your family.

AM: Yeah. Very strong. Out of fifteen kids on my, in my father's family, thirteen have had cancer. So [emphasis added].

(Interview with Affected Male, 19 July, 2001)

People regularly reported that physicians did not, regardless of the strong family histories of these patients, believe the patient that something was different this time, that something was wrong with their health. According to many people who have experienced HNPCC, the physicians did not practice what I have come to know from my experience on the College of Physicians and Surgeons of BC as a basic guideline of medical culture: listen to the patient and what they are telling you. For these families, their perception was often in contrast to the view of physicians whose primary focus is on the clinical identification of disease rather than on prevention or risk of disease. For families, cancer was a familiar and expected phenomenon that would almost inevitably make an appearance in their own lifeworld. Family members confront the lack of ultimate expert for their disease by taking on the role of clinical historian, health promoter and health advocate within the family. These individuals collect complex hereditary disease pedigrees, summarize clinical data about HNPCC, and communicate through in a variety of ways (letters, face to face conversations, e-mail, telephone) with the entire family.
Risks to Personhood from Genetics Testing and Counseling

Many individuals were very concerned about the potential impact of genetic counseling or testing results upon their ability to acquire life insurance. In order to avoid causing concerns for people, the issue of barriers to insurance was not raised as a specific issue unless people brought it up themselves. Many people did raise this concern:

**Interviewer:** Today. Is there anything that you wanted to add, uh, that I haven’t asked you? Or, anything else you want to add?

**At Risk Female:** Um, the only thing I had thought of that I thought you might ask about, were, um, my concerns about getting the testing. The negative aspects of getting the testing. Um, I forgot what they were. Um, the one thing that comes to mind is how it, it might... uh, not so much for me, but maybe my kids’ generation, is how it might affect their health care. Or, insurance, or things like that. Knowing that it’s there. Um, because all of this is so new. I don’t know how that’s going to affect. And then the other thing [throat clear] might be, being so focussed on colon cancer, might overlook something else. In my health care. And, um, that’s the only negative things that I can think of. About getting the testing. That kind of concerned me a bit, and... things to, uh, to think about.

(Interview with At Risk Female, 26 May, 2000)

The example also shows that many family members were reflexive about the impact of genetics services on their or their kids’ ability to acquire life insurance benefits. They were entirely aware of the fact that they would be discriminated against on the basis of the mere possibility of illness rather than its actual presence:

**Affected Male:** Yeah. To let them know, to see if they wanted to go ahead with it, too. Because usually that’s what, that’s... from what I understand, if they test me, I have it, then it is given... they will give it to my, uh, brothers and sister. If they want it. Just to check to see the gene, if it’s there. And then to eliminate the fact. And then that will be up to them.

Uh [pause] the, uh, ... my brother is a little worried. He’s got two girls. Uh, ten and twelve. And he’s worried about getting insurance. Life insurance. If he gets this tested. So. [Sigh] I just get the information and give it to him. If he’s worried about it, I’ll tell him to go get insurance first, then go get tested. [Laugh]

(Interview with Affected Male, 19 July, 2001)
The family members interviewed understood that this lack of ability to secure life insurance was a variable that imperiled their full personhood. Quite simply, people without this risk for a known genetic mutation are able to obtain life insurance whereas families with this elevated risk for a mutation for HNPCC cannot take this for granted:

**At Risk Female:**...Um, I had, I had never really though about the down side until recently. Um, when my mom pointed out to me that, maybe it's not such a good thing to know, in the sense that, if that knowledge ever became public, you know, available in one’s health records or public records, uh, although I don’t know how that would, but you know, life insurance, job ... sorry. Job, uh, job possibilities. [cat meowing] You know, these things that somebody might care whether or not you have a predisposition to cancer. It becomes a bit, you know, it depends, I guess, on how much you believe in the big brother state of the world. Um, whether or not that stuff, uh, could matter. **To somebody else. You know, obviously it’s important to me, but, is it going to matter to somebody else?**

(Interview with At Risk Female, 20 November, 2000)

This example shows how family members worry about the impact of genetic disease vocational opportunities as well as health insurance. Others also thought about the impact on the ability to obtain a loan for a home:

**Spouse of Affected Male:** We are, uh, quite positive about doing it. Um, I think the way I would feel about it right now, though, is that, um, we know that it’s important for, uh, our children to, and probably grandchildren, to be tested for it. To look into, uh, um, an early diagnosis. And, uh, to do what they can with their own doctors in, in, uh, pursuing that. One concern I have about genetic testing is, um, uh, some of the issues that have been raised recently, uh, about people who, um, have all of their genetic information in computer databanks. That, at some time in the future, there may be implications, for, uh, insurance, or employment, or getting a mortgage, or, you know, that kind of thing. I don’t know how valid that concern is, but it is something that, um, that I'd be interested in finding out more about. [emphasis added]

(Interview with Spouse of Affected Male, 4 December, 2000)

The above interview excerpt illustrates that many families had elaborate evaluations of genetic information that included an examination of both the benefits as well as the drawbacks in their analysis.
In some cases, it appears that people were not necessarily immediately aware of the potential impact of genetic susceptibility to illness on their insurability until they heard it from professionals:

**At Risk Female:** It was a farming community. I remember that. I think that’s the same thing. Where you’re not right in the middle of, you know, those little walk in clinics every time they sneeze.

They brought up, actually, another really interesting point. Getting off the sort of the medical side of it, um, that I hadn’t even considered, and I’m sure most people that walk into these genetic counsellors don’t even think about, is the, uh, the, the effect of knowing, um, in a, in a monetary way, uh, finding out that you have the gene and then all of a sudden trying to get life insurance. And now you have this positive gene, you know. They’re already finding that there is some problems. They’ve had one case, uh, of somebody that had a positive gene, or some, you know, terminal, uh, illness, and, uh, wasn’t able to get life insurance. They were refused. So, she said before, you know, before I went ahead and did anything, it would probably be a good idea to make sure that all that’s in order. It’s something to think about. That, you know, everybody’s going ahead and wanting to get all this genetic testing, or we’re heading that way, but, um, then, um, was it [genetic counselor]? The other one, [genetic counselor]? Said that this one insurance claim that they’ve been, been dealing with, or she’s had some dealings with, have a genetic counselor on staff. And, so, they’re telling, they’re telling the, the insurance people that it’s probably a good thing. In a sense. Because the people that have a positive gene will be checked every year, to see whether they have the cancer, or the disease, or whatever. Whereas your average person won’t have those kinds of tests. So that’s sort of a whole twist on it. That, um ... [emphasis added]

(Interview with At Risk Female, 7 February, 2000)

Note that the genetic counselor is purportedly prompting the individual acquire insurance before testing in order to escape the possibility that the results might prevent reasonable coverage. This example portrays that genetics counseling provides more than neutrally presented options based on risk assessments. In this situation, the individual reports that she had never considered the potential barriers to adequate insurance coverage brought about by risk for genetic disease before the genetic counselor raised it.

Part of the practice of the HCP is to collect and officially record all the families’ cancer experience and this was perceived as dangerous by some families. The following
example illustrates how even the process of collecting the family history is perceived as risky for families with HNPCC:

Affected Female: Oh, right. Um, that came up because, um, my husband had worked for a company, until just this, this year. So he had a, a, an in, insurance, um, [pause] a kind of insurance plan. With the company. And then he was freelance. So we had to get, um, new insurance. And, you know the answer to that question. Right? Of course, uh, when I put in that I've had cancer, I really had become [...] out. Because they, they don't want to, to insure you. And, uh, so then the issue came up, of, uh .. they kept asking if anybody in your family has had, uh, cancer. You know. You know, so, if I have, if I have to say I have two sisters who've had cancer, um, or, you know, or, and aunt and a cousin, you immediately start to look, look, uh, like, you know, not so great.

And then I started thinking about, um, about my son. You know, would this ... like, would he ... if he wanted to get insurance at some point, uh, would it be really difficult? To get insurance, uh, if, you know, he had to put down all his family members who've had cancer. Or what if he, you know, if he had ... if they ask you things like, have you been tested? Seen by a doctor, or tested, or, or anything in the last, uh [...] Um, and what if he didn't have cancer, but what if he had to put down, "Yes, I have been tested for, uh, hereditary colon cancer, and I have the gene"? Um, if he lived in the States, and in fact, he came from Michigan, and [...] you know, had health insurance. So, uh, that was just a little, you know, a little thing that popped up. That's regarding the testing. A negative. Of testing. [...] positive.

(Interview with Affected Female, 20 March, 2000)

Perhaps some additional discussion regarding the protection of privacy and confidentiality for families by HCP might help to allay this fear in families.

Concern held by families about insurance was not a dormant anxiety; it was a worry that had an impact on actual behavior. For example, some family members, where genetic testing was available in other jurisdictions, deliberately avoided obtaining genetic services in order to elude possible hindrance to purchasing health insurance:

Interviewer: And your sister and brother, they go for colonoscopies.

Affected Daughter: Yeah.

Interviewer: And, and have they had any genetic testing?

Affected Daughter: No, no.
Interviewer: Okay.


Affected Mother: She hasn’t.

Affected Daughter: No, she was going to, and then decided not to.

Affected Mother: [name of brother] decided not to because of his insurance. He travels a lot and he’s afraid in case they find the gene and he’s got it, the insurance one day will say, “We don’t insure people with that particular gene.” I don’t know.

(Interview with Affected Mother and Daughter, 12 December, 2000)

The fear that the disclosure of genetic test results (or the mere process of seeking testing or genetic counseling) could affect equitable access to health insurance was common among the family members interviewed. This situation also illustrates the divergent experiences of members of the same family. The sister and brother of the affected person being interviewed above have ready access to genetic testing for HNPCC in England while the affected person herself does not.

Co-Existence of Lay-perspectives and Genetics

Lay-perspectives and scientific perspectives co-exist for families. People can demonstrate elaborate understandings of the variables espoused by clinicians such as Mendelian genetics but also have elaborate ideas that appear contradictory to medical professionals. For example, an individual at risk for HNPCC illustrated her sophisticated knowledge of genetics by making reference to chromosomes and a conversation about the need for two mutations in a rare recessive disorder experienced by the child of a couple that are friends of hers and also made reference to the prevalence of a recessive gene mutation in Jewish populations. Yet, simultaneously she wondered
whether a mutation for HNPCC could “skip a generation” even if she herself or her husband did not have the mutation.

Patients and families appeared to be aware that there are disparities amongst clinicians with respect to their knowledge about hereditary colorectal cancer. Moreover, they were aware that clinical and genetic understandings have more cultural capital than lay-perspectives. However, while these perspectives compete for dominance in the clinical culture, this is not the case within the realm of lay understandings where they can peacefully co-exist. For example, people would sometimes preface their statements with a caveat noting that what they were about to say was not scientific, but was nonetheless important from their perspective:

**Interviewer:** Well actually, before I get ... before I ask, I ask the question, I’ll ask a different one. What do you think is the ... your sense of the cause of this cancer? What brings it about?

**Affected Female:** For me, personally? Um, well, we know that it’s genetic, if you look at it from a clinical perspective, but I would say to you, uh, with the experience of my life for probably ten years previous, a good part of ten years previous, I would say to you, um, for lack of a better word, anger. There was a lot of ... I went through some difficulties in a, in a relationship that brought on a lot of resentment and a lot of, a lot of pain, really. And, and I honestly feel that when you internalise that sort of thing, it’s going to affect you somewhere.

And part of me ... I know it, I know it doesn’t sound scientific, but at the same time, you can only internalise so much and it’s got to break free somewhere. And I really think, to some degree, that’s what opened the door to this finally exploding in my system. I went through a lot of, a lot of stuff. And actually, I’ve gone through some stuff since, but I think I let, I think I release a lot more. I don’t think I hold it up, uh, build it up like I used to. I don’t, I don’t hang on to it so much. Uh, again, probably in my experience, you know, uh, expanding life and the value of life, and, you know, what it has to offer, is just a matter of, you know, what’s that expression? Uh, don’t worry about the little things? You know? How’s that ...

(Interview with Affected Female, 20 July, 2001)

People know that lay-perspectives are different from scientific approaches to understanding, but they still maintain an important role in their understanding of cancer.
In the lay-perspective anger, over-internalization and pain bring cancer about.

Dramatically differing explanatory models do exist side by side within peoples' understanding. Individuals also demonstrated awareness of a genetic culture that is related but distinct from the medical culture.

**Lay perspectives on Skipping Generations**

Science was only one part of a complex ordering of peoples' experience. One of the common notions in families affected by HNPCC was that genetic mutations could skip generations. Consider the following excerpt from an interview with a woman at risk for HNPCC:

**At Risk Female:** My first marriage, yes. So, I... my sort of main reason for going for genetic testing, or genetic... yeah, genetic testing, was to find out more for her. Because if I don't carry the gene, then as least she's safe on one side. Because I would think she has a higher risk than I do. Having had the... such a history on both sides. Although, uh, the people with cancer aren't... you know, because it's another generation removed from her. But on her dad's side, it's his sister that had the cancer. So. I was more worried for her to have the testing. Or, if I had the testing, then could she have the testing. If I was positive, sort of idea.

**Interviewer:** Because it's one generation closer on the dad's side.

**At Risk Female:** Yeah.

**Interviewer:** You... there appears to be a higher risk there.

**At Risk Female:** Yeah.

**Interviewer:** Whereas because it's one generation once removed, there's a little bit less risk.

**At Risk Female:** Yeah.

**Interviewer:** On that side.

**At Risk Female:** Right.

(Interview with At Risk Female, 13 December, 2000)
The above passage illustrated a common theme included within lay understandings about genetic disease skipping generations so that risk for disease is absent in some generations and present in others. In the example below, the notion of mutations skipping generations is considered by a woman at risk for HNPCC when comments on whether she encourage her children, aged 17 and 12, to seek genetic testing:

At Risk Female: I guess depending [that she would encourage her children to seek genetic testing] on what the genetics counsellor tells me. If they say to me that, you know, there is a good chance that they also will be at risk because I have the gene or not and, if, what the chances are if I don’t as to whether they would skip a generation... then I would. If they wanted to. Talk to them about it at least. [emphasis added]

(Interview with At Risk Female, 21 January, 1999)

These examples convey two notions: the possibility of mutations skipping generations and the hazard associated with nearness to a generation that has manifested examples of the disease. This perspective assumes that risk is eliminated or greatly reduced as a family member is farther away from a relative who had been diagnosed with cancer. So, according to this perspective, grandchildren were much less likely to have a genetic mutation for HNPCC than their parents and the genetic mutation essentially fades away and becomes weaker as generations proliferate. Conversely, as one gets closer to an affected relative, the risk for manifestation of the disease also increases.

**Selection and Pre-selection**

This study revealed the process of self-selection and pre-selection at work in many families. The process of pre-selection involved the recognition by family members that one individual appeared more likely to develop HNPCC than other members of the family. This was often done on the basis of perceived similarities between an affected relative or ancestor and someone at risk for HNPCC who have not yet developed cancer.
These perceived similarities were usually seen to be in personality or biological characteristics. Self-selection involved family members identifying themselves as likely to develop HNPCC.

In some cases the process of self-selection appears to begin very early in life as a concern about the possibility for developing cancer and a sense of familiarity with cancer:

Affected Daughter: I did, I have grown up knowing, because my mother had sarcoma on her leg first. So I’ve grown up, small, as a young girl, knowing about it. And now my daughter, in turn. And when you grow up with that, it’s a very tough thing. Because once your mother gets through it, you as a young girl, as a young person, you have to start dealing with, do you have a fatal lump here? Or a bump Or you’ve got a pain somewhere. You have to ... y, you absorb that, and then you start thinking, “Have I got cancer?” Now, I had that when I was in my early teens. And now my daughter has the same thing.

Affected Mother: I guess she ...

Affected Daughter: History is repeating itself.

(Interview with Affected Mother and Daughter, 12 December, 2000)

This sense of familiarity can develop into a sense of major concern and worry:

Affected Daughter: You don’t [ ... ] than your, your mother. That was mine. Because I was so, so much younger. But then when ..., and in my teens, my mother’s okay. It’s fine. Then all of a sudden, it was like, I absorbed something. Something, um, very powerful, then, that is with me for the rest of my life. And that idea, uh, that, you know, you have ... this thing somewhere, or, let’s say, uh, you can find the lump or the nodule. And then you begin to think. Do I have it? And it’s not always, either. It’s not, you know, I’m not being paranoid. I mean, you can go by years with nothing, and then all of a sudden, I get stopped in my tracks by the reality that this is possible. Could it happen to me?

(Interview with Affected Mother and Daughter, 12 December, 2000)

In some instances, this sense of familiarity develops into a sense of expectation:

At Risk Female: Yeah, I think so. Um, I already have a suspicion that it probably is genetic, and I probably do have the gene. Um, the only reason I say that is because [throat clear] my whole life I’ve been told that I’m exactly like my dad, and I take after his side of the family, and, so, uh, why not have that too. [Laugh] So.
Selection can be made on the basis of perceived similarities in biology, personality or behavior.

The following example illustrates selection being made on the basis of perceived similarities in biology:

**At Risk Female:** I would say the chances are pretty good that I’m going to get it. That’s, that’s my view. My, um ... and I don’t know whether or not this is relevant or not, but, my father’s and my intestinal tract or system is pretty similar. So, to the extent there is a genetic component, I suspect that, um, that I’ll get it. Um, in the early ... early 1990’s, our eating habits were very very good, in terms of diet and, um, uh, sort of the cancer fighting kind of diet. Since my kids have been born, that has changed. [Chuckle] Uh, it’s just, it’s just been hard to feed them and feed us, and, and keep everybody happy. So, um, my son also has terrible eating habits, in terms of what he will or will not eat. And, he’s a very picky eater, so that has meant that our eating habits have, have declined, shall we say, in quality. Since, um, since about 1996. Although I think my husband and I have both come to the conclusion, recently, that that’s about to change. [emphasis added]

This self-selection is also done on the basis of intuitions that people have about similarities in everyday actions:

**Interviewer:** You mentioned, uh, a little while ago, that you had a sense that you might get cancer one day.

**At Risk Female:** Mm hm.

**Interviewer:** You just, you know something about yourself and, uh, and your similarities to your dad.

[meowing cat in background]

Can you comment a little bit more on that? Is that just an, an intuition that you have? Is it because of physical similarities that you’ve described between your dad and you? Are there other things too?

**At Risk Female:** Um, probably the two things that you said. **Intuition and, and physical similarity.** I, um ... my dad and I, as I get older, I realize my dad and I
are a lot more alike in, in like, many, many ways. Down to, and you’ll just think this is silly, but, um, uh [sigh] once you have kids, I don’t know if you have kids.

**Interviewer:** I do.

**At Risk Female:** Right. [Chuckle] Then, um, you start to see things that they do, that you realize, “Man, that’s just like something I do.” And not that long ago, I was just chatting with my mom, in, in, in her bathroom as I, as she was doing her hair or whatever, and I look over and I see my dad’s toothbrush. And my dad’s toothbrush is splayed. Like it’s been used to wash the floor, right?

**Interviewer:** [Laugh]

**At Risk Female:** And I just have to look. And I go, “That’s Dad’s toothbrush, isn’t it?” She said, “Yeah. Why?” I said, “Because that’s what my toothbrush looks like.” Um, and I just think that there are an awful lot of things, like right down to the pressure that you use to brush your teeth, um, that’s just, it’s just, that’s way ... life is way more genetically determined than I think we realize. And, um, as I, as I say, as I get older, I start to see a lot more similarities. Um, the degree to which I procrastinate, to, um, the fact that I like to run, like my dad. Um, these are all just things that seem to be genetically similar to him. So, um, between that and, um, yeah. I’m a fairly intuitive person, generally. So, between those two things, I think, I think, yeah. I’m going to get cancer some day, probably. [emphasis added]

(Interview with At Risk Female, 20 November, 2000)

In the above example, the individual at risk carefully notes similarities between her and her father including: the way they flatten their toothbrush, their tendency to procrastinate, their interest in physical activity and their intuitive disposition as all pointing towards her eventually developing cancer. These components existed in many of lay-perspectives on inheritance in the family members interviewed.

In some instances, families pre-select which family members they think are likely to develop the cancer. This is also done on the basis of perceived similarities between an affected relative and the at risk family member. This case illustrates a father’s perception of similarities between himself (affected) and his daughter (at risk):

**Affected Male:** Um, the youngest daughter is ... still lives at home. She’s a bit of a, of a worrier. I think it’s bothered her a bit. [Name removed] is very much like
me. She keeps stuff inside. She doesn’t let a lot out. You never know what’s going on with her. But it ... no, it hasn’t affected our relationship. As, as, you know, it, it seems as, as it always has been.

Yeah.

(Interview with Affected Male, 26 May 2000)

These comparisons in families are not neutral; they are perceived risk assessments and they are echoed throughout immediate families. This process appears to begin very early in life and appears to begin out of worry about the children developing the cancer.

**Support Groups as a Threat to Personhood**

One of the initial issues that emerged from the research was to attempt to examine why support groups for HNPCC or sporadic colon cancer do not exist. As part of the research, family members and clinicians were asked for their perspectives on support groups. A number of people interviewed suggested that the participants in support groups may be a different group, a group that identifies more closely with the role of cancer patient or cancer survivor. The “differentness” of this group is manifested in their apparent increased worry about depressing things and on cancer illness.

When asked about their health and how they would define their health most people defined themselves as healthy for the most part. Most people never mentioned cancer when assessing their health status. Consider the following example of an individual who has been diagnosed with and treated (surgery and chemotherapy) for colorectal cancer:

**Interviewer:**...How would you describe your, your health? Your overall health?

**Affected Male:** Uh, uh, actually, I think my overall health is probably as good as it’s ever been. Um, in the sense of, uh ... well, I’ve, I’ve lost weight in the last year. I feel sort of ... wouldn’t mind to lose more, but I’m, I mean, I’m happy with that. I, you know, I’ve exercised regularly for about fifteen years. And, um, my health helps me meet the demands of what I do. You know. I mean, I’m tired at the end of the day, but I’m not, I’m not stressed at my job. Um, I had high cholesterol. I was on medication. That went down. Now I’m off the medication, I’m off blood pressure pills. I have had mild hypertension. Um, I’ve had chronic
low back pain for thirty years. But I’ve managed that through different exercises and things that I do.

(Interview with Affected Male, 11 December, 2000)

People commented on their weight, their energy levels, the amount of exercise they did in a week and did not, as a rule, consider cancer to be related to their health status.

Initially, I thought that this may be due to some difficulty people experienced in talking about cancer with me but it was clear that when asked people were more than willing to talk about cancer. They would give detailed and thoughtful narratives about their experience with cancer. Cancer, however, did not appear to be related to peoples’ assessment of their present health.

It became increasingly clear that most people who have experienced cancer who were interviewed for this study, did not define themselves, as a rule, in terms of cancer or cancer experience. The participants interviewed appeared to very aware of the potential influence of cancer to shape their person:

Affected Female: Mm hm. Yeah, it’s just, like, I mean, it’s just like words. Different word, sort of word choices, too. Um, either can define, put you, like, in a victim situation. Or feel like you’re in a victim situation. Or they can empower you. Like, the word, ‘remission.’ Remission, to me, means you’re waiting for something to come back. Like, you’ve still got one toe in the sick pool. Like, you’re just waiting for it to come back. Well, for me, cancer wasn’t a welcome visitor in the first place. So, I’m very black and white in that. Either you have it or you don’t. It’s like, either you have green eyes or you don’t. Either you have, are black, or you’re white. You know. And you’re not, you’re not, um, it’s not like, “Oh, I’m ... I’ve got, I no longer have cancer but I’m waiting for it to possibly come back.” That’s just like ... so, for me, I say I’m cancer free. I’m not in remission. I’m cancer free. I don’t have it. My tests show, right now, I don’t have it. So, I, I’m cancer free. [emphasis added]

(Interview with Affected Female, 4 December, 2000)

In fact, many people worked hard to resist a construction of their person that was in any way predicated on cancer or the experience of cancer. The strategies that people
employed to avoid the perils of hereditary disease to their personhood are reviewed in the next chapter.

This chapter has provided some ethnographic data on what have hitherto been referred to as "lay perspectives". However, while complex lay understandings do exist that may be indeed at odds with the scientific and medical explanatory systems of professionals, this chapter has provided evidence that they may be simultaneously in line with and may even subsume medical and genetic knowledge. Peoples' evaluations of the health care system were complex and included comments on rural versus urban settings, chemotherapy and the knowledge base of professionals. Many had negative impressions of their experiences with treatment especially regarding their initial diagnosis and the knowledge base of clinicians. They provided elaborate analysis of genetics services (availability and waiting period), screening protocols and the efficacy of screening techniques such as the colonoscopy and some even commented on health care differences between the United States and Canada. While the interviews show understandings that could be termed lay perspectives such as: ideas about disease skipping generations, self-selection and pre-selection, they indicate something deeper: the ways that people address threats to personhood such as support groups or being categorized by others in terms of cancer as a disease. These narratives begin to provide support for a fresh theoretical position that refutes the rigid distinction between lay and professional understandings of hereditary cancer. Instead, this distinction may reflect an additional consecration of the cultural capital of medical and genetic professionals rather than a depiction with basis in fact. Ultimately, this chapter challenges the theoretical efficacy of the notion of "lay perspective" in that such a notion implicitly places the
patient and family point of view in a subordinate position to that of the medical or genetics professional. The next chapter utilizes further analysis of family and patient narratives to explore these issues more fully.
CHAPTER FIVE: THE CONSTRUCTION OF PERSONHOOD

This chapter provides the narrative data for one of the fundamental tenets of this study, that is, that individuals actively negotiate the meaning of HNPCC as part of a dialogue about their person. This chapter reviews family members’ awareness of a number of threats to their personhood including: public ideas about cancer, disesteem associated with the colon and the evacuation of waste, genetic guilt, genetic shame and ideas about cancer in the wider community. A theoretical distinction is made between shame and guilt in this study and the chapter is meant to provide evidence for the process of healing emplotment by people at risk for hereditary cancer. There are two types of clinical assessments: those done by clinicians about disease and those done by patients about clinicians. It is the latter that are examined in this section and the narratives show that kindness and empathy are given extra value by patients. The narratives of family members reveal an outgrowth of strategies that create a sense of agency and attempt to address threats to their protective cocoon. The interviews also highlight the importance of emotional capital and pure relationships as part of the process of healing emplotment. This chapter attempts to demonstrate some of the reflexive dynamics of personhood, the life politics of people faced with HNPCC and the ways that people faced with illness engage in campaigns to colonize their futures by rebuilding a sense of trust in the world of experience.

This chapter focuses on how people confront the social and biological threats of hereditary cancer as part of the process of healing emplotment. Central to healing emplotment is the creation of agency, hope for the future and the strengthening of the threatened protective cocoon of trust. The family members interviewed in this study
were definitely reflexive about threats to their person and they generated complex strategies to address these dangers. The dangerous social variables for personhood include shame associated with the site of the cancer, genetic guilt and negative ideas about the personhood of cancer patients in the wider community. This chapter reviews strategies employed by families affected by HNPCC to address these menacing social factors.

My first glimpse into the depth of experience in families living with cancer came before I had interviewed anyone with HNPCC as I walked into an elevator in the cancer agency and saw a poster advertising a support group session for children who had lost or were in danger of losing a parent to cancer. The poster, pictured below, outlined the activities of a support club that would include art and music for school-aged children:

I tried to imagine the experiences of the children participating in this art therapy support group as they tried to develop strategies to heal and move on to successful young lives. The class was aimed at school-aged children and for a moment I pictured my own seven
year old participating in this situation. Later, in interviewing a woman affected with
cancer I heard her describe similar experiences as a child:

**Affected Female:** I remember everything. I remember him ... the nurse coming
to give him, um, his enema to prep for the colonoscopy. Um, I remember the
procedure of the colonoscopy. Um, we lived in Yellowknife at the time, and we
had to write in our news book, and I drew a picture of my dad on a table, and I
explained the whole procedure in, like, in the book.

**Interviewer:** And the news book is for school children? Is that what you ..

**Affected Female:** Yeah.

**Interviewer:** ... mean? Oh, okay.

**Affected Female:** You, you write your own, your own, your ... you write your
daily news. It's like a diary, right?

**Interviewer:** Okay.

**Affected Female:** Yeah. And then you just say what's going on in your life, of
whatever.

**Interviewer:** And so how old would you have been then? About?

**Affected Female:** Mm, grade one.

**Interviewer:** Grade one. When did it ... at that time, did you think about colon
cancer? What were your ideas about it, at that point?

**Affected Female:** Mm, well, I mean, for myself, I remember prior to finding out
... I mean, they were inept in Yellowknife, initially, because my dad ... they told,
they thought it was, they said, "Oh, it's just an ulcer." And then when he went to
Edmonton, um ... but I vividly remember coming home from school, and my dad
would be on the couch, like, holding his stomach because he was in so much pain.
Um, I remember, um, the, the changing, like, his ... when he came home, he, they
... he, his incision was on the horizontal. It was different.

**Interviewer:** Mm hm.

**Affected Female:** Um, and, um, he ... and his bandages always had to get
changed. Because it was weeping. And he lost a lot of weight. Um, the doctor,
um, told them that, um, he had to drink a beer, or whatever, to help stimulate his
appetite. Um. And I remember just, also, like, the preps. Um, for the
colonoscopy, and the prep for surgery. Um, I, I remember teasing him about having to eat jello. [Chuckle]

And, uh, it’s, um, and just, um, [pause] just the fact that its just like, that I ... well, my dad was told basically to put it, his affairs in order. Um, because it wasn’t as, I guess, popular [chuckle] of a cancer back then. Um, or at least it didn’t seem like it was. And, um, just the fact that I knew that my dad might not be around for a long time. But, so that was scary. But I mean, I knew my dad was, um, a strong man, and I looked up to my dad, and I knew that he would make it. So. Because my dad told me he would. So [chuckle] it was like ...

Interviewer: [ ... ]

Affected Female: And of course, when you’re little, yeah, you believe everything. You know, that your parents, especially when you admire them and look up to them. You know. You just believe everything they say.

(Interview with Affected Female, 19 December, 2000)

I knew then that peoples’ experiences with the fateful moments of cancer were utterly immense and that my research project could only hope to provide a momentary impression of the depth of their understandings and the profundity of their healing emplotment for sustaining their personhood.

**Threat To Personhood and the Shame of Colon Cancer**

In contrast to guilt that pertains to anxiety about infractions against others (such as the passing on of a genetic mutation), shame is a more pervasive to the project of the self. Shameful variables threaten to undermine the integrity of an individual’s overall narrative about their personhood by unveiling invalidating characteristics (Giddens 1997). The most universal issue of concern regarding shame associated with colon cancer pertains to colostomies and the evacuation of waste. This was true of both clinicians and families. When asked about negative social aspects of colon cancer, at risk or affected people and family members almost always mentioned the possibility of a colostomy. A colostomy refers to the removal or partial removal of the colon that necessitates the use of a colostomy bag for storing and a stoma for evacuating waste.
The need to permanently evacuate waste through a colostomy bag is a seriously
invalidating characteristic for a person:

**Interviewer:** Can you tell me about any, uh, stigma associated with colon
cancer?

**At Risk Female:** Oh, yeah. I mean, uh ... my parents actually were, were pretty
open about it. Um, and certainly within the family. They told, um my dad’s
extended family. I mean, he told his siblings and, and um, uh, friends that he had
colon cancer. **Um, but, uh, a lot of people felt, I think ... they, they felt
uncomfortable about it.** They didn’t ask him a lot of questions. Um, they, they
probably didn’t want to know all the **gory details.** Um, **but within our family,**
**there’s definitely no, no stigma.** So, um. **Socially, yes. Within the family, no.**

**Interviewer:** So, when you talk about, um, details and things like that, are you
talking about ... and stigma ... are you talking about, socially, colon cancer per se,
or cancer?

**At Risk Female:** Colon cancer.

**Interviewer:** Colon cancer.

**At Risk Female:** Just colon cancer. And I think people are, you know ... breast
cancer, lung cancer, I think people are becoming a lot more aware. Uh, um, about
those kinds of diseases. **But since colon cancer, um, involves a lot of personal
stuff, um, people don’t want to know too much about it.** If anything, actually,
my dad has been more private about his prostate cancer. Um, and has chosen not
to tell people. I don’t know whether or not that’s because of, um, what happened
when he had his colon cancer, and the way people treated him. I suspect that it is.
Um, I think he, he feels that, um, this one, this one seems to be a bit more of a
private matter for him. [emphasis added]

*(Interview with At Risk Female, 20 November, 2000)*

The family member comments on the “personal stuff” and “gory details” associated with
colon cancer, that is, those that relate to the evacuation of waste and how stigma exist in
the social but not familial context. She notes that the site of cancer can add specific
component of stigma in some cancers such as HNPCC and prostate cancer. The at risk
family member also describes how the issue is a familiar one within the immediate family
and, as a result, it is no longer a source of shame.
Consider the following excerpt from an interview with a person at risk for HNPCC:

At Risk Female: ... It started back east where my family is in Quebec and my dad got cancer when he was 42 or 43 and he got it again five years later... a certain period of time supposedly if you don't get it you won't get it again. So they did the surgery and removed a small part of his bowel then they did it again and removed all of the large intestine but still he doesn't have a colostomy he still everything is fine just most of the large bowel is gone then his brother, both his brothers, got it one severely enough that he has a colostomy—bag...[emphasis added]

(Interview with At Risk Female, 31 January, 1999)

The participant is careful to reassure me as well as herself that the worst did not occur; her relative can still evacuate waste in a conventional manner. Some individuals at risk for HNPCC appeared more worried about the possibility of a colostomy than anything else, even death itself:

Affected Female: Yeah, I actually just, I just thought of something else too, that, that, and actually, that didn’t come up. Um, uh, is ... and I think of it now, when you think of what you not ... of, of the not, the not glamorous part too, is that, uh, that there's not only the fear of, of cancer, of death, right, but the fear of, um, colostomy bags. That’s, um ... I mean, that’s ... I just remember that that’s, you know, also came up. And I mean, uh, and because of, because of the, the stigma of that, would be, you know, would be ... like, everything that’s having to do with that. With um, uh, decisions as to, to what you do when you have, um, the surgery. Like, I, I, I ... because my sisters had a right hemicolectomy, that’s what I figured that I would have to have, right? And the doctor had said to me, “We have three choices. We do nothing, we do a right hemicolectomy, or we do a subtotal colectomy.” A subtotal seemed to me really a lot, and I was afraid that, that if they did that, I would have to have a colostomy bag, right. So, this wasn’t necessary. And then it was later, when I read that they recommended subtotal colectomies, I thought, “Huh, gee. If I’d know ahead of time and I opted for that, would I, would I have ...” Um, which brought up a whole different ... so there’s, there’s sort of that kind of thing. Except, with this particular kind of cancer, you know ... [emphasis added]

(Interview with Affected Female, 20 March, 2000)

The following excerpt provides another illustration that the stigma associated with a colostomy is immense:
**Interviewer:** Can you tell me a little bit about any stigma that you’ve experienced around cancer, or colon cancer?

**Spouse of Affected Male:** I haven’t experienced any, no. Um, I think probably because he does not have a colostomy. Which a lot of colon cancer patients do. Have to live with a colostomy. Because his, his brother did. And his brother would have been the person, probably, that could have answered that question better, had he still been alive. Um he ... from the time he was forty, had a colostomy. But he had a wonderful attitude about it. It was like, “Well, is this what, what it takes for me to live? Well, then I’ll live with this.” You know. “I’ll deal with it.” And his wife was very much the same. But certainly friends of theirs, and certain people he knew, said, “Ugh, I’d’ I’d just, I’d never live with that. I’d never want to live with that.” Sort of thing. So, there was a sort of “Ugh” kind of feeling from other people, that he had to deal with that. He was very good with it. It didn’t bother us, of course. And, um, we haven’t had to live with that...

(Interview with Spouse of Affected Male, 26 May, 2000)

A number of family members and clinicians almost equated the concept of stigma and the colostomy in colorectal cancer. From a cultural perspective, the severity of the disease is defined on the basis of whether someone had a colostomy. This cultural assessment of seriousness may contrast to a clinical evaluation that would tend to assess the severity of the disease based on the location of the cancer and its bearing on prognosis for long term survival of the patient.

The issue of shame associated with the site of the cancer was spoken about by many of the family members. This was not usually mentioned as a source of stigma by clinicians but was common theme in the patient and family narratives when discussing support groups and communication about their experiences:

**Affected Female:** Well, it’s hard to, it’s hard to get ... I mean, if you, um, uh ... nobody, um ... and I think maybe that relates to sort of what you said about support groups. I mean, nobody wants to hear about your colon. [Laugh]. Um, you know, as, um, my thera ... um ... [pause] Yeah, that, that’s sort of an, an issue. Is that it’s, you know, not one of those, sort of, uh [pause] um ... And yeah. It’s sort of not the , you know sort of thing you can bring up ... or, I mean, I guess you can. But, but there’s a little less ... it sort of, yeah, it is sort of , you know, a, an icky kind of thing.
It appeared that strong stigma definitely exists about colon cancer but that the family members interviewed appeared to have developed strong coping skills that have made them comfortable talking about these issues. Every interview participant appeared very willing to talk about issues of stigma, the site of the cancer, invasive screening techniques (e.g. colonoscopy) and the possibility of colostomy.

The following interview shows how the colonoscopy for some participants carried specific shame associated with it:

**Interviewer:** Have there ever been any issues of, sort of, stigma around cancer? That you’ve experienced, or worried about talking with people about, or ...

**At Risk Female:** Um, colon cancer, I guess, in the beginning, when it first became an issue in our family, um, it was kind of hard. I was a lot younger. You know, harder to talk about when ... I don’t think I talked to my friends about it. But, uh, I find more recently, it’s, um, much more in the media, and people are talking about it, and, um, I don’t think there’s a stigma about it now. I think it’s changed a lot in the last five years, ten years. It’s, um, a lot more talked about.

**Interviewer:** This is colon cancer.

**At Risk Female:** Colon cancer. Yeah.

**Interviewer:** And in your early experience, there was some sort of nervousness around talking about colon cancer, per se.

**At Risk Female:** I think so, yeah. Kind of an embarrassment. Yeah. About the testing procedures, and things like that. But, you know, I think that’s changed. It might just be me, growing up, too. I don’t know. [Laugh] But I think it’s changed.

The example also shows how that over time her embarrassment regarding colon cancer, its site and screening became less powerful as she became older and more experienced with the issues. The excerpt also demonstrates that the colon is culturally de-valued and
treatment of this body area brings shame that needs to be overcome with age to avoid threats to personhood.

The report that people struggled more with shame when they were younger was echoed in other interviews. One participant, after the tape recorder was turned off, added one more comment about shame. She noted that it is an embarrassing procedure; an invasive experience, but especially for her adolescent son (aged 17) who wants to be “macho” and “manly” and, as a result, has worried that his friends will discover that he has experienced the colonoscopy procedure. The following response to a question about comfort levels in the family in talking about experience with colon cancer illustrates that not all members of a family cope in the same way:

**At Risk Female:** Yeah, not really. Not really. Um, uh, probably because my mother was a nurse and, and just spoke about these things. It was never, um, anything really hidden. I mean, you know, she would speak of the body just normally. I mean, there was never any shame or any, anything like that. Um, I don’t really feel a great deal of ... I, I suppose my brother maybe found it quite degrading. You know. When he was going through it. And I understand that. But I, I don’t, you know, I don’t, uh, dwell on that.

(Interview with At Risk Female, 20 November, 2000)

All of these examples illustrate the idea presented by numerous family members that the skills for contending with shame associated with colon cancer have to be developed by means of a familiar deepness of experience.

**Threats to Protective Cocoon of Personhood by Cancer in General**

When I first contacted one of the people interviewed for the study, she left me a message regarding her family’s strong predisposition to what she called colon “ca” spelling out the two letters, c and a, rather than actually saying the entire word cancer. Some other interview respondents referred to cancer as “the big C”. These words
seemed to speak to a culturally forbidding side of cancer thereby making it a friendlier and less socially loaded word.

However, most of the people interviewed were clearly comfortable talking about their experiences with cancer. Some pointed to the fact that cancer is normal occurrence in most peoples’ lives:

**Interviewer:** ... do you talk about colon cancer, and are there issues around that for you, in terms of talking about colon cancer? Or, do you get different reactions from people, or is it just ...

**Affected Male:** Well, it’s interesting. I think, mm, in talking about it, I would say everybody I talked to shared some personal story about how cancer’s touched them. Whether they’re you know, uh, uh, themselves, or a relative, or a friend. I mean, almost without exception. Um, and it was quite surprising. In fact, it, it, it almost kind of gave permission, or opened the door for them to say, “Yeah, and when I had this abdominal surgery, I was six months on my back. And I ...” You know. I mean, it was really, you know, and it was like a, you know, everyone was kind of out there, you know?

**Interviewer:** It opened up a dialogue that wouldn’t necessarily ... that normally you wouldn’t have.

**Affected Male:** Yeah. I mean, they didn’t come up to me six months earlier and say, you know, “My brother, or my sister-in-law died of it.” You know. But when I mention it, and “Oh, my sister-in-law, you know, they opened her up, and they couldn’t do anything.” You know. And, uh, and just people talk very freely about it. Which, it was ... I don’t know if it was ... it was interesting, anyway. But I, I guess it was amazing how that every, there wasn’t an exception, I don’t think. To anyone I told, that wasn’t touched by it in one way or another.

(Interview with Affected Male, 11 December, 2000)

The passage below provides an account of an implicit uneasiness or trepidation that people feel with respect to talking about cancer and yet it has been present in most families in one form or another, present, but whispered below the threshold of public discussion:

**Affected Male:** ... you know, when people, uh, you know, uh, people get cancer, it’s the “big C.” And he says, “When you get gout, no one says, ‘oh, you got the big G.’ You know. We don’t know everything about the big ...” You know.
He’s kind of demystifying it, and all, and, um, so where, let’s see. Why I started thinking about that. Um...

(Interview with Affected Male, 11 December, 2000)

These narratives illustrate threats to personhood from ideas about cancer in the wider community.

**Genetic Guilt and Shame: Inherited Responsibility and Blame**

This study revealed that there is a powerful element of genetic guilt encountered by people who indicated that they had experienced guilty feelings as a result of having “passed” this disorder on to their children:

**Affected Male:** ...It, it makes you really [pause] think, uh, almost feel guilty at times, that, that that I’ve got this and, and, I, you know, I could pass it on to the kids. Um, maybe I should have gone in for a check-up a couple of months earlier. Or whether it made any difference or not. You know, there’s ... all sorts of that goes through your mind. It’s, uh, it’s, yes, it’s, it’s affected me quite a bit, I think. More than, more than I realize in myself, I think. At times. It’s, uh ... I, I don’t do things that I used to do. I, I have a really hard time, uh, concentrating on anything. You know, getting into doing things that I used to like doing. Like, I carve and, and, uh, paint, and that. And I can’t sit down and ... for ten minutes and concentrate on a carving, sort of thing. I just sort of give it up and, and I haven’t been doing that sort of thing. It’s uh ... yes it’s affected my life an awful lot. [emphasis added]

(Interview with Affected Male, 26 May, 2000)

The following excerpt from an interview with an affected mother and her affected daughter (who also has children) illustrates this sense of genetic guilt across two generations:

**Affected Mother:** No, no, no, no. It was not. My husband that, uh ... but he died from it. I mean, it, uh, spread. It metastasized in his liver, everywhere. Uh, [pause] so maybe, you know, one becomes a bit immune. I mean, uh, when you live with it all your life. At least, I have.

**Affected Daughter:** I think the hardest thing is children.

**Affected Mother:** It is children. The thought of your children, Uh, I, I mean, I must admit. When, uh, [affected daughter] got hers, I was devastated. Because I thought it’s my fault she’s got it. Because of me.
Affected Daughter: Mm, I remember you telling me that.

Interviewer: In terms of getting it because of you, in terms of it being passed?

Affected Mother: Yes, that’s right.

Interviewer: To her?

Affected Mother: And because of a gene, or something. I mean, I don’t believe you inherit the cancer. But you must inherit the tendency. And then something triggers it, and it starts. I was talking to my niece, the one that, had, uh a hysterectomy with the cancer. Whose father died of, uh, [ ... ] colon cancer. And she’s doing research. She’s a very clever, uh, woman. And, um, she was saying that the latest she read is that as soon as a cancer starts somewhere in the body, it sends messages everywhere. It doesn’t mean that cancer is going to develop in all those places which have received the message, but it’s likely that it will.

(Interview with Affected Mother and Daughter, 12 December, 2000)

For those interviewed, the possibility that genetic disease might lay in waiting in a child or a grandchild was a source of great sorrow. This “genetic guilt” was a common theme in those people at risk for HNPCC with children:

Affected Female: Um, well, he doesn’t really ... [pause] he, he hasn’t really discussed it. Um, I mean, you know, we, we’ve sort of discussed you know, when I had, I had the surgery, and sort of, all the things about the testing. And, and he’s he, uh, [pause] just sort of go, goes, uh ... I think, sort of basically, you know, he feels the same way as I do. Is that, um, uh, that it would be really good to have testing. Like, I mean, he’s concerned, um [pause] yeah, he sort of has the same concerns as I have. About [boy’s name] and [girl’s name], about, you know, the kids. But, yeah, it’s never been, you know a sort of, um, [pause] issue in the sense of, you know, what I said about the in-laws, about him considering me, you know, deficient. You know, what a terrible thing to be passing on to your children. You know, I should have your teeth and your colon before we got married. [Laugh] We’re ... we’re ... So, yeah. Yeah.

(Interview with Affected Female, 20 March, 2000)

Whenever participants mentioned the potential impact of HNPCC on their children they often paused and were emotional. For at risk or affected parents with HNPCC, the possibility that they might die before their children grew up was also an event that many had considered.
A number of respondents reported that some family members, particularly those related by marriage, attributed a genetic blame towards the one side of the family that was seen as the possessor of the bad genes. Consider the following example from an excerpt with an unaffected spouse of an affected individual:

**Interviewer**: Tell me a little bit about, uh, your family’s experience with colorectal cancer.

**Spouse of Affected**: My family? Or my, my with him? Our whole family?

**Interviewer**: Mm hm. [emphasis added]

In this instance, when asked about the effects of genetic susceptibility to illness upon the family, this particular spouse (unaffected) was careful to note the origin of the illness in question originated from the other side of the family before answering the question. While this may appear logical in terms of genetics, my direct experience in the interviews unveiled something subtler, an ever so faint resentment or bitterness directed towards the spouse that seemed larger than disappointment resulting from the unexpected arrival of serious illness. This unspoken resentment manifested itself in the ways that spouses described the impact of genetic susceptibility to illness that was not bounded within a single individual, their marriage partner, but possibly extended into all their descendants (their children, their grandchildren) thereby altering family identity without end.

Other individuals interviewed also carefully paused to identify from which “side” of the family the HNPCC had originated. This may be in part an artifact of genetic counseling that minutely examine families that are normally socially constructed in terms of genetic pathways. The determination of the features of a family primarily in terms of bio-genetic association may represent something extra in the case of inherited illness, a
rift created by the culture of genetics. This shameful rift can be a serious threat to the practical consciousness of a people affected by HNPCC.

In another example, an affected woman reported that her in-laws were always careful to point out that the illness experienced by members of the family were part of her side of the family and not their side:

**Interviewer:** Who do you, who do you talk to about it on that level?

**Affected Female:** Um ...

**Interviewer:** Who knows about this?

**Affected Female:** Well, what ...

**Interviewer:** In terms of friends, or ...

**Affected Female:** Um, well I have, uh, [pause] uh, I have friends. And I have, you know, talked with friends that, uh, know all the details, and it’s just a, you know, a very good ... And they don’t, you know ... they, they’re very straightforward about it. I have ... I think, particularly, what I’m thinking about is, is my in-laws. Who are not uh, uh ... which I think might be an example of, of how, um [pause] it sort of [pause] or, some of the more negative aspects of it, socially. In that, you know, they don’t really want to know about it. That, particularly.

And also, the fact that it’s genetic, I find, becomes, um, [pause] uh, a, um, [pause] sort of a mark. I think. Yeah, in a way it’s a mark against me. It’s like, “Oh, well, at least it’s, you know it’s her that has the bad genes.” It’s like ... you’d be amazed, how many times in conversations with my husband’s family, ‘good genes’ comes up. [Laugh] Um, over, you know, teeth, or something. And it’s, “Oh, well, good genes.” You know. Oh, well, it’s good genes.

**Interviewer:** Right.

**Affected Female:** I mean, it’s the ... I mean, it seems to me that, sort of, the intonation is that there are, um, bad genes, and there are a bit of a, um, um ... a lot of moral feeling about these, about this [throat clear] Sort of a thing. Sort of like that. So, uh, [pause] so I think there might be that ... aspect comes up sometimes. It’s just sort of feeling, uh, less than, less than perfect. Or being less than, um, genetically kind of inferior Um.

**Interviewer:** Does that come up with your husband and you at all, in discussion?
Affected Female: No. No. Mm mm [negative]. [Long pause]. And it’s not really ... you know, I ... it’s not a lot, it’s not, uh, [pause]. Yeah it’s just been sort of the odd, the odd re, the odd remark, you know. So. Um. [...] But but that’s probably an issue that I’m sure that comes up for people. Is, you know, if it’s a genetic genetic thing, it’s sort of a, um [pause] you know, a black mark [emphasis added]

(Interview with Affected Individual, 20 March, 2000)

The distinction between people who have good genes versus those who have bad genes is in fact questionable genetically given that it is very likely that every human being is comprised of both “good” (non-mutated) and “bad” (mutated) genes. This is an example of genetic shame within a family and it appears in some cases to be an attempt by family members to segregate the lineal place of origin for HNPCC and assign blame to one individual. There was evidence in the interviews that the process of genetic blaming occurs in both affected and unaffected sides of a family.

In some instances, affected individuals were also careful to affix a certain inherited blame to their side of the family. In this situation, at risk or affected individuals were careful to absorb responsibility for the occurrence of inherited illness in their family, that is to say, they would carefully note that their side of the family was responsible for the arrival of HNPCC in the family. In this instance it would not be enough to simply point out that an illness has occurred to a member of family. It would be necessary to identify the direction from which it came in terms of inheritance as an significant clarification as part of moral discernment in the culture of inherited illness.

Using Genetics to Deflect Shame

The genetic mutation for HNPCC was sometimes, in contrast, utilized by individuals to deflect genetic shame.

Affected Male: I would think they should be. I would definitely think they should be. Particularly if it showed up in, in, one of the other daughters. If, you
know, if, if something showed up in [younger daughter] which ... she’s already, already been in, and, and had polyps found. Already. Um, I would definitely think those kids should be checked, genetically checked at least, and and if there’s, if the marker’s there, or whatever the problem is, if it’s there, then real diligent supervision and, and, and check-up after that.

You sort of ... In my case, I, you know, I think I did pretty well everything I could to keep on top of it. But still, it got away somehow. You know someone ... either, either it was missed at one check-up or it was extremely aggressive. [pause] Because generally they say these things take five years, at least [emphasized in original], to go from a polyp to, to a cancer. And uh, as I say, I’ve been checked-up every two years. [deep breath] And, [pause] then, it was there. So, yeah.

(Interview with Affected Male, 21 May, 2000)

In this situation, the individual states that he did everything that he possibly could to avoid the disease. Throughout the interview he describes the many preventative activities (diet, athletic exercise, vigilant screening) that he employed. The arrival of HNPCC was due to the genetic mutation and it is not in any way his fault. It is important for the respondent to note, then, that genetic fate, powerfully, intervened in his life world and that no action by him would not have altered this reality.

Rebuilding the Protective Cocoon of the Person and Rebuilding Trust Utilizing Genetics Services

When asked why they sought genetic services (counseling or testing), many people reported that they had sought out these services as a result of encouragement from a particular family member who had championed the importance of acquiring genetic information. In some cases, the individual themselves actually stated that they personally were not interested in seeking genetic information but were convinced to do so due to pressure from the family. The following excerpt from an interview with an individual at risk for HNPCC illustrates this point:

Interviewer: And what ultimately influenced your decision to come on board with testing?
At Risk Female: Well I think my uncle, really. My parents, my Dad, really, didn’t say much one way or the other. Uhm, my mom wanted to know why I don’t know. She never really said. She just wanted us all to be tested I guess so she could breath a sigh of relief if we didn’t have the gene and to worry if we did [chuckle]. But my uncle was really interested in following it. He had gone along with [name removed] this lady who was in charge of the study back there. He talks to her all the time and they, you know, look at the data and stuff and he just kept saying to me, you need to know and I said well, why do I need to know? If I’m gonna get it I’m gonna get it but, uh, I just finally gave in to them and then said okay I’ll do it. I really don’t have the desire myself to know one way or the other and before I had gone back east I talked to my doctor and he said “why would you wanna know?” he says, uhm, “its just one more thing to worry about” and not that I go to my doctor anyways and he says: “it will be just one thing to worry about if you know that you have it” And I said I don’t think it’s so much worrying about that because it doesn’t worry me. It really doesn’t. I don’t know how I’ll feel if I test positive maybe that’ll change things but, uh, maybe people will just go and have their testing done once a year like they should, whatever. He really wasn’t really too keen on it all.

Interviewer: This is your doctor?

At Risk Female: My doctor, yeh, my family doctor.

Interviewer: Your gp?.

At Risk Female: My gp, ya. [emphasis added]

(Interview with an At Risk Female, 21 January, 1999)

In this situation a family member who is interested in the science of genetics appears to be taking on a leadership role in promoting the pursuit of genetics information in the family. It is interesting to note that the general practitioner was arguing against the testing. Several other individuals reported similar experiences: that they had had to invest a tremendous amount of energy in convincing their family physician to refer them to the Hereditary Cancer Agency for genetics counseling. It appears that in most cases interest in seeking genetic services was triggered from within the family and not from an attending physician.
Some of the families have actually had experience with genetic testing. Many of these families are spread out throughout the country. This means that some of the individuals can go through testing where it is available while those who live in jurisdictions where it is not offered cannot. Consider the following example that illustrates this disparity between jurisdictions of Canada:

At Risk Female: Yeah. I think ...that’s my opinion. You know, that is my, definitely my opinion. That, uh, I think it’s an individual thing. And I think that if you’re somebody like my one brother, who did have the test, because my uncle, my parents probably as well, wanted us all to be tested, he did have the test. But he didn’t want to know the results. So he must obviously feel that if it was, you know, if it was positive, he would handle it, or, or didn’t know how he would handle it, so he’d rather not, uh, know. But he still goes every year, very faithfully. And in that sense, um, you kind of, you know, if you’re going to go ahead and have the testing, I think you’re going to want to know the results. Because, why would you want to go for a test every year if you didn’t have to. I just think that’s a waste. I would hate to think that he would have polyps, and it would be negative. That he wasn’t, didn’t test positive for this gene, and yet that he still would have done that. So ... [emphasis added]

(Interview with At Risk Female, 2000)

The excerpt illustrates two important findings. Firstly, disparities based on geographic differences in Canada mean that the same family could have dramatic different standards of care and access to services. Secondly, this example shows peoples’ reasons for seeking genetic testing are not necessarily based on autonomous personal decision making but are determined by family dynamics. This example and others shows that the protective cocoon of personhood extends beyond the individual to the family, that is, key family members take on the role of extending emotional inoculation and healing emplotment beyond individuals by fortifying a protective mantle around families.
Strategies for Protecting the Protective Cocoon of Personhood

One of the most common explanations that people reported for pursuing genetic testing was to improve their access to clinical screening (primarily colonoscopy) for HNPCC. The following example illustrates this point:

Spouse: So, for instance, I have had colonoscopy, and I intend to try and do it every two or three years. Now, I’m not sure, um, you know, whether that’s going to be ... I think that would be allowed. But, you know, if I needed some kind of ... if, uh, genetic testing indicated I was predisposed to colon cancer, I would think, you, you know, in the future, then that would be the kind of, um, uh, um, you know, credential [chuckle] you’d need to, to be tested with, you know, high frequency.

(Interview with Spouse of Affected Female, 3 August, 2000)

This “credential” that the family member describes was one that a number of people interviewed described as a possible benefit from genetic counseling. This refers to a kind of cultural capital that genetics services provide with respect to increasing family access to clinical services. Another possible gain that people listed was that if the test were negative, the need for the credential would be eliminated because the family member would not have to undergo colonoscopy screening for HNPCC if they were found not to have the genetic mutation.

Every person at risk for or affected by HNPCC was asked who they would tell about their results of genetic testing should they pursue it. People were also asked who they had told about their experience with or risk for HNPCC. Most of the people who had been diagnosed with colorectal cancer reported that they had not kept their illness a secret and that they had told most of their close friends and family. With respect to the outcome from genetic testing most people reported that they would be more private about sharing these results. The main fear that people had with respect to sharing genetic results related to possible barriers to obtaining life insurance. The following excerpt from
an interview with a father whose children are at risk for the mutation communicates this concern:

**Interviewer:** If you were to receive genetic testing, uh, if it were to become available and you were to receive it, um, who would you share those results with?

**Spouse:** [Breath intake]

**Interviewer:** Or would you?

**Spouse:** I wouldn't share them with anyone I didn't have to. Um, I might share it with, uh, doctors if we were seeking help. So, for instance, if we had ... if genetic testing was, um, allowed us to have more frequent screening or something like that, that would be about the only reason I would want to disclose the results.

**Interviewer:** What is your concern around disclosing, uh, results?

**Spouse:** Well, I just think that, for purposes of insurance and so on, that, um, one could, could definitely be discriminated against, on, on that sort of basis.

(Interview with Spouse of Affected Female, 2 August, 2000)

A number of people who had children also worried about the impact of a genetic mutation on their children's access to affordable life insurance.

This worry about life insurance also extended to concerns about a known family history. A number of families were worried that the process of engaging in genetics counseling might flag their increased incidence of cancer to a life insurance company and that they might be obligated to reveal this when seeking coverage. In this instance, genetics counseling itself, without genetics testing, was seen as jeopardous to families intending to seek life insurance.

**Threats or Aid to Personhood: the Clinical Realm**

People affected by or at risk for HNPCC were sensitive about threats to their personhood brought about by popular assumptions shared by professionals and the wider
public about cancer patients. The following excerpt illustrates this heightened awareness:

**Affected Female:** It was primarily in the Cancer Agency, when they first meet you. Because they don’t know your coping mechanisms. They don’t know you as an individual. Because, um, someone who called ... I called them on it, and it’s just like, “You don’t have to talk sloooowly for me. It’s not like I’m stupid.” And all of a sudden, whack. Comprehension. Like, they talk slowly. “You might bring someone, because it’s a lot of information to assimilate.” And it’s like, “No, I’m pretty on the ball. You, what you tell me, I’m going to remember.”

**Interviewer:** Mm hm.

**Affected Female:** And, and [chuckle] ...

**Interviewer:** Mm hm.

**Affected Female:** ... it’s like, I’m not all of a sudden brain dead. It’s like, I have colon cancer. It’s the other end of my anatomy. [Chuckle] It’s like, it’s not the head part.

**Interviewer:** Okay.

**Affected Female:** Um. So, um, and it was ... and I just found, uh, I guess because they see you as ... because you lose a lot of weight from that, that you’re very frail, physic, to look at, physically, you, you look very frail. But, it’s like, I’m not glass. It’s like, I’m very mentally and emotionally strong. And it’s like ... so it’s insulting to, I guess, to me, when people ... it’s sort of like, um, you’re, you can see this, um, if someone ... if their first language is not English, then you’ll see people who are English all of a sudden speaking slower and louder. And the person’s not deaf. [emphasis added]

(Interview with Affected Female, 19 December, 2000)

In this example, the individual reports that many professionals interact with individuals with cancer in an overly cautious manner with a depthless empathy due to a misguided idea that cancer makes people frail. The individuals interviewed were very aware of widespread notions about treating people with cancer and in many cases they reacted to these implicit assumptions strongly.
Sometimes these issues became even more significant for families who had invested more into a single interaction with a clinician. For the clinician the event might be only one of many in their busy day interacting with patients and families but for a family that has traveled a long distance for a short interview every detail in the exchange may be significant. Consider the following example:

**Spouse:** Before surgery. Hormone treatment. And, um, we had terrible experiences with, uh, with the first urologist that he was referred to.

**Interviewer:** What would be an example of a bad experience?

**Spouse:** Well first of all, um, just getting information from him. Uh, meeting with him. We had done a lot of, uh, preparation in coming to Vancouver to discuss the diagnosis and the treatment options, and trying to get an understanding of, um, uh, the stage and, you know, all, all of the questions that we had done a lot of preparation. *And we basically came in to his office and he came in, he gave us two minutes of his time, and he had his hand on the door knob. Uh, he was rushing off somewhere else. And we basically drove five hours to ...*

**Affected Male:** To get here.

**Spouse:** To get here. And have, uh, you know, ten or fifteen minutes of his time. And each time that we had dealings with him, we had to go from the office where he was supposed to be, to some distant part of the hospital to meet with him in some ...

**Affected Male:** Yeah. [emphasis added]

*(Interview with Spouse and Affected Male, 4 December, 2000)*

For the family members, time moved slower than it did for the busy urban clinician and the minute details of the interview were meaningful. The clinician, likely not cognizant of these non verbal signals, had unsuspectingly shown disrespect for the family, disregarded their investment of time in seeing him and signaled a lack of caring for their situation.
A number of the family members appeared to evaluate their experience with the clinical realm on the basis of their impression of the medical practitioner's level of empathy or kindness. Consider the following assessment from the spouse about the quality of medical treatment that his wife experienced for HNPCC:

**Interviewer:** What were your perspectives about the clinic, uh, as, uh, a husband? Just accompanying his partner there?

**Spouse:** We were very impressed. Positively impressed. Um, [pause] I guess, uh, you know, the people, um, really seemed to know what they were doing. Um, now, I haven’t had very much to do with the doctors. So, I was only there once, I think, uh, the first meeting with her doctor. I guess that would be her, um, oncologist? I wasn’t as positively impressed by him. You know, he didn’t seem to be a very, uh, um, empathetic person. He didn’t, you know, he is kind of the stereotype of what everybody says about doctors. Well, it seemed to be very much true in his case. So, uh there didn’t seem to be anything wrong with him [presumably in terms of technical level of clinical skill]. Um, in a, you know, a terrible way, though. Um, and the nurses, or whatever their status would be, you know, the people who are administering chemotherapy and so on, were, were great. Um, you know, very, uh, good at, you know, relating with people. You know, who are in that situation. As well as, you know, seemed to know what they were doing very well, as well. [emphasis added]

(Interview with Spouse of Affected Female, 3 August, 2000)

The individual being interviewed was a university professor in the sciences who presumably understood the scientific and technical side of the interaction. However, he did not primarily, like most others interviewed, evaluate experiences in the hospital or clinic in terms of these measures, but in terms of the level of genuine empathy and understanding that they communicated to the families living with the illness. Caring from professionals helps to build the trust that is a valuable part of a healing narrative.

The following example illustrates how one family compares their experiences in two different cancer agencies in order to emphasize the importance of medical caring in their clinical setting:
**Interviewer:** What have your experiences been like with the clinic, and, and with the hospital in your, from your point of view?

**Affected Male:** Well, uh, in [City of Cancer Agency 1], the ... where ... because I’m, we’re dealing with the colonoscopy. Or, uh, the, uh, colon cancer. Um, it, it is a totally different atmosphere than here. It’s, um, it’s more of a ... the whole thing is more of, um ... like you’re part of a family. The whole, uh, [Cancer Agency 1] is, is, um, is a family business. They, they know that you’re, you’re special. Because of the problems that you’ve got. And, uh, they treat you very warmly, and, um, and, and try to make you as comfortable as possible.

They ... there are no, um, there are no road blocks. Nothing is in the way. You have a free, um, opportunity to access anything that you want or need. It’s there and they get it for you, or they’ll, you know, you can um ... I just, I just felt that they were, they would bend over backwards to do anything for you. And they were nice about it. Uh, they didn’t make you wait. They didn’t ... you d, you were never really in discomfort. You were always being cared for very carefully. Whereas, um, uh, I think ... as I said, it’s more of a family approach.

I feel, here [Cancer Agency 2] that you’re more of a, um, of a, a commodity. That, that has to go through a system. And it’s, um, it’s not, uh ... it doesn’t have the same warmth. It’s like, um, a procedure. Uh, step one, two, three, four. And you just, you just have to go through these doors. And they’re not, uh ... it’s, it’s just like a, a clinical thing. It has no warmth to it at all. It, it, um, it’s, it’s not, um, it’s not as supportive. I, I do believe that they have, uh, support groups, and things like that. But I never was involved in them. I never got, never felt I, I needed them because the family support was, was more for me. Or, it was, it would work better for me. And besides, I’ve always been, um, capable of, of doing my own thing, sort of. And able to use that energy that I had.

**Spouse of Affected Male:** Can I say something here?

**Interviewer:** Yes, absolutely.

**Spouse of Affected Male:** Uh when you’re talking about the [Cancer Agency 1], one of the, uh, really remarkable things there, the volunteers that are everywhere.

**Affected Male:** Mm hm.

**Spouse of Affected Male.** Uh, they help you up down this hall, and you get you to the department, and **bring you coffee, or if you need a quilt, or...**

**Affected Male:** Well, there are some. When you come in the door. And the volunteers here are, they’ll tell you, “Oh, you have to go up these stairs, down that hall.” You know. They don’t take you... in the [Cancer Agency 2], but in [Cancer Agency 1] they would say to you: “I’ll take you there.”

**Interviewer:** Is this...
Affected Male: It’s different.
(Interview with Affected Male and Spouse, 4 December, 2000)

Helping someone down the hallway, bringing them a quilt or a coffee may not explicitly factor in the clinical culture as a criterion for appraisal but for families, the “family approach” described above was almost universally described as the most important variable in their assessment of clinical services. A family approach is conducive to the enhancement of the protective cocoon that is an essential part of a successful healing narrative.

“It’s a Chemo Kind of a Day”: Illness in the Lifeworld

Those individuals interviewed who had experienced cancer or who were at increased risk for it did not want their illness to modify the narrative structure in their life, that is, cancer was not allowed a large role in the narrative that defined their person. People made it clear that their illnesses occurred mostly in everyday life rather than as discrete medical encounters in clinics. Many of those interviewed for the study were not actually absent from their work or from fulfilling their daily responsibilities for very long. The shortness of their involvement in the clinical realm appeared to be partially due to necessity and partially due to choice. In contrast to clinical recommendations that might advise long-term bed rest and rehabilitation, many patients who have undergone surgery, chemotherapy or radiation therapy simply didn’t gradually re-enter their social world. This appeared in part because people simply did not have the resources, either financially or in terms of support from family, friends or others, to absolve themselves from their obligations (e.g. the need to earn an income, to pay the mortgage, to mind the children or to clean the house). In other respects, this seemed to be due to the fact that people were
actively resisting a perceived threat to their personhood posed by a lengthy characterization of them as sick with cancer or too much time in the jurisdiction of the clinic. Consider the following example of a police officer continuing duty while receiving chemotherapy:

**Interviewer:** Okay. And who did you tell about your colon cancer? It sounded like you told everybody.

**Affected Female:** Yeah, I’m very open about it. I’m not ashamed. I’m not just, like, [chuckle] I mean, I have cancer, it doesn’t have me. As far as, like, it’s ... it doesn’t define who I am. It’s like ...

**Interviewer:** Mm hm.

**Affected Female:** ... um, just the fact that, you know, you’ve got, I don’t know. You gr ... and I’ve got green eyes. Uh, and I could have been brown eyes. It’s just, like ...

**Interviewer:** Mm hm.

**Affected Female:** ... it doesn’t define who I am. It’s just, like, it’s just something that you have.

**Interviewer:** Were you working at the time? Obviously you were working, uh, at the time that you went in for your colonoscopy.

**Affected Female:** Mm hm.

**Interviewer:** And you had been planning to do a marathon.

**Affected Female:** Mm hm.

**Interviewer:** And so, how did that affect you? In terms of the suddenness of all this in your life? How did you perceive yourself? Did you, did you, I mean, you must have immediately taken time off work, or, and?

**Affected Female:** Well, it was something that I had to, um, deal with. And, um, I just basically wanted to deal with it. And, uh, that’s it. It’s like, um, because I didn’t let it dictate my life. Like, I still did everything that I like to do.

**Interviewer:** Mm.
**Affected Female:** Um, I'm, I guess, very independent and stubborn. [Chuckle] I mean, half the time, I mean, through chemo, I worked through most of my chemo. Um, I mean, uh, really it ... uh, sometimes I would just have to go home, because, I mean, I'd just be vomiting in the waste bucket on the way, and carrying it on the way to the bathroom. And I'd go, "Well I guess it's a chemo day."
And I'd laugh, and go home. [emphasis added]

*Interview with Affected Female, 19 December, 2000*

This example illustrated how illness occurs within the life world rather than in the clinic, partially by necessity and partially by design of those experiencing the illness who do not want their person to be medicalized or biologized. The police officer, in this instance, was not required to work for financial reasons; she chose to continue working for reasons related to her active involvement in the construction of her personhood. People affected by HNPCC appear to work hard constructing their person so that they are understood and understand themselves as full participants in the social world:

**Interviewer:** ... why is this important? And, in, in fact, to ...

**Affected Female:** It's like, what ... describe your personality. Or, it's like, one word to describe your personality. Well, your personality, you're multifaceted. It's just, like, you can be humorous, you can be this. It's just, like, I'm cancer ... I'm not just a cancer survivor. And it's, like, I'm, like, uh, a wor ... I ... a worker. I'm a friend. I'm an athlete. I'm an athlete. I'm a friend. I'm an athlete. I'm a friend. I'm an athlete. I'm ... uh, it's just, like, in the big ... I guess I lo, always look at the big picture. It's, it's only one little blip. In my life. [emphasis added]

*Interview with Affected Female, 19 December, 2000*

The "little blip" that the individual refers to is her cancer experience, that is, cancer is only a small part of her experience that has no large role in defining her person.

**Cultural ideas about Cancer and Personhood**

People were reflexively aware of the potential impact of cancer on their social tenure. Ideas about cancer that many individuals were fighting against appeared to contain the following elements:

- People with cancer make use of and need support groups
• People with cancer are fragile
• People with cancer are weak
• People with cancer are going to die
• People with cancer are sad
• People with cancer need empathy
• People with cancer are forever tainted; they are never cured; their disease goes into remission but cancer is still lurking
• People with cancer must have learned a lot from a specific cancer experience
• People with cancer must be frightened about the possibility of impending death

There were many examples of people combating this social construction of individuals who have experienced cancer. Consider the following excerpt from an interview with someone who has been affected by cancer:

**Affected Female:** Um, I guess, for me, it’s just, like, um [pause] um, I guess, for me, it would be, like, exercise, um, spending time with friends, and that, um, it’s just, like, I’m very open to talk about cancer. But they don’t treat me any different. Um, so ...

**Interviewer:** Your ...

**Affected Female:** ... so you still have. And I guess, um, like, when you, when you go to the Cancer Agency, like, I realized that they do, um, a lot of ... uh, I mean, it was so familiar, some of the techniques. Because I was going to go into counseling psychology, and I had started to do some post graduate work. Studies, and stuff like that. So, I was laughing. Because it, I was just, like, they treat you like you’re fragile and you’re going to break. And it’s, like I said, I didn’t let it dictate my life. I still did everything ...

**Interviewer:** Mm hm.

**Affected Female:** ... that I like to do. But sometimes it wasn’t to the extent. Like, I listened to my body. So, if I was tired, like, I would not go as hard, or whatever. But I still did every activity that I like to do. And I carried on my life just like I normally would. Um, and, I mean ... because one time, I went to the Cancer Agency, and I had been mountain biking, and I bit it. And I was bruised and scratched, and, she was, like, “Where did you get all those bruises and that? Are you getting out for the occasional walk?” And I said, “Yeah, I was mountain biking. Like, what do you mean, occasional walk?” [Chuckle] Like, no, it’s like, I’m carrying on as normal. Um, it’s, um ... and like I said, I just, for me, I don’t dwell on things you can’t change. Because then you’re wasting too much time. Um. And I’ve never really taken things for granted, I guess. Um, I mean, because I was almost killed in a car accident when I was seventeen. So
people say, “Did it change your life perspective?” It’s, like, “Well, no. I had that a long time ago.” [Chuckle] And even before that, knowing, being told that my father could die, you realize that life is very precious. And it’s like, you have to live each moment to the fullest.

And, um, so, I mean, it’s just like, I know for some people, like, the support groups are helpful to them. But, for me, I’m not gonna ... I didn’t want to spend it with people that are si ... I don’t want to spend my time with people that are sick. So, I didn’t go to support groups. Um, I didn’t go. Like, you wrote down, ‘support groups,’ it looks like. I’ve been in them. No, I haven’t been to support groups.

(Interview with Affected Female, 19 December, 2000)

In the case of HNPCC, peoples’ life perspectives had been changed a long time prior to the diagnosis of cancer in them personally. The loss of close relatives to cancer had already become a large part of their lifeworld. Most people who had experienced cancer wanted to be understood as full persons.

**Strategies for Addressing the Risk to Personhood**

People had a variety of strategies for creating a sense of agency when faced with a disruption in their health status. These strategies took on a variety of forms including seeking general health knowledge through a variety of sources, seeking genetic information, or increasing their role in making decisions about their bodies and evaluating the benefit of clinical or genetic tests. For example, the following woman who had experienced cancer performed extensive research examining various courses of clinical action before making her own decisions about what action to take (or not take):

**Affected Female:** I loved it [volunteering in a hospice]. Well, I wasn’t working for part of it. I mean, I was ... the, the end result of the chemotherapy was, you know, I found myself the following spring trying to, to do a garden in the yard, and within an hour, I was exhausted. Like, a, an 80 year old woman. Sort of thing. And I had called my doctor and said, “What the heck is going on? I just ... I have no stamina for anything at all. An hour later I want a nap and I’m just beat.” And, you know, she told me what, what the chemotherapy done had done to the muscle and the tissue and everything else was definitely going to have an impact. It would take time for that to find its strength again. And then I found myself on the Internet, as you said earlier, and I’m looking, okay, what is the
effect on my lungs. What is the effect on my liver. And then, there I am, all of a sudden, once it’s all been said and done and the chemo’s finished, the doctor’s setting me up for these tests to, to do ultrasounds on my lungs and on my liver, and it’s like, “Okay.” You know. There, there’s something that they did not tell me.

It’s, it’s not a, you know, it’s not a nice thing to find, to feel deceived, going through something that you didn’t want to go through in the first place. So then I find out what the impact is on the scarring in the lung, and the damage it can do to the lung. And then, you know, how ... oh, of course, we know that our liver and our kidneys filter everything, and of course, there I am, sitting back going, “Well why didn’t people tell me these things?” Like, I had a right to be told. It was my body. You know. I’ve started going through these other tests recently, or went through those other tests recently because, you know, the next step to colon cancer is, um, uterine cancer. And endometrial biopsies. And so far I’ve been doing.

And, you know, they got the result back of one of the tests, and they wanted to go in with a, a radioactive iodine now, and check something that they found in my liver. Well, what they found in my liver was, like, a little vein, like a varicose vein that they’d found six years ago and said it was nothing to be concerned with, because that’s all it really is. It’s not going to develop into anything. So the same thing they recognised there this time. And they’re pretty sure that it’s the exact same thing. It’s maybe a bit larger, but it’s nothing to be concerned about. But, you know they ... now they want to dump, you know, as I say, uh, radioactive iodine in my system to bring a picture up to look at this. And I said to my doctor, “Not a chance. It’s my body. I make the call now.” And this is nothing. If it’s there, it’s the exact same spot, things like that. Everything to identify, we’re looking at the exact same thing. No thank you. And the only reason they want to do it is because my medical history says let’s be sure. Well, I can appreciate the perspective, but this is still my body.

So I’ve really learned to take more control over my body. You know, not just ... and there was also that. I mean, here I am being bombarded by different things, chemical and otherwise, and not getting the information to let me know exactly what I’m walking into. Only that ... and not even that it’s going to save my life, only that it’s a protective measure. It’s a prev, uh, a preventive measure. Hoping it will save you. Hoping it will save you. Where does that leave you? You know?

But I made it. I’m still here [laugh] I’m still here, and I’m helping other people. That’s great. [emphasis added]

(Interview with Affected Female, 20 July, 2001)

This individual is clearly generating power over potential clinical intrusions in her life.

The control over her body, the fact that “she makes the call now”, the protective and preventative measures that she describes are not clinical or scientific, they are part of her
healing emplotment that enables the very survival of her person. She has made her body her final sanctuary of agency; it is an inner sanctum that protects her from externalizing forces.

A number of people utilized the pursuit of genetic and clinical information to address the perception of risks by creating control in their lives:

Affected Female: Yeah, oh, yeah, I think there, there has. Um. It's added, um, [pause] uh, another, um, sort of a dimension of, of, uh ... or, or what can I say. It's raised the anxiety level. I think. Um, [pause] or, or it's added something to the, the general anxiety level about, you know, uh, you know, your children or your health, or whatever. It's, um, it's put this thing, which is, which is, um [pause] not if, but when. You know? Uh ... And, and I think in, in some ways, um, part of my wanting to, to, you know, all of the information, is, is that it gives me some control. It's because it's something that ... other than that, I don't have any control. I mean, I, you know, I mean I could lower my stress levels and I could eat more fibre, but, but you know, if I do that, if I have the gene, I'll still get ... you know, I still have a ninety percent chance of getting colon cancer. So it's not anything that I can, you know, do anything else about. So basically I can't, I can't change whether or not, um .. well, I, I've got it. But I can't change whether or not I have it, or I get it again. But, but I can, um, do something about getting it in time. That sort of thing. [emphasis added]

(Interview with Affected Female, 20 March, 2000)

This individual speaks about employing a strategy to regain lost control. She attempts to balance off guilt about possibly passing the genetic mutation to her children, worry about health by seeking information and making lifestyle changes (reducing stress and cholesterol levels) to marshal some control over her health trajectory.

Some family members experienced a tremendous loss of control, guilt and worry about personal blame associated with the arrival of HNPCC. The following excerpt from an interview with the spouse of an affected male shows that she experienced desperation as the caregiver to the family:

Interviewer: Well, thank you very much. Is there any final thing to add?
Affected Male: [Chuckle] I don’t think so. But if, uh, there’s anything that comes up in the future, I think probably we could, you know ...

Spouse: There is the one little thing if it is relevant at all. One of the things that happens when cancer hits the family, is there is, uh, this desperate search to try to understand why. You know, what caused this? What did I eat? What did I, what did I do? What contributed to, uh, to this? And I think, um, both the person with cancer, having had it myself, and, and the care giver or the family, are in this desperate search to find out what they did wrong. And so there’s, uh, a certain amount of guilt. And, and, um ...

Affected Male: I never felt guilt. Really.

Spouse: Well, I did. I felt ...

Affected Male: I know you did. But I ...

Spouse: I felt that perhaps, um, you know, we didn’t follow the right diet, or we did this wrong and that wrong and ...

Affected Male: Mm.

Spouse: Mm.

Interviewer: You’re trying to figure out what causes it.

Spouse: Mm hm.

Affected Male: Yeah.

Spouse: Mm hm.

Affected Male: I never did. Not, I never felt that. I ...

Spouse: So, understanding that there’s the hereditary element is certainly, um, helpful.

Affected Male: It is. I think that’s ...

Spouse: In alleviating ...

Affected Male: I, I didn’t take blame for it. I, I felt that, um, it was there as a genetic ... it, it was passed on to me and I ... little I could do with it. With, about it, except deal with it.

Spouse: Mm hm.
The interview shows how families worry about personal blame and how a genetic mutation can ease this concern by shifting the burden of responsibility away from variables that they could have controlled (e.g. diet or exercise).

Other people also assertively took control over decisions regarding potential treatment or courses of action. These were taken over from clinicians and carefully guarded as personal philosophical decisions rather than being governed from within the clinical realm. According to the viewpoint of numerous participants, the scientific side of the cancer is only an interesting aside, and the real issues are more personal and relate to factors associated with agency such as: control over as diet, exercise, vigilance over clinical surveillance, the pursuit of medical or genetic information. Some individuals even considered the images taken by x-rays or CAT scans to be their own private property:

**Affected Female:** Um, no, I didn’t interview them all. Um, I just also ... when I was referred to a certain doctor, I would ask other people, um, I’ve got several friends that are in the medical field, and that, and I would say, “What do you know about this person? Are they good? What’s their reputation like?” Um, for my oncologist, I ... for my GP, I did. I interviewed him quite extensively. Um, and given, giving them a lot of hypothetical situations. Like, “What would you do?” And, um, for me, I would prefer the GP or a doctor just to say, if they don’t know that area. I have more respect for them if they say, “I don’t know, but I’ll refer you to someone that does. That’s that, that’s their specialty.” Whereas, um, some doctors, they try and be everything. And, um, they will say, “Oh,” you know, and sort of hedge their way through it.

And, um, and, and the thing was, like, when I ... with my oncologist, um, I interviewed her. And I asked her what her feelings were in regards to, um, seeing a naturopath. And, and a variety of, like, other different things. And she was really good, because she said, “Well that’s not my area of expertise, so I can’t really comment on that. Um, but I can comment on, like, what I’ve been trained for by my schooling.” And so I was, like, very appreciative to that. And she was very open. And, let’s say, very straightforward.

Um, and also, like, with my surgeon. Um, like, I’m not an uninformed person. Um, and, and he should ... like they hadn’t ... he would show me, like,
my charts. They’ve all been very open. Because I want to see my charts. I want to see my pictures. And, um... because I do know quite a bit. So I... and they would show me, like, why they were doing this, and explain the reasons why, and what to expect. And then, that way, nothing comes out of the blue. Because I think that if you know what’s going to happen, or, I mean, yeah. Some, sometimes things are beyond your control, but at least if you know what is normally going to happen, um, then you can prepare yourself mentally. Um, and physically, for it. But [pause] ...

(Interview with Affected Female, 19 December, 2000).

The reference in the excerpt to interviewing the clinician regarding her acceptance of naturopaths also illustrates that patients incorporate more than conventional therapies in their healing strategies. Note that the charts are hers, they are her pictures, and the construction of this ownership is an essential part of the emplotment of her healing. She is in control of these technological representations of her person. In the institution, the pictures and charts that she refers to are type of healthcare commodity that she struggles to personalize.

**Narrating Ideas about the causes of HNPCC as part of Healing**

People had numerous ideas about the cause of cancer. In some ways, these competing causes appeared to be a strategies for creating control over their health trajectory. They included genetics but also blended other causes into their explanatory model. Consider the following excerpt from an interview with a person who is at risk for HNPCC:

**At Risk Female:** I’m 43. Um. I’ve done restaurant work. Um, mostly in the kitchens. Uh, dishwasher, short order, stuff like that. Um, uh, worked in ginseng farms. Um, and again, that’s another kind of chemical that goes on to the, you know, spraying the fields for that. You’re crawling in it. Okay? Um. Yeah, much of my has been... okay, uh, recently it’s, I suppose, in the past five years, five, six years, anyway, has been with, uh, TV. Television. Um, okay? So, you’re behind a camera. Okay? Uh, you’re constantly looking through that. You, you’ve got electric around you all the time. Does that mean anything? Who knows. Okay. I mean, when it comes to the, uh, when it comes to a lot
of cancer causing agents, whether it’s food, water, um, electric magnetic fields ——

Affected Sister: Microwave.

At Risk Female: ——whatever. Okay? Computers. Who knows whether, you know, uh, how do you know for sure? You know. You’ve been exposed to these things. And, and a lot it, a lot of times with cancer, I mean, uh, one of the things they’re looking for in, uh, hereditary colon cancer or any of the cancers is they’re looking for something common. Common to that family. Okay? Um, I often question that myself, and wonder, well, maybe it was the Brantford water. Uh, we, we all drank from that. We were all exposed to it. Was it our environment? Uh, we lived, uh, um, quite often around farms. A lot of us were in farms, uh, farmer’s fields, and so on. Did that have anything to do with it? So, um, I often question that. As far as environmental foods. What about the foods that we ate?

Interviewer: Huh.

At Risk Female: Things have changed in foods over the past 30, 40 years. In the way they’re produced, in the way they’re marketed. The way it goes from the field to the supermarket. That’s all changed. A lot of that, uh, a lot of their packaging has changed. Does that mean anything? Don’t know. Uh, we’ve been exposed to it for 30, 40 years. It could. Who knows. [emphasis added]

(Interview with At Risk Female, 20 July, 2001)

The interviewee speculates about a number of variables including electromagnetic fields, toxic water, processed foods or chemical sprays, all of which are thought to be possible causes or contributing factors to cancer in their family. A number of other participants in the study speculated about the role of environmental factors bringing about HNPCC:

Interviewer: And, what in, uh, just in your own words, from your perspective, are the causes of, of, uh, cancer in your family? Or in just colon cancer?

At Risk Female: Um, I think the ... uh, well, well I ... there probably is a genetic component. It’s my belief that ... or, there’s a couple things that I think could have happened. My dad was born in Trail, as was his sister. And, his mom lived there for quite a while too, obviously. Um, during the thirties and forties. Um, and they ... my dad’s dad worked for the smelter.

Interviewer: Cominco.

At Risk Female: Cominco [a chemical plant and smelter]. And I have to believe that there was ... I mean, at that time there was no controls on emissions and
whatnot. And I'm sure that there is probably a component of that going on. I also believe that it's, uh, diet related. I can't comment on my, my, my grandmother's and my aunt's diet, but I, I know what my parents eat. It's, it's definitely not a cancer fighting diet. [Chuckle] Yeah. [emphasis added]

(Interview with At Risk Female, 20 November, 2000)

The interview excerpt illustrates the multifactorial causal model (in this case diet, pollution and genetics) that many family members utilize to address the cause of cancer. Peoples' ideas about cause were complex and they were never one-dimensional. They were multi-layered and this helped with the emplotment of healing. Scientific, genetic and clinical cultures were often not given the most important role in explaining HNPCC; they were only small components of a many-sided puzzle of causality underlying healing emplotment.

In the following excerpt, a woman at risk for HNPCC who is going to genetics counseling for the first time the day following the interview describes a variety of determinants of HNPCC and demonstrates that the genetic information won't necessarily change her future decisions:

Interviewer: Okay, the information that you receive there, depending on what the information, uh, is, whether you were to have testing and you were to have a positive result or a negative result in what way would that affect your decisions, your future decisions, would it change how you

At Risk Female: I don't think it would change anything. I think I try and eat healthy and I exercise lots, uh, I try to do the same thing for my kids so either way you still wanna live the same lifestyle. There are things that they say to avoid and things that they say to do and stuff on these little pamphlets that they hand out about HNPCC before you have the testing done that's what my sister got and it was a little list of stuff. Basically I've done that ever since my father got cancer the second time and then both his brothers. There were all these things, you know, like, uh: charred foods, try not to, uh, you know, to when you barbecue not to char foods and uh avoid fat and exercise and high fibre diet and all that sort of stuff. It's just the way I eat normally. [emphasis added]

(Interview with At Risk Female, 21 January, 1999)
This individual notes that she has had an elevated sense of risk for a long time (since her father was diagnosed a second time with cancer). It is her family’s experience with cancer and not the genetic information that affects her understanding of cancer, her behavior and lifestyle choices. She describes her wish to shift her focus from the strength of a genetic mutation in bringing about HNPCC to her personal control in preventing the illness. She further notes that she believes that it is not possible to control whether she has a genetic mutation for HNPCC but she can control her diet so this is where she invests her energy. She goes on to describe how her thinking about the cause of HNPCC has included many different causes besides genetic variables:

**Interviewer:** So since you became aware of that issue, uhm, you modified your lifestyle a bit?

**At Risk Female:** That’s right, yup.

**Interviewer:** What date would that have been approximately?

**At Risk Female:** Oh, I think I was probably in my early twenties so that would be, what, 15, 16 years ago.

**Interviewer:** So at that point you made a decision from a lifestyle point of view?

**At Risk Female:** Uh huh. Well at that point in time I really thought, not so much in the genetics part of it, but I really thought it had a lot to do with diet. I’ve always been a fanatic about talking about foods and how I eat and all that stuff and where I grew up it was very unhealthy eating habits. They hardly eat any vegetables and fruits and high meat, high fat and everybody dies of cancer in that small town of some form or another.

**Interviewer:** What town is it?

**At Risk Female:** It’s [town name and region].

**Interviewer:** [town name].

**At Risk Female:** It’s [region described]. A small fishing village. Very unhealthy lifestyle when it comes to eating.
Interviewer: So at that point

At Risk Female: Ya, so it wasn’t to do with the genetics or when that came to light. It was the cancer itself and colon cancer itself it makes sense to me that it has, you know it’s going through your digestive system and to me it just adds up it will have a lot to do with what you put inside your body and that was I think that was what my father’s doctors, sort of, talked about quite a bit, the diet, that he changed his lifestyle. [emphasis added]

(Interview with At Risk Female, 21 January, 1999)

The example portrays the small town, the place of origin for her family, as comprised of residents who all die of cancer as a result of unhealthy choices about their diet. She acknowledges genetics but concurrently creates agency where she can: through diet and lifestyle—so that she can carry on with hope in the risky world.

The notion that diet was responsible for bringing about colorectal cancer and perhaps the mutation for HNPCC was a very common theme in the interviews. Consider the following example:

Interviewer: Can you tell me a little bit about, um, the hereditary side of cancer? How do you think it, um, is, is actually passed on from one, one generation to the next?

At Risk Female: That’s a very good question. I have thought of that over and over and over. I’ve wondered if it goes through breast milk, or if it goes through ... I have no idea. I truly have no idea if it’s, if, if it’s even contagious, or something. I mean, that sounds so bizarre and so ridiculous, but I think of everything. Is this a virus that could be passed from living together? Is this, you know, the way we eat. Uh, um, the water we’re drinking, and that this particular family should have so much of it. You know? But I have really no idea. [emphasis added]

(Interview with At Risk Female, 20 March, 2000)

This was a common component of understandings of families, that is, that unhealthy behaviors and bad choices (in terms of diet and activity level in particular) lead to cancer:

Affected Female: Um, I didn’t know that that was ... no. I mean, I, I don’t think that that actual, uh, that actually came up. But we ... because, uh, but we knew it was [pause] uh ... Because I think there was still a question, um ... One of the ... my, my niece who is the doctor wondered whether it was something that we had
eaten. As children. She was, had decided that it was probably, um, superheated lard. We [laugh] grew up in a restaurant. Uh, my mother had a small restaurant. Where there was a lot of it. And they also had a chip stand when my sisters were small. There was a lot of, um, [pause] fried foods and chips. And she seemed to think that maybe it was the fact that, that there were all these greasy ... uh, you know, that they put them in lard. And it would be, you know, she would cook it and then it would be allowed to cool. To stay. And then she would reheat it. And [...] was saying that maybe it was something that we, um, [pause] you know, that we’d eaten. But I think that was sort of wishful thinking. And hoping, maybe that it was something we’d eaten? [Laugh] As opposed to the fact that it’s going to be something that um, uh, [pause] was still affecting other people. In the family. Because there was a lot of, you know ... Between my three sisters, or, the three of us, there are nine ... oh, no, not nine. Fifteen children. [emphasis added]

(Interview with Affected Female, 20 March, 2000)

The way that this perspective was delivered, such as the nervous laugh after describing the fatty diet as a cause, demonstrates that people were aware that the perspective that they were sharing might not have as much linguistic (cultural) capital as that of the scientific and medical explanation of HNPCC.

The concept of stress was another factor that people attributed as a cause for the arrival of colon cancer:

**Interviewer:** Can you tell me just a little bit, in your own words, of what you, you see as the cause of this cancer? The cancer that you’ve experienced?

**Affected Female:** The cause? Mm, well, some area in the body, some messages get mixed up. The cells go ... is this what you’re meaning?

**Interviewer:** There isn’t a right answer [here I am careful not to assert one understanding over another]

**Affected Female:** Awry, awry, and they start multiplying and multiplying. I think something switches them on. Um, now I, I hope that, uh, by a healthy lifestyle, by taking the right supplements, I’ve done my research on the latest, uh, from different, uh, um, medical, um, in, information that you get, uh, regarding vitamins, how they can help to protect you, uh, slow down growth, prevent all these things. And, um, you know, I take all those. I like to think that you can prevent the switch from being turned, turned on. I think stress. It, it’s a whole mixture of things. That if you could be in control, staying control, you can help prevent the switch. [emphasis added]
One of the possible reasons that people focused on factors such as stress, diet and exercise may be that they are amenable to control whereas genetic mutations are not:

**At Risk Spouse of Affected Female:** Well, I think, you know, the most... for me, the thing that I guess is most reassuring is, if I think I'm doing what I can to minimize the chance of getting it, or to maximize the chance of discovering it as early as possible. So, um, it, you know, these are pretty concrete strategies. Uh, change, you know, a fairly conservative diet. Um, my wife is even more conservative. I, you know... she's essentially a vegetarian now, and, um, you know, won't eat barbecued foods, and you know, just avoids a lot of things that she has heard may be carcinogenic. I'm somewhat cautious about that. Um, and certainly, we really try to avoid, um, pesticides and other kinds of contaminants in our food and water. Um, you know, we're, we're willing to spend the extra to buy organic food, uh, to a large extent. Um, and as I said, you know, I, I have, uh, gone and had myself checked by colonoscopy, and, um, you know, I, I intend to keep going back regularly for that.

Many individuals like this individual, at risk or affected by HNPCC place a great deal of their energy into "concrete" variables that can be used to construct a sense of control such as: diet, exercise and clinical surveillance. Interestingly in the case of clinical surveillance, it appears that peoples' attempts to marshal control over surveillance are constrained by forces outside their control such as the availability of the screening technique (colonoscopy).

The following example illustrates how genetics are sometimes downplayed relative to factors that might contain more opportunity for chance (due to the lack of 100% penetrance) and personal control (less determination):

**Interviewer:** Question. What, in your view, causes colon cancer?

**Affected Male:** [Sigh] Well, that's... ooh. That's a tough one. Um, I feel it's... there's a lot of environmental causes. I feel there's genetic causes. Um, which is the most? I think, probably in my case, it's genetic, but if the genetic disposition is there to get it, what triggers it to start? I mean, is that environmental? That's almost [pause] um, I feel it's, it's probably primarily environmental. And if you
have the genetic disposition to, to get it, it's going to be that much easier for you to get it, I think. **I don't think it's just straight genetics, period.** [emphasis added]

(Interview with Affected Male, 26 May, 2000)

Note that the interviewer has not specifically asked about the causal power of genetics in bringing about HNPCC. The respondent downplays risk and proactively puts genetics in a subordinate position to environmental factors. If the issue were "straight genetics, period" then there might not be as much opportunity for personal domination over the health trajectory.

Many of the people interviewed would often laugh or apologize before or after sharing a point of view that was not obviously medical or scientific. This seemed to signal an awareness that these perspectives were of a lower ranking relative to more established medical and scientific explanations:

**Affected Female:** Right. Except that, the fact that, that, um, you know, the other two people in, in my father's family who had it. I mean, they had a different, you know, the disease was not ... um, they didn't [...]. They had a different, um, they, you know, they had the same disease, except they weren't, you know, except that they weren't eating those, those tainted chips. [Laugh].

(Interview with Affected Female, 20 March, 2000)

Even though these explanations may not have been readily accepted by the community of medical practitioners (of which I may have in this case been included), they were still influential in peoples' cosmology about HNPCC as an inherited illness (important enough to mention).

Another common item observed in the peoples' interviews was the notion that personality or temperament could influence the arrival of HNPCC:

**Interviewer:** Can you describe, in your own words, what you, your understanding, uh, uh, of the causes of colon cancer would be?
At Risk Female: Well, the little bit I’ve heard, um, the little bit I’ve read, I think diet probably plays a little bit in factoring in. Um [pause] perhaps temperament too, in a way. I, I just strangely have that feeling. Um, my mother always thought that she would have it. Which was rather strange. She always said, “I will have bowel cancer too.” Long before she had it. Long before she was ever diagnosed or was ever sick. So, um, I don’t know. I, I, I know I’ve spoken to [Doctor’s Name], my, my doctor down here, and he, and we talk, you know, about fibre and things that were the old theories. And he still feels that there’s something to that, even though new research seems to not be so sure of that. [emphasis added]

(Interview with At Risk Female, 20 November, 2000)

The most common personality trait associated with the appearance of cancer in lay perspectives appear to be those associated with a negative outlook, pessimism and worry:

Interviewer: When you talk about temperament, can you elaborate on that a little bit? What you mean by that?

At Risk Female: Well, my maternal grandmother was a little bit pessimistic. My brother had a pessimistic streak. Uh, my mother not quite so much, but a little. And my mother’s brother, who has colon cancer, is a very strong pessimist. And I just find that interesting.

Interviewer: Any other temperament traits that you would ...

At Risk Female: Mmm.

Interviewer: Associate with that, or think about with respect to cancer?

At Risk Female: A little short tempered. But that’s, that’s pretty much it, I think. [emphasis added]

(Interview with At Risk Female, 20 November, 2000)

Personality factors appeared especially prominent in the process of self-selection and pre-selection of particular individuals who family members believed to be at increased perceived risk.

Personality attributes are also perceived as being influential in the outcome of cancer once it has arrived. The following excerpt from a family member at risk for
HNPCC describes attitudes that can prolong life versus those that can shorten it in people diagnosed with cancer:

**Interviewer:** And how was your ... how would you say it’s [throat clear] there’s been quite a bit of cancer in, in your family. How has it affected your family? How would you describe that?

**At Risk Female:** I, um, I think probably, ultimately, our family does not view cancer as, uh, as a death sentence. I think that there, um, there’s a lot to be said for, um, your will in whether or not you want to survive cancer. Um, my grandfather, on my mom’s side, when he was diagnosed with liver cancer, pretty much said, “Okay, that’s the end of it for me.” And, and died within [pause] oh, I think, two months. And, um, my aunt, my dad’s sister, did not have that attitude. Even though she knew it was pretty, pretty much towards the end. And she lived for two years. With, with the viewpoint that she wanted to stay alive as long as possible. And, um, my father did a lot of, um, meditation and, um, just, I’d say, inward focus on his disease, and spent a lot of time trying to heal himself. And I think that all of us in our family believe that that was significant, in terms of his getting better. And his beating cancer the first time, and hopefully this time too. You know. [emphasis added]

(Interview with At Risk Female, 20 November, 2000)

The power of a “positive attitude” in engaging “will” in healing was a very important variable for this family (and others) and they described very specific visual images (e.g. the battle of the Force in defeating the evil Storm Troopers in Star Wars) to engage this force to overcome cancer cells in their father’s body. People appropriate what they can to help them combat powerlessness in order to carry on with some degree of certainty that their agency (e.g. enacting their will or modifying their personality) will rebuild the blanket of trust in their person.

Healing plots often contain a number of layers of causality regarding cancer where genetic mutations are understood as only one of many causal variables. One of the fundamental questions underlying many narratives about cancer is “what caused the genetic mutation”?
A number of at risk and affected people appeared to perceive genetics as a feature of HNPCC but not necessarily a cause. Consider the following excerpt from an interview with a woman who had experienced cancer:

Affected Female: Well, they don’t know the causes. Or they wouldn’t be doing research. [Laugh] Um, but basically, what, just, with the genetics basically, um, with ... there’s different, two different types that could be hereditary. And what happens, as you get one s, set, like one set of DNA from your, one strand from your mom, one strand from your dad. And, um, what happens is, on the chromosomes, on either a T or a 5, they found that, uh, there will be, like a genetic marker. If you are a carrier. And what happens is, um, when the cells, before the cell, uh, cell divides, what happens is, um, it has to make sure all, like, you get, like ...that everything, all, like, all the ducks are lined up in a row, basically, with all your genes. And if one gene isn’t working, well, then the cell’s not supposed to divide. So what happens is, um, sometimes, for some odd reason, they won’t ... like, your gene, like your chromosomes are like your checkpoints. To say, uh, like, so that before the cell divides, like, they are like, “Okay, everything is okay.” And if something, if, if that information gets bypassed and one of them isn’t working, well then you’ve got a deficiency. Um, and it starts to di, divide, and then you’ve got all these other cells that are now deficient. Because the, they, now they’ve ... because that’s all divided. Now you’ve got, like, two cells that have one not, one chromosome not working. And then it, like, it exacerbates. And it keeps going like that. So. That’s basically what she had said. In the interview. [Chuckle] I don’t know. I, I, yeah. [emphasis added]

(Interview with Affected Female, 19 December, 2000)

Like many of the people interviewed, this individual demonstrates knowledge of the genetic roots of HNPCC but she does not necessarily see the genetics as the root cause.

The following example illustrates an interest that a number of affected or at risk individuals had in focusing on the original cause of the genetic mutation rather than of the HNPCC that is currently being manifested in their family:

Interviewer: If you don’t mind my asking, what does your husband think about all of this?

At Risk Female: Well, he’s supportive. Ya. He does, I mean, whatever I wanna do I talked to his mom who, uhm, is a registered nurse, uh, who taught nursing for a number of years and is closely related to the medical field and I don’t think she really thinks its necessary. Uhm you say to her that it’s a hereditary cancer, but,
she says it had to start somewhere so it’s not all hereditary. That’s her perception of the thing so why put yourself through something that then let’s people know that you have a positive gene and she just doesn’t want people to dwell on things I guess. You know?

Interviewer: What does she mean by that, in terms of it “has to start somewhere”?

At Risk Female: Well, she means, meaning okay my father had it. Meaning we all had to start somewhere. Where did this evolve from? Was it from eating, you know, meat or you know or at the very beginning of evolvement. I mean, where does it come from? It had to start somewhere. A gene is not just there. Was it always, I mean, is it just a genetic thing? Is it related to what you eat? Does it, you know, can it pop up in a person? [emphasis added]

(Interview with At Risk Female, 21 December, 1999)

In the above example, the mother-in-law appears to have elevated cultural capital as the interpreter of genetic and medical information for the family. She appears to be dissuading the family from seeking genetic information by downplaying the authority of genetic variables by asserting that it is not an ultimate cause. This technique of bringing into focus different levels of causal analysis in one instance and then adjusting the causal lens in an opposite direction in another appeared to be a tactic employed by families to create a sense of dominion over the state of their health.

It appears as though many family members see genetic mutations as a characteristic of HNPCC but not an ultimate cause. This notion seems to be related to a more widespread notion that every illness has a genetic component but that its arrival is brought about as a result of both environmental and genetic factors (nature and nurture):

Interviewer: In your own words, uh, what, what are, what are the causes of this cancer? Of this colon cancer?

Spouse of Affected Female: Well, I heard something just recently in the news that, um, uh, at least one study has found that, um, more of the, uh, cause of cancer can be apportioned to environmental than hereditary effects. So I would assu ... my sort of concept is that, um, environmental factors, um such as
the things we eat, um, probably have a, um ... are the most important factor. And so, um, various carcinogens can act, um, in the case of the colon, uh, can affect the um, the tissue directly. And, and, in, you know, some way stimulate tumor growth. Um, and um, there’s also clearly a genetic disposition that, you know, is in our family. Uh, some, at least three genes, I guess, have been directly linked to colon cancer. Uh, to my knowledge. Um, so there is a ... again, my concept is that people with a predisposition like this will be more sensitive to the environmental stimulants and more readily develop a cancer, um, uh, upon exposure. [emphasis added]

(Interview with Spouse of At Risk Female, 3 August, 2000)

People do not necessarily see the difference between the impact of a person’s genetic make-up on the manifestation of a given disease and the presence of a genetic mutation that is entirely necessary for the expression of diseases such as cystic fibrosis, BRCA1 breast cancer or HNPCC. In this instance, it seemed important for some people interviewed to suggest that genetics is not the first source of cause in the arrival of cancer in the family. Families wonder what brought about the genetic mutation originally (e.g. diet, lifestyle) and what causes the genetic illness to reveal itself. According to this belief, HNPCC is initiated for some reason outside of genetics and this appears to allow affected and at risk individuals to construct some sense of control over the arrival of the disease (by controlling their diet for example). Healing emplotment generates hope that people can control their life trajectory even in the face of the immense power of genetic fortune.

The fact that HNPCC does not have 100% penetrance may be partially the source of this possibility:

At Risk Female: ... Well, uh, I guess probably the reason that I would, would be interested is to find out whether or not, um, if I have that genetic compon ... I guess it really, you know, when you really think about it, ultimately, it doesn’t matter. You should live your life like, um, to, to prevent that possibility, if possible. Um, eat properly, live, live your life in a, in a way that would not put you at risk for cancer. Um, I guess if, if you find out that you have the genetic component, then you’re going to work doubly hard to make sure that you
do that. It's, well, I assume that while there's ... you have a genetic predisposition towards cancer, that doesn't, it's not necessarily a guarantee that you're going to get it. Um, I guess just ... it's just ... information is, is always helpful. [emphasis added]

(Interview with At Risk Female, 20 November, 2000)

Families hope to exercise whatever control they can by "living their lives" to reduce risk as much as possible in order to prevent the arrival of HNPCC. Another common theme in peoples' understandings of the cause of cancer was that of a grander or more original cause. There was also usually a familial expert such as an individual with some clinical expertise (as emphasized earlier where an at risk female described a family member that was a former nursing instructor). The familial expert in one family, for instance, told an at risk female that she shouldn't become too concerned about genetics because "it had to start somewhere" meaning that it was originally caused sometime ago by another factor, that is, the mutation itself. The issue of heredity was being downplayed here as part of a larger cosmology that arrives at the conclusion that the appearance of illness is ultimately contextual in the broadest historical sense (over thousands of years in this case) by making explicit reference to evolution. Here the deterministic elements of cause represented by genetics were being downplayed as secondary to the influence of factors that could be more readily controlled such as diet, mental attitude and exercise level.

**Healing Emplotment Addressing the Imbalance of Power of Clinicians**

Clinicians are institutionally consecrated to make decisions and advise about patient treatment (e.g. surgery, surveillance, radiation, chemotherapy), to choose the best method for detecting disease (e.g. CT scan, blood test, fecal occult test, x-ray, biopsy, physical examination, genetic test) and to interpret information that is collected about the patient (test result, family history, symptoms). Institutionally, they are also sanctified as
the stewards of information about the patients such as the results of tests, imaging studies or patient files. Test results such as x-rays, blood tests, tissue samples and consultant reports are kept in the hospital. They are typically seen as the property of the institution and not of the individuals. The individual may have access to some form of the clinical information (especially in light of the Freedom of Information Act) but the original form of this information such as their complete patient file, tissue blocks, blood samples, x-rays and CT scans are not considered private property nor are they typically allowed to leave the bounds of the institution.

Some affected individuals and people at risk for HNPCC attempted to even up their sense of decision-making with respect to the clinical power over the detection and treatment of their disease. These individuals utilized a number of strategies to increase their personal power and to reduce clinical power over their lives. These strategies will be discussed in turn.

The first agency-producing strategy was to redefine the relationship between the clinician and the patient. In this situation, the clinician's role was recast from being someone with untouchable expertise who does something to the patient to someone who is in a sense employed by the patient to complete a task at the bidding of the patient. This remodeling of roles was either done as a mental exercise in the mind of the patient or it was done as part of an explicit re-negotiation of the patient–clinician relationship. For example, one patient chose to interview the clinician as an employer might interview potential consultant employees for a contract. Consider the following example:

**Affected Female:** Because it was a large tumor. And, um, but ... for me, I guess, um, my, my strength came ... um, had a large support network. So. Um, my ... I'm very close with my family. I'm very close with my, um, friends. And members from my department, um, came in all the time to see me in the hospital.
So. Um, and, uh, and they ... an example is, they threw a great big surprise party for me when I got sick. And over two hundred and sixty members [police] showed up. So, it was really ... all the way from my chief, down. So it was, um, good that way.

Um, and, um, I guess for me, it's just, like, I'm a fighter. It's just like, I don't, I don't sort of just accept things for what happened. **I'm very hard on my doctors.** Because I do interview my doctors. Um, through researching and that. I asked, talked to people. Um, I didn't go to any support groups. And the reason being, is, um, for me, I'm not a person that whines or, like, if some, if someone asks you, "Well, how are you feeling?" I'm not going to say, "Well, let me tell you. I have this and that, and this and that." It's just like, for me, it was just like, if I was having a bad day, um, I'd just say, "Well, it's a chemo kind of day." But you find something positive. And, such as, like, uh, the fact that you open your eyes. Like, I mean, that's a positive thing. Um, it's a sunny day. Or you've got great friends, or great family. Or, um, and, um, and I don't know.

I just, I, um, interviewed doctors and stuff like that. Because a lot of people, they just accept that you can, um, that what you get, um, whoever is assigned to you, and because they've got a stethoscope and a white jacket, that, um, that they must know everything. But they don't. They're human. Um, and I've told my doctors, it's just like, well, um, I want to know, like, where did you finish in your class? Because someone's gotta finish at the bottom. And if you're it, I don't want you. [Laugh] And if you ... are you open, um, to different things? Um, like, a lot of people just accept that, oh okay, when the doctors says, "You take this pill or that pill." It's like, well, um ... but they don't look at different, um, things, like ...[emphasis added] (Interview with Affected Female, 19 December, 2000)

Note that the strategy employed by this person creates an even higher form of power than that held by a patient who is utilizing a customer service provider model. In a customer service provision model the customer can choose to purchase a service whereas in an employer consultant employee model the employer can terminate the contract of the consultant and take away the entire contract. In their healing narrative, the person affected by HNPCC attempts to counter the balance of cultural capital between themselves and clinicians.

**Creating Agency through Surveillance and Suspicion**

In the second agency-producing strategy people actively make decisions about the occurrence and ownership of clinical tests. This took one of two contrasting forms. One
was to avoid tests and clinical studies while the other was to advocate them. There were several clear examples of people refusing to take tests as an attempt to create agency. Those who chose the opposing strategy, that is, to take on the stewardship over their clinical surveillance, often advocate levels of surveillance that were higher than those suggested by their physician or levels that were not allowable in the healthcare sector (e.g. colonoscopy, genetic testing).

In the situation where patients advocated more frequent surveillance through colonoscopies, they also developed a skepticism about the knowledge of their attending physician about HNPCC and in particular its surveillance:

**Spouse**: Well, I think, you know, the most ... for me, the thing that I guess is most reassuring is, if I think I’m doing what I can to minimize the chance of getting it, or to maximize the chance of discovering it as early as possible. So, um, it, you know, these are pretty concrete strategies. Uh, change, you know, a fairly conservative diet. Um, my wife is even more conservative. I, you know ... she’s essentially a vegetarian now, and, um, you know, won’t eat barbecued foods, and you know, just avoids a lot of things that she has heard may be carcinogenic. I’m somewhat cautious about that. Um, and certainly, we really try to avoid, um, pesticides and other kinds of contaminants in our food and water. Um, you know, we’re, we’re willing to spend the extra to buy organic food, uh, to a large extent. Um, and as I said, you know, I, I have, uh, gone and had myself checked by colonoscopy, and, um, you know, I, I intend to keep going back regularly for that. Um, and, I guess the other thing is, um, we learned from [wife]’s experience that really, even for the medical diagnosis, the, you know, the patient is maybe the most important person. Um, you know, she did not get diagnosed until it was almost too late. Um, and I think, in retrospect, we’re going to be a lot less willing to, uh, you know, accept it if, you know, one of us doesn’t feel well. Um, we would be very proactive in, you know, trying to find out why, and go to, you know, m ... other doctors if, if, you know, the first one can’t figure it out. Um, and to trust our own, you know, uh, ideas on the matter more than just taking the doctor’s word [emphasis added].

_(Interview with Spouse of Affected Female, 3 August, 2000)_

Most of the people at risk for or affected by HNPCC have become active stewards over their own health by controlling diet, exercise levels and clinical surveillance regimes.
They often advocate more stringent surveillance guidelines than those suggested by their attending physician or that can be readily obtained through regular channels of the publicly-funded health care system.

Agency created through ownership of test results took its most obvious form in a situation where a patient refused to provide consent for clinicians to look at the results of tests unless she was present. One of the best examples of strategy for creating agency previously outlined in chapter three was a situation where a patient managed to obtain the only original copies of several of her CT scans and refused to allow clinicians to see them without the patient being present. As the patient could not be present, this segment of the patient’s image studies was left blank in the presentation of the case in the clinical conference.

The third strategy for agency production was to refuse certain types of treatments and to portray health outcomes as outside the power of clinicians. That is to say, clinical interventions are seen in this strategy as inefficacious and almost epiphenomenal to the fate of the patient. In this scenario, patient health, disease, death and life are seen as outside the power of the clinicians and people adhering to this perspective simply accept fate. They dramatically reduce the significance of clinical control over fate.

A consistent weakness in the medical system that was pointed out time and time again by patients and families related to the information that they received from clinicians regarding surveillance protocols relating to colonoscopies. In practice, there appears to be a tremendous diversity between the recommendations made by clinicians regarding how often or if colonoscopies are recommended. The patients and family members perceive this as one of the most important mechanisms for creating power and they
regularly talk of differing information that they receive from gastroenterologists and
family practitioners. As a result, they are somewhat suspicious of the clinical knowledge
in this area:

Affected Female: Um, for me, it’s just like, if you’re ... the more informed you
are, um, [pause] if, basically, sometimes if you don’t look out for yourself, um ... and a prime example is, um, as far as your follow up. A lot of people, they don’t
know. Well, I’m supposed to get, I think, a colonoscopy every year, or whatever. And they expect the doctor’s office to contact them. Well, [chuckle] that’s, um, I
mean, it’s an unfortunate state of affairs. Um, because a lot of times, if you’re not
on top of your stuff, people won’t contact, won’t be contacting you. Because, I
mean, for me, I’m very proactive in my, um, recovery. Um. Also, if you
know what to expect. It’s just, um, it also helps alleviate a lot of, like, stress.
‘Cause a lot of people will stress. Sort of the unknown. Like, if you go for a
colonoscopy, you’re like, “Oh, my goodness.” Like, “What are they doing?” Or,
“Why is this for?” And, and some people are just afraid to ask. That’s what I
find. I ... it’s just like, I want to know beginning to end. I mean, why are you
choosing this over that? And, um, and also if you kn, look, like, researching and
stuff like that, then you’re more aware that there is options for some things.
Rather than just accepting that this person is saying that this is so. Well, if you
question them, sometimes they don’t know, themselves. It, it’s just like, “Well, I
was taught that.” Well, that’s not a good enough reason. For me. So.
(Interview with Affected Female, 19 December, 2000)

Patients and family members become their own health care stewards in order to colonize
their future and reduce the power of fortune. This is an area where people can create
power and control over their health that is independent of the genetic root of their disease.
The genetics is, in fact, distinct from the issue of clinical surveillance. Families soon
learn that clinical surveillance is one of the few areas where there actually appears to be a
source of clinical power over preventing death from CRC.

Agency through Knowledge

The fourth strategy for creating agency was sought through the pursuit of a broad
base of knowledge about HNPCC that was used as a way of constructing personal power
for the people interviewed. Patients and families worked hard to create control over
knowledge to avoid feeling as though they were simply at the mercy of fate or the clinical world:

**Affected Female:** Um, but, uh, so for me, I guess, I took ... the way I looked at it is, like I sa, um, I took the *kitchen sink approach*. And I basically was willing to try just about anything. If someone said, “Stand on your head and say ‘yabadabadoo’ twenty times a day.” That it would help me. Well, I was willing to try that. And if it didn’t work for me, then I would throw that out of my repertoire.

Um, also, um, for me, uh, so I wasn’t going to let my dad get through it and not me. Uh, you know, we were very competitive. But in a good way. It’s like, I ... if he can get through it, I can get through it. Um, and I guess also, probably just, um, [pause] knowing that, um, I guess probably just that knowledge, for me, is like, the best source of power.

(Interview with Affected Female, 19 December, 2000)

Creating a sense of power is an important part of the healing process for patients. This individual actively combats the danger of powerlessness in genetic cancer through the appropriation of as much power with respect to detecting and avoiding HNPCC as possible.

Individuals affected by genetic cancer work hard to enhance their practical consciousness, that is, the security system for their person. The people interviewed were very eager to appropriate power through information. Consider the following example illustrating the enhanced level of knowledge that family members have about HNPCC:

**Affected Female:** And, uh ... but my doctor said, he assured me that, you know, both my sisters were in their sixties, so, you know, and that that’s something ... that colon cancers take some time. When I was sixty, um ... and I should just continue on my five year plan. And what happened was that I’d gotten mixed up. And maybe wasn’t keeping track of when I’d gone. Anyway, I ... it ended up that I was a year and a half early when I said, “Oh I think that this is the year that I should have, um, my colonoscopy.” And [pause] you know, had it. And the doctors expected to find, um, nothing. But I had an in situ carcinoma. So I was really lucky. And I’m probably the only person who ever went into a doctor’s office, got called in and they said, you know, “You have an *in situ carcinoma*” and said, “Oh, great!” [Laugh]. “Oh, good! Oh yes, that I can deal with.”

**Interviewer:** You knew ...
Affected Female:: Yeah.

Interviewer: Quite a bit about it.

Affected Female:: Yes. Yeah. Yeah. At this point, that sounded to me like that was ... uh, because she'd phoned me up the night before. I'd had the colonoscopy, waited the two weeks, I got a call from the doctor's office, saying, uh, at 4:31 that day, saying "The doctor wants you to come in tomorrow morning at nine o'clock." And, uh, [pause] so I, I phoned up a niece who is a doctor, and said, "Look, she's called me in tomorrow morning. What do you think she wants to tell me?" And she said, "Well, it's not that she's about to give you good news." [Laugh]. She said, "You can expect that she's going to, um, you know, tell you something that's not that good." So, you know, of course I had that time to kind of wonder and to make deals. Like, okay, well, I need this long, or maybe it's, you know, maybe it's not, uh, that bad yet, or whatever. And, so when I went in the morning and she said that it was in situ carcinoma, I was really relieved. Because that was, that was not a problem at all. By then. I was, uh, you know, prepared for something more [pause] than that. And, so it was good news for me.

Um, so that was three of us within eight years. The same year that we decided, uh, [...] Like, my sister, my middle sister had a right hemicolecctomy and I had right hemicolecctomy. Sort of opted for, uh, for that. Um, although afterwards, I read that they recommended subtotal colostomy. So, um, but it's, you know, it's been two years for me and it's been four years for my sister, and we haven't seen any cancer recur. Um.

Interviewer: Where did you read that? About recommendations?

Affected Female:: On the internet.

Interviewer: On the internet?

Affected Female:: Yeah. I just, you know, searched out sites.

Interviewer: Uh huh. On colon cancer, or?

Affected Female: On colon cancer, yes.

Interviewer: Do you also look on, uh, look at HNPCC?

Affected Female:: Yes, yes. [emphasis added]

(Interview with Affected Female, 20 March, 2000)

This particular individual demonstrates precise knowledge about sporadic colorectal cancer as well as HNPCC in addition to expertise about diagnosis, treatment and
prognosis with respect to specific carcinomas (in situ in this case). She had not yet experienced genetic counseling at the time of her diagnosis with colorectal cancer. She and other individuals from families at risk for HNPCC could define HNPCC and the Amsterdam Criteria\textsuperscript{35} for diagnosing HNPCC as well as describe highly technical treatments and clinical surveillance techniques associated with the disorder. She has also attempted to counter the increased cultural capital enjoyed by medical practitioners by appropriating their technical and clinical language. The appropriation of this knowledge helps to colonize her future and to reduce the power of genetic fortune.

Families appropriated power through information about HNPCC in many ways:

**Interviewer:** Where did you, um... when you say that there's a genetic component to it, can you elaborate on that a little bit? [...] I guess I'm interested in some of the research you've done.

**Spouse of Affected Male:** Okay.

**Interviewer:** And where you've done your research. On the internet, or reading, or...

**Spouse of Affected Male:** Okay. Uh, the internet, for sure. Um, reading. "Scientific American" had a, um, a wonderful publication that came out right around that time. Um, I guess, um, I can't really be, be that specific anymore. I mean, it's been four years, now.

(Interview with Spouse of Affected Male, 4 December, 2000)

The interviews showed that people at risk and affected by HNPCC had sought out and collected information from friends who are clinicians or connected to the clinical world

\textsuperscript{35}The Amsterdam Criteria were originally established for research purposes (and they turned out to be impractical for clinical practice) in 1991. They instruct physicians to consider HNPCC when three family members have colon cancer, two generations of the family are affected by colon cancer and at least one of the family members is diagnosed before the age of 50 (Sandrick 1999). There has been a move in recent years to replace them with modified criteria such as the Bethesda Criteria. An individual would be considered for genetic testing for HNPCC under the Bethesda Criteria if: (1) the patient meets the Amsterdam Criteria; (2) the individual has two or more HNPCC related tumours; (3) the individual has a first-degree relative with HNPCC-related cancer; (4) one of the HNPCC related cancers in the family occurred before the age of 45; (5) the individual was diagnosed with colon or endometrial cancer before the
(increased cultural capital) in some way as well as from people who have had similar experiences (increased symbolic capital). They further strengthened their practical consciousness by drawing information from formal sources including: the BCCA library, the internet, the regular library, databases (e.g. Medline), television, radio, the print media and medical journals.

Family members demonstrated in depth knowledge of the benefits and drawbacks of genetics testing. The following example shows an individual’s knowledge of the possibility of false negatives in genetics counseling:

**Affected Female:** Um, I think when they were, you know, when they were adults, I would ... I mean, it would, it would be up to them. But I would suggest it. Um, that they, that they would. Um, the only thing that concerns me, also, is, because of some of the things that I’ve read is that, is that there can be, um mistakes made. In the testing. And that you can get a, a **false negative**. Is that?

*Is that? I think I’ve heard that.* [emphasis added]

(Interview with Affected Female 20 March, 2000)

This excerpt illustrates knowledge of the benefits of genetics testing in eliminating the need for surveillance and worry about children carrying the mutation:

**Affected Female:** That was interesting, because, uh ...[pause]. When [genetic counsellor] told me that, um, [pause] I think I was, was, I think I was ha... uh, relieved. I think I was, I was glad to hear that. Because, um, it seemed then that it was ... and, and I think the fact that [throat clear] there was a gene that you could test for. [Throat clear] I think it was ... um, I was relieved that, well, um, that you could be tested and then you would know whether or not you had it. And if you didn’t have it, your chances were the same as anyone else’s. And if you did, then, um, you would be under, uh, a greater surveillance, and so your chances of catching anything would be better. Um, so I had sort of positive feelings about what she had told me. And then I told my sister, whose reaction was, uh, [pause] uh, not so positive. Hers was, you know, that “Oh no, we have, you know, this gene, and uh, sort of, who’s going to be next?” Um, and I was, you know, then also feeling, feeling bad, that, uh, that you had this gene that you were then passing on to your children. So, um ... [long pause] Yeah. She didn’t, didn’t take the news quite as well as I had taken it. [Laugh] Um.

(Interview with Affected Female, 20 March, 2000)

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Age of 45. These more open criteria allow more family members to obtain testing, and ultimately, to be diagnosed with HNPCC.
Note that she sees a genetic test as a way to colonize the future and to reduce the power of fortune but her sister does not. This perspective allows her to be “relieved” while her sister’s approach leads her to not “take the news quite as well”. The clear understanding of the issues associated with genetics testing by this particular woman was representative of most others in the study sample.

**Addressing Fortune and the Ultimate Externalizing Factor: Death**

*“When Your Ticket’s Up; Your Ticket’s Up”*

Often, people interviewed here had encountered death in their immediate family at a very early age. People were reflexive about this issue and had established ways of addressing the increased power of fortune as part of their healing emplotment.

Numerous affected and at risk people noted that death and the occurrence of cancer was out of their control, that it rested in the hands of fortune. People appeared to make this notation in their narratives as a strategy to release their need to colonize a future territory of personhood that was unattainable.

This release from control over the unruly elements of fortune freed people to focus on governing those things in their lives that they felt could be controlled such as diet, exercise, clinical surveillance and the quest for genetic and medical knowledge:

**Interviewer:** How did you get connected with the genetics counseling program?

**At Risk Female:** Uhm, I really am learning about it second hand too, the genetics part of it. It started back east where my family is in Quebec and my dad got cancer when he was 42 or 43 and he got it again five years later... a certain period of time supposedly if you don’t get it you won’t get it again. So they did the surgery and removed a small part of his bowel then they did it again and removed all of the large intestine but still he doesn’t have a colostomy he still everything is fine just most of the large bowel is gone then his brother, both his brothers, got it one severely enough that he has a colostomy—bag--and another brother got it, around the same time in their lives, they were all in their forties, and then a few years ago, I’m not really sure when this all started like I say I’m on the other side of Canada and I don’t know how
it all came to be, but there’s this lady [name removed] whose in charge of coordinating the genetics part of it back there and she’d contacted my family and everybody I guess everybody went for testing and my parents have been on me for years to have it done but I really didn’t have any desire to do it but you know if I get cancer I get cancer. Basically, that’s how I felt about it. But, uhm, I was back east about two or three years ago when my uncle, one of the ones who’s had cancer, is very interested in the scientific aspects of it or whatever and I said so I said oh alright I’ll go and I guess they just sort of want to know if we have it or not. He doesn’t have any children and my other uncle he has one daughter and she has been tested for the gene and I believe she tested positive. There’s seven kids in my family and, uh, four, and uh, four is positive I believe, my one sister they can’t tell like a funny chromosome or something they can’t tell if it’s positive or negative, they’re not really sure and one, one tested, uh, negative, so four, five, six and there’s just myself left. And two of my brothers have been tested and had cancer, one at twenty-six which is very very young. He just had beginning stages of early polyps or whatever but they were malignant and to a large extent last year. [emphasis added] (Interview with At Risk Female, 31 January, 1999)

Many of the participants de-emphasize cancer and connect it to more general concepts of fortune, “if I get cancer I get cancer”. Note that the individual also notes that the main reason to seek genetic testing was due to pressure from the family and not a personal desire to seek these services. The following excerpt from an interview with a person who had experienced cancer suggests, as others have, that the reconciling the issue of the inevitability of death in all lives is an existential question that everyone has to face:

**Affected Female:** ...Because if you, I mean, that’s what I mean. I think, again, like, knowledge is power. Like, I mean, if you know, you’ve got a higher predisposition, I mean, um [pause] hypothetically, you would hope that people would, um, make different choices in their lifestyle. But some people don’t [chuckle] regardless of what information that they know. But, um, if you wanna, like, increase your chances. **But when your ticket’s up, your ticket’s up, I guess.** That’s the way I look at it, too. Like, people say I could die on my job. It’s like, because, it’s like, um, it’s like, well, yeah, I could. But when your ticket’s up, your ticket’s up. I mean, you could get hit by a bus. I mean, we’ve been to fatals [deaths observed as a police officer] where, one Christmas, people were waiting for a bus, and two cars hit one another and went sliding on in, and wiped out a whole bunch of people waiting for the bus. So. Waiting for the bus, you could say, is increasing your [chuckle] your risk of death, you know. It’s like, it’s ... that’s that I mean. Like, if ... you have no say. Just freak things happen. And it’s like, um ... [emphasis added] (Interview with Affected Female, 19 December, 2000)
She makes the point that death is not specific to cancer. Many people interviewed attempted to normalize the notion of death in their healing narratives. Death is a larger issue for people's construction of their person that is not simply related to cancer. It is a larger category faced by all persons. Control was swept away from cancer in people's narratives; they are not different from all other persons who must all face death.

**The Reflexive Dynamics of Personhood**

Complex notions of hereditary illness exist within families. These perspectives are often referred to as 'lay-perspectives' and are thought to be antithetical to medical knowledge and are sometimes seen as barriers to genetic understandings related to cancer. However, this research has shown that the perspectives of families likely to have a mutation for HNPCC are complex and that they often incorporate genetic knowledge as a component, but only a partial element, of their overall understanding of their condition and their experience with cancer. That is to say, genetic information is only a small part of the complex narrative arrangement of a family's experience with colon cancer. Other variables, such as medical or clinical information, the need to confront the possibility of death, the protection of personhood, the construction of agency and the need to displace blame or personal responsibility are powerful parts of their narrative ordering of their experience. In fact, it appears that the acquisition of genetic information is utilized as a tool in the service of these ends rather than as an end in itself. People employ strategies for creating power and for resisting any threat posed by cancer to their practical consciousness, the security system for personhood.

Initially, when people were asked about themselves, they tended to remark on their marital status, where they were born, how many brothers and sisters they had, whether
they had kids, their education and their vocational background. It appeared conventional for people to define themselves along these few predictable variables. When people were asked to talk about themselves, these were the narratives that they immediately reached for and it appeared as though this line of questioning was almost expected.

As the questions probed a little deeper and people were asked to describe a typical week, the answers appeared to become a little bit more difficult to produce immediately. Individuals began to open up about their experiences with cancer and it then appeared to become easier to talk about how they define and understand themselves. Cancer appeared to provide an opportunity for people to expand to more complex issues surrounding meaning and to unveil distilled notions of personhood.

People were often keenly aware of the dynamics of personhood and the threat cancer could have upon their status as a full person. Many shared complex perspectives on the process by which personhood is nurtured or undermined and others offered musings about their philosophy of life.

Many of the narratives clearly contained a reflexive component:

**Interviewer:** Do you have anything else to add, in terms of the overall interview?

[long pause]

**Affected Male:** I, I guess, uh, and maybe I was trying to say it before. You’re kind of right there with the illness. An illness that can kill you. And, you know, there’s sort of no hiding behind mommy, or relying on some, on something else. I mean, it’s just you and that reality. And, um, I mean, no one can really help you with that. In, in, in, in, in a final sense. I mean, I understand that you can have people around that are supportive, but, like if you ever ... it’s you and yourself. They are dealing with that. You know. Um, you know, I, I found that interesting. And, so, uh, [pause] I mean, you’re facing yourself, I think. At that moment. And it’s ... I mean, I, and maybe it leads to, you know, things you might have thoughts about your life. Or, I mean, and the woman in the, in the, uh, chemo room was crying about her children, and you know, and you know, if she’s going to die, what’s going to happen to them? And, that kind of ... and, [pause] again, I
mean, this was a profound sense of self. In the, in the experience of, you know, this could really kill me, and [pause] just . . . [emphasis added]

(Interview with Affected Male, 11 December, 2000)

A number of participants tried to impart a sense of their reflexivity regarding their personhood through their narratives. Consider the following response from an individual when asked about experiences with colon cancer:

**Affected Female:** “Um, [pause], well, it uh, it definitely makes you, um, realize, I mean, you, you set your... mainly, it’s finding yourself as an individual...”

(Interview with Affected Female, 19 December, 2000)

This personal discovery described by the respondent encompassed more than the experience of illness in the body; it commented on the potential social consequences of illness for the status of personhood. People didn’t want to be merely a “cliche” and were aware of the public narratives about the personhood of individuals with cancer. They wanted to talk about something deeper, to give a deep analysis of their experience, to share a more heartfelt sense of knowing:

**Interviewer:** ... is, how would you describe the, the most significant impact of cancer on your life? Or, has there been a significant impact?

**Affected Male:** Well, you know, you, I, I can’t even say ... you know, there’s a whole series of things that went together. You know. Um, in that, in that, in this last three year period. Certainly beginning with that. Um, I think I’m better off for it. [Chuckle] You know. Um, it, you know, I mean, it, it’s not even like, um, you know, there’s only the moment to live in, as opposed to, you know, planning for the future, so enjoy. I mean, it’s not like that gross a, oh wow, I, I realized, you know, you’re on borrowed time. Or it’s, you know, it’s, it’s not, you know. Um, it’s more subtle than that. But there’s, um ... I’m, I’m more at peace, I think. Um. With, uh ... I mean, that, that was I guess a major life event. And the, the follow up of it, and the thing with my parents, and my mother dying, and, and, and just ... I mean, it was, I mean, it was sort of ... I don’t know if it surprised me, but it was interesting to me, frankly, that I wasn’t scared at all. I mean, about it...

(Interview with Affected Male, 11 December, 2000)
Some offered philosophical perspectives about life politics, in particular, about the importance of recognizing people's contributions, their full status as persons, as contributors to the world, no matter what stage in life they are at:

**Interviewer:** So, you were just, to begin with, telling me a little bit about, uh, what you've done, in terms of work. And, and, and you said you worked in a hospice.

**Affected Female:** I did. I worked ... well, not ... I worked in, um, a care facility. In, in a ward that was dealing with people who were imminent. With people who knew, these people knew, within days or weeks or months, that they were actually going to die. So they had reached that point of their life which, I guess for me, was, it ... well, with my experience with the colon cancer and ... it was not a good experience. I'll tell you a little bit about that. But that was where I found my closure. And actually, what it did was open my life up to be more inspired. And recognise, yeah, it's, it's unfortunate, because, **what I learned from that was, you know, we see these care facilities and we go through these doors, and all we see is old people. But these people have lives that were contributing to the society, and they had value.** So I ended up, you know, being inspired by that, and realise that sitting there, it became less about me having come through what I did. Like, really just to really, you know, appreciating that. You know [emphasis added].

(Interview with Affected Female, 20 July, 2001)

The above passage shows an awareness of personhood and the process by which it is threatened by serious interruptions in health so that people are seen on only one dimension, in this case, as an old person rather than as a full person with value who has made contributions to society.

Sometimes individuals also made suggestions about what life is about for them and hinted that it might be what life is about for all of us (life politics):

**Interviewer:** I have one last question. I think you've already answered this, but. If you were to, to summarise in a nutshell what the most, um, [pause] biggest influence this has had on your life or your thinking, um, how would you describe it?

**Affected Female:** The biggest influence? Yeah, I think I've probably said that ten times over. It's just opened up my expansion of, you know, what it is to still be here, doing things. And what it is to understand people's contribution and the
value that they’ve made to our society. And to see death, as you said, from a, a much more understanding, open perspective. It’s not ... you know, it’s a fact of life, really. But, you know, to be more compassionate to those who have been through it.

And, you know, it ... unfortunately, we are, in many ways, observed of, as numbers. And, and you know, get in line, sort of thing. And it’s not about that. You know, at the end of people’s lives, uh, you know, in their later years when they’ve done working and their children are gone and everything else, the most important thing to them is their friends. You know. It’s friends. It’s about people. Life is not about things and, you know, where I’m going on my next holiday. It’s about how we affect people’s lives that we pass through. So. Yeah. That’s my book. [Laugh]

Interviewer: I agree.

Affected Female: Absolutely.

Interviewer: Maybe that’s going to be the title.

Affected Female: I don’t know, I don’t know.

Interviewer: Well, do you have anything else to say?

Affected Female: No.

Interviewer: Any […]

Affected Female: No, no I, no, I think that’s fair. You have to buy my book. [Laugh] [emphasis added]

(Interview with Affected Female, 20 July, 2001)

Life for this person is not about things (commodities), it is about gathering emotional capital through friends and in pure relationships with people that she has met and touched. This sense of meaning of human experience and life itself as most centrally located in the social relationships between our friends, families and the people we’ve known was a common theme in the narratives that people shared.

Creating Power Through the Cancer Experience

In contrast to popular ideas about cancer robbing individuals of their lives, many of the people interviewed in this study described their cancer experience as having given
them more control over their lives. Many individuals described how they took over the reins of defining themselves and negotiating their identity in society. Families appear to actively employ strategies that redefined their illness and themselves in ways that transcended whether disease was present or absent. Many people appeared to attempt to take away some of the authority of clinicians and individuals developed their own sense of self-governance over their personhood. In order to accomplish this goal, patients and family members re-defined decisions about potential treatment or courses of action (such as seeking genetic information or testing) as personal philosophical decisions that they carefully guarded. Using this strategy, the model for decision making was turned upside down from a system where decisions are made primarily by clinicians in consultation with patients to an alternative approach where decisions are made primarily by patients in consultation with clinicians. In this representation, courses of action affecting the person and the family become philosophical and personal rather than clinical. Authority over health is no longer entirely or even mostly clinical. That which was formerly governed from within the clinical realm also becomes social in that whole family dynamics are taken into consideration when deciding whether to pursue genetic counseling or testing. Numerous affected and at risk people reported that the reason that they had sought genetic testing or counseling was due to the wishes of a particular family member (usually a person who had taken on a health promotion role) or concern for their family. Here, a sense of agency is created by carefully constructing the responsibility for decisions as the rightful responsibility of the patient and family rather than the charge of the dutiful clinician.
Colonizing the Future Through Health Promotion and Advocacy

The World Health Organization (WHO) describes health promotion as: “the process of enabling people to increase control over, and to improve their health” (W.H.O. 1999). With respect to HNPCC, the responsibility for maintaining screening and surveillance and to share information with those at risk tends to be taken up by family members rather than clinicians. This was a technique utilized by people at risk for cancer to colonize the future and guard against the threats of HNPCC.

It was often the case that one individual in a family had taken on an informal role as a health advocate for the family as well as both the steward and champion of genetic information. These family members carefully documented and charted their family cancer and screening history. In one case for example, the individual occupying this role provided a detailed document that not only described five generations of a large family’s experience with cancer, but also noted whether or not each individual family member had been offered screening (colonoscopy) and whether they had actually been for screening:

At Risk Female: ...Researching, okay, trying to find out everybody. Uh, the order, uh, generations, uh, who’s been scoped, who’s even thought about getting done. Um, it turns out that we’ve covered ... the first generation’s dead. The second generation, um, we’ve got the one dead, but, uh, everyone’s been done in, in the second generation, and they’re clean. Okay? In the third generation, everyone but four has been done. Okay? With, uh, um, everyone clean, with one person having a polyp that was found and removed. In the fourth generation, only two people have been done. And there is, like, 20 people there. Only two people done. We have spread the information, out, we’ve, we know that there’s one of them that’s having really problems, both front and back, and, and he’s about 26 or 28 years old. Done nothing. Um. The fifth generation will be coming up. But the fourth generation, uh, as far as, from my understanding from, um, the genetics counselling, is that, um, the fourth generation is next in line. Most of the ones in the fourth generation are, are over the age of 20. There’s only a few. Um, a half a dozen. Five or six that are under the age of 20. All the rest of them are between 20 and 30, 36 years old, 38 years old. They have not been done. Um.

But we’ve provided the information to them. Either through photocopies, through the Internet, or through the computer, to let them know, “Hey, this family
does have a history. There is something you can do about it. Um, or face the consequences.” So, education wise, uh, information, it’s been sent out. We can’t do anything more. Um. Once, if any, if anyone in the fourth generation starts to get it and so on, it’s not like we didn’t try and tell them.

(Interview with At Risk Female, 20 July, 2001)

It also indicated whether the results of screening procedures were “clean” for each member of the five generation (including the grandchildren and children) family. Family members face uncertainty by becoming authorities.

The individuals who took on the role of health promoter essentially tell other family members what to do with respect to genetic as well as clinical services:

Interviewer: Do you think that, at some point, um ... I guess it’s difficult to tell, but at some point that she would go for genetics counselling? At some point in the future, or anything like that?

At Risk Female: Well, I would think that she would. If the testing ever becomes available, then she would go. Because she would know through me. If the testing becomes available.

Interviewer: So essentially, you have the ... a role in the family, at some level, as the information gatherer.

At Risk Female: Definitely. Because I’m a nurse, and that makes a difference too.

Interviewer: And you interpret the information.

At Risk Female: Yeah... I told my sister when I returned from there, you know, and, uh, all the information, and that she, she’d make sure that she was getting her colonoscopies on a regular basis. Um, he had, uh, just done a, um, a sigmoidoscopy before. And sigmoidoscopies aren’t good enough to detect high level cancers. So, uh, I made sure that she knew that she had to get a colonoscopy, and not a sigmoidoscopy. So. She just tells her doctor what she wants. [Laugh]

(Interview with At Risk Female, 13 December, 2000)

This individual not only provides interpretation she also forms conclusion and makes recommendations (that are followed by family members) about the appropriateness of
particular clinical interventions and genetic testing services. She goes farther than interpreting and sharing information; she actually provides direction for her family member. Due to the fact that she is a nurse, she possesses some cultural capital that is significant.

There were a number of examples where one family member provides direct management of the clinical care and genetic services for other family members. In some cases, one family member also controlled information about genetic risk for HNPCC:

**Interviewer:** Can you tell me a little bit about your risk for colon cancer? How, how do you feel your risk is? Or, what level of risk do you have?

**At Risk Female:** Well, I think my risk is getting lower, as I get older. I was happy to get over fifty seven, when my mother and brother had it. But, um, yes. I think I’m starting to feel that maybe I’m going to beat it. Because I’m getting older and nothing’s happened yet. So, uh ... but I am well aware that there’s a pretty good risk that I could get it. But I’m also convinced that if I do, I’m going to catch it early.

**Interviewer:** How about risk for other family members? Have you talked about risk with your kids at all, or ...?

**At Risk Female:** Um, not so much risk, as ... I don’t want to terrify them.

(Interview with At Risk Female, 20 November, 2000)

In this case, this woman’s kids are adults (they are both over thirty years of age). A number of people reported that the only reason that they sought out genetic services (counseling and testing) was for the family or for a particular family member. This finding is in contrast to the notion that patients make decisions as autonomous individuals; many of the people interviewed in this study made their decisions within a social network based on existing family dynamics, roles and expectations.
Some respondents note that they take on the role of health advocate and promoter in their family but they do so without the cultural capital of a medical or genetic practitioner and that this sometimes makes their role difficult:

**At Risk Female:** And, uh, explained about this family. Uh, as far as how many in the family had had or been diagnosed with colon cancer. Who had died, who had lived, whatever. And, um, so that letter came back to, to K. The next thing, K. had contacted me and said, “You know, we got a chance for, you know, to see genetic counsellors again, or one or … one person can go down there, okay, and talk … you know, to represent the family and so on.” And, uh, anyway so she asked if I wanted to be a part of it, and of course I did. You know by now, like I say.

But, uh, the thing is, is, is, all the information I had learned from the Internet about this nonpolyposis colon cancer, I was explaining to K., that there is a difference with the types of cancers. Okay? With the information I had found out how nonpolyposis works, and all this other stuff. She came back sarcastically with answers like, “What, are you doctor now? What, you know it all?” I thought, “Okay.” So now I’m starting to, I’m starting to feel perhaps what T. had felt in 1993. Suddenly there’s this, um, the anger and frustration. Darts are flying, everything else. And I thought, “You know, this isn’t nice.” Um, there was, there was friction. Okay... [emphasis added]

(Interview with At Risk Female, 20 July, 2001)

The respondent describes how a person who is newly motivated by HNPCC or the risk of it is frustrated, as her sister had been earlier, by the family’s lack of willingness to accept the information that she and others have collected on their behalf. She generously shares detailed family information with me including copies of medical assessments and reports as well as an incredibly detailed chart of the family’s history of cancer illness. Before sharing each new document she carefully asks for permission from all those present. The records are clearly viewed as the possessions of the entire family and not of one individual. In particular, she asks whether the family history, collected by the family members and not a clinician, can be given to me because it reveals a family secret. The group speaks with informal hand signals and points to a particular section of the document without showing it to me. The mother nods her approval and they reveal the
family secret. There is one more family member that none of the narratives have accounted for and this is a son whose whereabouts is unknown. I do not probe further but understand that this represents a mark of potential embarrassment with respect to the potential stigma of an unanticipated child or a child with unsettled origins who may have been given up for adoption.

**Whose Responsibility is it to Promote Health?**

The interviews showed that the responsibility for health promotion within a family with a family cancer syndrome often tended to be carried out not by medical professionals but by a concerned family member. Medical practitioners tend to focus on the treatment of disease that is actually present in a particular patient. While they will sometimes concentrate on prevention in a single individual by suggesting clinical surveillance such as colonoscopies, their central focus is still on an individual patient rather than on the family. As a result, individual family members tend to take on the role of promoting prevention and health within the wider family. This is sometimes difficult because they take on this role without credentials that legitimize their role as health care advocate and health promoter. Some individuals described how they experienced anger and frustration after taking on the responsibility for sharing information about genetic susceptibility to illness and advocating for various courses of action such as clinical surveillance, genetic counseling, genetic testing or disclosure about risk to other family members. This anger may originate from the fact that some family members feel a very real sense of responsibility for sharing information with the family, a responsibility for advocating for certain courses of action, but do not have the cultural capital to be taken seriously by all family members. Some individuals described friction brought into the
family as a result of the new role taken on by the person taking on the role of knowledge provider, information collector or health advocate.

Many patients were aware of the literature on clinical surveillance protocols. In some cases, they were aware of differences between different jurisdictions in the world:

**Affected Male**: I was done twice in the first year. First time to diagnose it, I think six months later, and then I think six months after that. Then the question was, how often now? And I think the next recommendation calls for three. And I just had it, I think, last January. So maybe it was two years later. Um, I guess it, it might have been through reading some of the things that, you know, um, through [my wife]'s medical journals where they summarize things. But some of it comes from, obviously, just, you know, research all around the world. And you see some ... and, and it ... what, what they do say is, they’re, I mean, you know, there’s different points of view on it. That’s clear. And, you know, then I knew this one guy who, like, goes to Seattle every year and has it. You know. Um, you’ve got better treatment. I don’t, you know, um. So there is a, uh, a worry there. I guess.

(Interview with Affected Male, 11 December, 2000)

In many cases the knowledge base of family members regarding HNPCC was so developed that it seemed imprecise to describe them as lay-perspectives when it was possible that it might rival that of many general practitioners.

**The Reflexive Project of the Person**

A common theme in the interviews was the view that the adversity from the experience of illness brought about a strengthening of peoples’ character. It appeared that those affected by cancer were attempting to find a sense of meaning or purpose to the illness. Many reported that their experience with the illness had allowed them to develop more in depth understandings of themselves. For many people at risk for HNPCC, this process of personal development had started long before they had personally been diagnosed with cancer. They had become very self reflective based on early experience
with cancer. In the following instance, this young woman who has been affected by colon cancer and whose father had also been diagnosed with colon cancer when she was in pre-school describes how she had developed her own life politics by the time that she was a teenager:

**Affected Female:**...And I’ve never really taken things for granted, I guess. Um, I mean, because I was almost killed in a car accident when I was seventeen. So people say, “Did it change your life perspective?” It’s, like, “Well, no. I had that a long time ago.” [Chuckle] And even before that, knowing, being told that my father could die, you realize that life is very precious. And it’s like, you have to live each moment to the fullest. [emphasis added]

(Interview with Affected Female, 19 December, 2000)

The “That” to which she refers is something that many people tried to share with me in their narratives. It was something that this young woman had learned long ago as a pre-school child watching her father experience colon cancer. There was a depth of character and understanding of one’s person that people were eager to share:

**Affected Female:** Unless adversities give, I think, depth to your character. Like, it’s just basically like they say. If, um, how can you know joy if you haven’t experienced pain? And, you know, how can you know happiness if you haven’t had an unhappy moment? Like, I don’t think you really truly appreciate what you have until it, there’s a possibility of it being taken away. And that’s what I believe. But, um, but, uh ...

**Interviewer:** Do you think that that possibility is always there for people, but they’re not necessarily aware of it? All people? Are some people more aware of it?

**Affected Female:** I think some people are, are aware of their own mortality. Um, it’s just like, um, but, I mean, for me, it’s like, yeah, I, I’m aware of it. I mean, but I don’t let it consume my day. Like, because, like they say, that bad, horrible saying. There’s two things you can depend on: death and taxes. [Laugh] In life, you know. So, it’s like, well ... and like I said, I don’t like to waste to much time worrying about things you can’t change. So. Why worry about it? Why not enjoy what ... you only have one life, so you may as well make it the

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36 I am referring to clinicians in the wider physician community and not those who are direct participants in the HCP. In the latter case, they would be very aware of current clinical surveillance protocols for HNPCC.
best that you can. Rather than wor, worrying about it and getting depressed. Just, I don’t know.

(Interview with Affected Female, 19 December, 2000)

A greater sense of well-developed personal insight and understanding appeared to be one of the most important parts of how people at risk for HNPCC defined their person.

**Emotional Capital, Pure Relationships and Changing Time Horizons**

This disease appears much earlier than sporadic colon cancer. Many of the individuals interviewed in this study had been affected by HNPCC, had young families and were in the middle or beginning of their careers. This caused many people to rethink and modify their life plans. A number of family members commented on how they had modified the time horizons of their life narrative:

**Affected Male:** Yeah, yeah. We used to talk about, um, [pause] dreams off in the future. You know, the big houses, a new car, travelling the world, and that, and now we talk about this week. Next week. You know, things we want to do now. Whereas it used to be, when we get enough money we’ll do this. And, and whatnot. And now it’s, let’s think about doing this now. Let’s go, you know, if we want to go a week holiday on the Oregon coast, well, let’s jump in the car and do it. And we do it. You know.

(Interview with Affected Male, 26 May, 2000)

The excerpt shows that the affected male and his spouse now place more value on emotional capital than on material capital personalized redefining the focus of their mutual autobiographical narrative and life plans. When I met them, they had placed a lot more value in emotional capital and had invested in developing a pure relationship.

Numerous people talked about how they had changed the arrangement of their life goals from long-term to the more immediate:

**Spouse of Affected Male:** Um, but ... and then on the other, the other side of that coin, we have been able to talk about the future plans, talk about [pause] what I would do in the future. Um, as far as money and handling this or that. Learning how to do things around the house. Um, learning to take responsibility for things that I haven’t done before. Um, not financial. Those ... I’ve always handled that,
but just things that go wrong in the house. You know, that he’s always taken care of. Um, he’s been very aware of getting things done. That have been not done. Um, little things like getting the driveway paved, and, and getting a new furnace, because he doesn’t want me to have to worry about the heating system, and that sort of thing. So, he’s been given time to [sigh] finish things. Tie up loose ends. That sort of thing.

We’ve also looked at life in a little different way. Um, before it was always, “We’ll do this when we retire. We’ll do that in the future. We’ll do such and such.” Mainly travel and whatnot, and, uh, “We don’t have the money now, but some day we will” sort of thing. And now, since he’s been sick, it’s more an immediate thing. It’s like, “Well, let’s do it now.” “Do we have the money?” “Well, I don’t know. We’ll find it somewhere.” You know. “What are we going to do about the future?” “Well, we’ll let that take care of itself.” We’re more living for the moment. Taking every bit of enjoyment we can out of today, rather than putting it off some time in the future. **Because the future is now for him. This is all there is.** So we’ve taken a lot of our money that we had put aside for retirement and spent it. And gone to Europe, and we took a trip around North America last year, and we went to Bali this spring, and, you know, just had fun. Because what else can you do? This is what your life is now. And, if you save all your money for the future, well, you may not have a future to enjoy it. You know. So, I’d rather spend it with him, than spend it as a widow. So, uh, that, that has changed our life. Um, the way we look at things, and how we do things. [Sniff] But, um. [emphasis added]

(Interview with Spouse of Affected Male, 26 May, 2000)

His diagnosis with cancer was a fateful moment where their mutual life story line, at least potentially, had been dramatically abbreviated. While this observation may appear to simply build on the old cliché statement: live for today not tomorrow, this was a very significant perspective shared by many of the family members interviewed. It was common for those interviewed to make a point of telling how their ranking of short and long-term activities had been reversed and that they had rewritten their priorities.

The case of two professors and their young family is illustrative. Both the individuals interviewed, one affected and one at risk for HNPCC, were careful to make that point that they had re-written their priorities as a result of their direct experience with HNPCC. Both had been extremely committed to their careers and each spent many long hours each day researching and writing at a university. They employed a nanny to mind
their two small children in their absence. When the mother developed what appeared to be end stage serious colorectal cancer their world was turned upside down. The nanny’s hours were dramatically cut back as were the hours of work for both the husband and wife. While they both remained committed to their careers, they gave what used to be longer-term priorities more primacy and no longer deferred them until later (e.g. investing time with their children in the day to day, time spent together as a couple, time together as a family):

**Interviewer:** Can you talk about how, um, or whether or not colon cancer, the discovery of colon cancer, uh, uh, in your life, affected your relationship?

**Spouse of Affected Female:** Oh, I’m sure it did. Um, in a lot of ways. I think that, um, you know, initially, I had to respond, uh, by just trying to help her through, you know, such a difficult time. You know. When she was in the hospital. Prior to surgery, especially. Um, and I’ve, you know, never had to do that before. Um, [pause] as more of a long term result, I guess it’s, I don’t know. It’s, um, maybe, uh, uh, an additional step in, uh, my commitment to her. Um, you know, I realized that, uh, that, you know, something like this can happen, and that I have to, uh, or at least, I’ve chosen to, um, be there to help in that kind of a situation. Um, and also I think it’s, you know, given me, uh, the sense that our time together could be very limited. You know. We don’t know, uh, how long it may last. And we have to really, um, make the best of it.

(Interview with Spouse of Affected Female, 3 August, 2000)

This couple had made emotional capital as more valuable than cultural, material and symbolic capital. They had invested their emotional capital in a pure relationship. A number of others interviewed made a similar point: every day prior to their direct experience with illness they had taken the chance that there would be a series of tomorrows. When they had found out that there wasn’t necessarily a long future life ahead of them, they were more generous with themselves before tomorrow arrived.

Good (1996) described subjunctivizing strategies employed by people faced with serious disruptions in their health. Similar strategies were observed in this study as a
large part of the narrative repertoire of the individuals faced with the possibility of a tragic outcome associated with HNPCC. They tried to create multiple possibilities for the future, possibilities that didn’t necessarily include cancer. The following interview excerpt from an interview with a woman at risk for HNPCC comments on the process of creating possibilities directly:

**Interviewer:** What do you think the ... or is there a particular aspect of, um, in your family’s experience with cancer, that has been the most informative, or the most powerful? What would it be?

**At Risk Female:** I, I think the most, most powerful thing is, is, um, uh, the possibility. And when I say that, the possibility that you can overcome cancer. If the circumstances are right, in the sense that it’s been caught early enough and you’re not so far down the line that you’re, you know, you can’t, you cannot heal yourself. Um, but that, that there is a possibility that you can be in your own well being. In your, you know, recovery, in your repair, in your fighting of the disease.

(20 November, 2000)

People attempted to create strategies for engendering hope through the active stewardship of their person. People employed a number of other techniques for enhancing the possibilities for prevention and healing including: vigilant clinical surveillance, the search for genetic information, the regulation of lifestyle factors and the control of medical intrusions into the lifeworld all provided additional layers of opportunity to command the healing process.

If the earlier chapters introducing the study and providing an overview of the context and theoretical framework were the prose of this study, then the patient and family narratives are its poetry. This chapter has attempted to illustrate the process of healing emplotment by family members at risk for HNPCC including: pursuing genetic information or services, taking control over clinical surveillance and treatment, disseminating knowledge, maintaining authority over tests and imaging studies of their
bodies and initiating personal diet and exercise programs. It has also provided a
description of some of the strategies employed by family members to create agency in the
power imbalance created by disease and the practitioners who treat it. Family members
showed awareness in the interviews of the subordinate point of view of any position that
was not directly medical or genetic. Nevertheless, their narratives still brought together
many different points of view outside of those of medicine and genetics about their
illness. Maintaining several ideas about the cause of HNPCC, then, appears to be a
strategy for increasing agency. Family members appear, at times, to downplay the power
of genetics in terms of its causal power in favor of variables that they appear to be more
controllable (e.g. place of residence, stress, diet, exercise, personal attitude). In this way,
lay perspectives about cause can be seen as more than interesting mythology, they can be
understood as a strategic bid to counterbalance the power of genetics. The narratives
presented here are part of an ongoing personhood story with a healing plot. They are
exceedingly complex and do not exist in any real way as separate from medicine and
genetics. Many different positions are unified within them because the narratives have a
higher and more personal purpose. This higher purpose will be explored in the final
chapter of this dissertation. However, before turning to the concluding section of this
study, the next chapter examines interviews with clinicians in order to analyze
professional understandings of HNPCC.
CHAPTER SIX: CLINICAL NARRATIVES

This chapter utilizes interviews with clinicians, mostly oncologists, to examine the process of therapeutic emplotment. It provides some data to support the proposition raised in chapter three, that is, that genetics and medicine are distinct from one another and may represent two different cultures. The oncologists interviewed here, as a rule, saw the hereditary cancer program as distinct. The HCP was understood to have expertise, authority and responsibility for addressing HNPCC. Oncologists did not believe themselves to be experts in the genetic aspects of HNPCC. They treat the disease as sporadic and not as hereditary cancer. Treatment is seen to be the responsibility of the oncologist while the management of risk and counseling for HNPCC rests with someone else. Surveillance is also perceived as the responsibility of another clinician (presumably a gastroenterologist). In short, oncologists treat disease and the object of their work is primarily seen as cancer that is bounded within a particular patient. Their object is not a family. The interviews illustrate that clinical knowledge about HNPCC is somewhat sketchy (e.g. incidence, specific characteristics, screening protocols, whether they had treated someone with the disease). A number of the oncologists were also unsure about the genetics of HNPCC (whether the genetic mutation had been discovered, whether there is a HNPCC colon cancer registry or whether testing was available). Many were not sure whether they had ever treated someone with HNPCC even though it seemed likely that they would have (based on epidemiological estimates). Ultimately, this chapter begins to unravel the mystery of who makes the diagnosis of HNPCC (or at least, who doesn’t).
The diagnosis of HNPCC began as a mystery and remained so, even after the interviews with the clinicians. Who, then, makes the diagnosis of HNPCC? The HCP has a long waiting list (up to two years), doesn’t have specific resources for addressing HNPCC and the patients need to be referred from somewhere, but where? The gastroenterologist seemed to be the likely candidate however the interviews did not confirm this hypothesis. The family history is crucial for recognizing HNPCC. It appears that the oncologists interviewed do not necessarily take the full family history of a patient. This is already completed by a different clinician. This may account, in part, for the fact that HNPCC does not appear to be consistently diagnosed.

Perhaps the most influential institutional arrangements that affect medical practitioners and as a result the families at risk for HNPCC are the absence of a genetic test and a system for remunerating clinicians for preventative work they undertake with those at high risk for but as yet without actual disease. Some oncologists reported that the structure of the fee system does not allow for sessions to provide extra elements such as information about HNPCC or discussions about death. Without these elements in the institutional or systemic landscape, HNPCC as a specific disease does not appear to exist in the wider culture of medicine. In contrast, in the Hereditary Cancer Program, a hotspot of genetics expertise, HNPCC occupies a large part of the discussion and focus for consideration. Most oncologists also reported that genetic testing would not significantly affect their role as clinicians. It is clear from the interviews with oncologists that the genetics of HNPCC have not, to date, had any significant impact on medical practice. These data also suggest that genetics and medicine are distinct and that they may represent different cultures.
This section examines the process of therapeutic emplotment embodied in the clinical narratives of oncologists and attempts to illustrate that professional responsibilities are institutionally consecrated with respect to the provision of treatment and genetic services. In particular, different oncologists work in very specific treatment modalities. In contrast, genetics experts and those associated with the Hereditary Cancer Program have been institutionally vested with the responsibility for providing genetic diagnosis, testing and counseling. Medical practitioners do not diagnose HNPCC, even if they know that it exists in one of their patients. These same practitioners do not perceive patients as having enough cultural capital (linguistic capital or credentials) to understand HNPCC. This means that in practice, oncologists will discuss HNPCC with colleagues but not with patients.

**Connecting with the Clinicians**

Unlike the patient and family interviews that took on a conversational style with free flowing narratives from the respondents, I did not have what appeared to be a relaxed or informal connection with clinicians. It seemed difficult to break through the barriers of professional conventionality. It appeared that many of the clinicians were nervous about the style of the interview as they jostled for a sense of “where I was going” or “what the purpose of the interview was” once they realized that I was not simply looking for technical information that could be acquired from them in the same way that I would extract information from a Medline computer. The professionals seemed more at ease with questions that probed at medical knowledge base such as:

- What is HNPCC?
- What are the Amsterdam Criteria?
As well, it was clear that finding the edge of knowledge of a clinician also made them uncomfortable.

**Two Cultures: Genetics and Medicine**

It appears that, at least in the case of HNPCC, the genetic and medical cultures are distinct from one another. All of the clinical narratives revealed that the provision of genetic information is generally thought to be a part of the responsibility of someone else, notably, a genetics specialist or a practitioner associated with the Hereditary Cancer Program. Consider the following example from an interview with an oncologist:

**Interviewer:** Do you think patients are being told that they are likely to have HNPCC? With ... who meet the Amsterdam Criteria?

**Medical Oncologist:** Um, certainly if I had a patient who met the Amsterdam Criteria, I would say, “Gee, [laugh] you know, you have a very strong history here, and you may meet the criteria for a family cancer syndrome.” But I’ve not had a patient who met those criteria, yet.

**Interviewer:** And in that case you would say, “And it looks like it might be HNPCC.”

**Medical Oncologist:** Um, would I give them the actual name for it? Probably. Probably. I’ve not been in that position yet.

**Interviewer:** What would influence your decision to, to do it or not to do it? And what were ... and just getting a sense of, like, when you say probably ...

**Medical Oncologist:** I guess my concern is, I would say, “Gee, it looks like you have a family cancer syndrome, here. And other people in your family could be at high risk for developing colon cancer. Why don’t we have you speak to our family cancer program.” Because that’s the kind of language I’ve used before in my other patients. For example, the pancreatic cancer patients I told you about. So, I, I don’t know if I would have used the word, HNPCC.

**Interviewer:** You’d rather essentially refer it to an area that was dedicated to dealing with hereditary cancers?

**Medical Oncologist:** [Breath intake]

**Interviewer:** Like the Hereditary Cancer Program.
Medical Oncologist: When we have that in our, in our province, and they’re set up to be able to, uh, counsel people regarding, um, what that exactly means, yes. I’d, I’d like to be able to have them do that. Keeping in mind that when I see a patient, it, it ... usually, the agenda is to be able to figure out whether this particular patient needs, you know, chemotherapy or not. And if they do, what, what are the risks and benefits of that treatment. And that’s a lot of information to give to somebody within, in an hour. It’s overwhelming. And then to go on to all of the specifics about a hereditary cancer, um, problem. Number one, I don’t feel that I’m properly equipped to do it. And number two, I don’t think that I can, um, do as good a job in the amount of time that I have, given the other things that I have to do for that patient. [emphasis added]  
(Interview with a Medical Oncologist, 5 July, 2000)

This interview excerpt illustrates a few key points. Firstly, the primary responsibility of the medical oncologist is on the treatment of cancer disease utilizing chemotherapy. Secondly, the genetics of colon cancer is seen to be part of the expertise and responsibility of someone else who is part of the genetic culture, such as someone who works in the Hereditary Cancer Program. Thirdly, it shows that HNPCC, even if suspected to exist in a family, would not necessarily be discussed with the patient.

Every oncologist interviewed saw the Hereditary Cancer Program as responsible for the provision of specific information to families about HNPCC including facts about: diagnosis, genetic risk and recommendations for prevention:

Interviewer: I guess ... well, can you tell me a little bit about the role a medical oncologist is?

Medical Oncologist: Um, well, I think that’s ... I, I think that on a whole, you know, medical oncologists like myself are chemotherapists. We all have our difference of specialties, and some of us are more interested in the, uh, genetic syndromes.

Interviewer: Mm hm.

Medical Oncologist: Um, as a whole, here, we’re so busy that, you know, a lot of, um, the, um, genetic testing, the genetic, um, um, workups, the consultations with families, all that’s done, you know, by, um, [clinician associated with the HCP] and, and that genetic group [the HCP]. And it may be just that we’re too
busy and we don’t have the skills, really, to um, you know, deal with some of the ethical issues that you, you sort of talked about before. So, I, I think we’re more of a ... may, **maybe our role is as a gatekeeper, is to try to, you know, when these people, you know, show up, and there may be a hint, um, that they are part of this group, that we refer them on to further testing.** [emphasis added]

(Interview with Medical Oncologist, 23 June, 2000)

The following excerpt supports the observation that oncologists rely heavily on the HCP as the primary source of expertise for HNPCC:

**Interviewer:** Okay. Um, okay. Uh, can you tell me a little bit about your understandings of hereditary colon cancer?

**Medical Oncologist:** Uum, sure. I guess, first of all, the thing that we always think about are the cancer family syndromes, like the Lynch, uh, syndromes. And, um, using the Amsterdam Criteria to pick out patients who are in the, um, different family cancer syndromes. But, in addition to that, patients who have colon cancer, their immediate families are also at risk for developing colon cancer. At an increased risk compared to the general population.

**Um, so, I don’t know a lot about the specific screening tests that are available for those families.** Currently, if I see a patient who has, who meets, um, the specific criteria, **then I’ll send them to the Hereditary Cancer Program.** And if I have a patient who doesn’t meet those criteria, I will remind them that their family members are at increased risk for developing the disease, and they should make sure they get their proper screening done. [emphasis added]

(Interview with Medical Oncologist, 5 July, 2000)

Most of the other oncologists interviewed also reported that they felt that they did not have enough expertise or resources to deal with the genetic aspect of patients with HNPCC. They had, however, treated the disease as though it were sporadic colorectal cancer before referring the patient.

Oncologists, as a rule, focus on the treatment of cancer disease in a particular patient. They do not characterize the patient as part of a family for the purposes of clinical treatment. The family is clinically irrelevant unless one of the other family members manifests a cancer. The following interview illustrates this clinical understanding:
Interviewer: Is there any difference in dealing with the family? That, uh, in your experience, that has a strong family history? Versus dealing with ... or, a patient with a strong family history, just in terms of your experience treating them? Or is it, is it the same?

Radiation Oncologist: Hm. It depends a bit on ... uh, some people have ... you don’t, never see the family. You just hear about the family history and that’s all there is to it. And then you, uh, you advise them that there is a per... you know, that they have a risk. And you advise patients who you don’t think have HNPCC that their kids have a slightly higher incidence of colorectal cancer and so they should be, uh, um, make their doctors aware. Um, [pause] I don’t, I don’t think there’s a ... I don’t have a lot of dealings with the families. And that’s probably because I refer them on anyway for, for counseling, and it may be the families show up for that.

Interviewer: Are there differences in your recommendations for clinical surveillance? Between a HNPPC patient and a sporadic?

Radiation Oncologist: N... uh, well, it ... see, it depends who’s doing the clinical surveillance. Because really, the single most important thing to get is a colonoscopy, and that’s not actually my recommendation or my treatment. I, I refer them on to somebody to have that done. But the frequency of the examinations is, um, is really their, their responsibility. Now, it’s my understanding that the, um, the sort of, um, polyp to carcinoma progression can be shorter in the HNPPC patient, so the screening should be a bit more frequent. But that’s not actually something that I am doing, because I am referring them on to somebody who’s going to scope them. 

(Interview with a Radiation Oncologist #1, 9 June, 2000)

The interview shows that the object of the oncologist is primarily cancer that is bounded within a particular patient. The culture of oncology does not focus on the family. The family is the responsibility of some other professional such as a general practitioner or someone who does genetics counseling (the HCP). In fact, the HCP does not have resources to provide counseling for all families with HNPPC and there is a long waiting period to obtain genetics counseling (six to 18 months). Moreover, there is a long waiting period to obtain colonoscopy and some communities do not have a colonoscope or a professional to operate this instrument (usually a gastroenterologist). This would mean that there could be a long waiting period between when a referral was made and
when an individual patient received counseling or colonoscopy during which time their polyps could be progressing to carcinoma. This would only address the individual patient who presented with the index case of cancer to the oncologist and not their wider family.

The interview illustrates that oncologists perceive the determination of the frequency of clinical exams to be the responsibility of another clinician ('someone who's going to scope them'). It is interesting to note, however, that the oncologist makes the observation that progression from polyp to carcinoma is sometimes faster in patients with HNPCC. Other oncologists supported the clinical opinion that HNPCC might progress more rapidly:

**Interviewer**: So, just out of curiosity, um, on screen, on screening, how often does a person usually, or would a, would a person suggest that they get screened? If they’re ... based on the family history?

**Surgical Oncologist**: Yes, and if, if a person has a strong family history, uh, they would, they, um ...if they meet the criteria ... For instance, if, you take the, the worst case scenario, then, uh, I think the uh, HEA recommends, uh, screening every couple of years. A colonoscopy every, uh, every one or two years. Uh, starting at age forty. Um, but at a minimum, um going every five years. Um, because, I believe the polyps can occur much faster, uh, and transform much faster in a syndrome than they can in, uh, just the regular, standard population. So I think the ... that’s the HEA recommendations. Early screening and more frequent screening, with colonoscopy, not just occult blood screening. [emphasis added]

(Interview with Surgical Oncologist, 9 May, 2000)

This appears to imply the need for more vigilant surveillance not only in individual patients but also in the family members at risk for HNPCC. That is to say, it appears to be a clinical justification for expanding the scope of clinical focus from the individual patient to include their family in that more frequent colonoscopies could detect polyps in people at risk for HNPCC.
It appeared that some oncologists leave it up to their patient to tell their family members to seek out other specialists to perform clinical screening for HNPCC:

**Interviewer:** With a hereditary cancer, um, does your role of ... extend beyond the individual patient, as a surgeon, to include the family members? Or is ... are you mostly dealing with, focussing on the one patient?

**Surgical Oncologist:** Mostly focussed on the one patient. Um, I, I don’t, I don’t do colonoscopies myself, so, uh, if I have a patient with a strong family history, I try to ensure that they encourage their siblings to, uh, go for a screening. Uh, and, you know, I don’t, but I don’t actively try and draw them into my office, or anything, because I’m a surgeon. I encourage them to see their family doctor and get referred for screening at an early age.

**Interviewer:** Hm.

**Surgical Oncologist:** But I don’t, uh, document it, or record it, or make any other effort to ensure that that’s happening. [emphasis added]

(Interview with Surgical Oncologist, 9 May, 2000)

Given that the oncologists interviewed in this study reported that patients have a low level of information retention following clinical interview with oncologists this would be concerning:

**Interviewer:** Just a couple of final questions. Um, how well do you feel that patients understand what it is that you’ve told them about ...

**Radiation Oncologist:** Well, I mean they ... there’s good data to suggest that they understand about ten percent of it. Or, retain about ten percent of what’s said. Um, it’ll be ... I mean, there are various things. [ Name removed ] is doing a study tape recording the interview with the patient. And it would be quite interesting to ask the ones who bring a list, as to whether they, the following day, know the answer to their questions. Because, routinely, what they say is, they pull out the lists after you’ve finished talking to them, and then they say, “Well, you’ve answered all these.” Um, and that happens consistently. [Laugh] And it would be interesting to know whether, the following day, they can remember what the answers were to the various questions.

(Interview with a Radiation Oncologist #1, 9 June, 2000)
If a patient does not retain the majority of what is said in an interaction with an oncologist, then it would follow that many might also forget to tell their family members about the need for colonoscopies.

Broadly speaking, all of the oncologists interviewed felt that their responsibility was primarily the treatment of cancer while the responsibility for the management of risk and counseling for HNPCC rested somewhere else:

**Interviewer**: What kinds of things in particular would you discuss with a patient with colon cancer, as a radiation oncologist?

**Radiation Oncologist**: Um, mostly a treatment. Um, that’s the main focus of the initial consultation. It’s why they’re here. So they’re usually here, you know, right before the surgery, so that we can give some treatment for them to help the surgery. Or they’ve had the surgery, and there are high risk features to suggest that you have to give them some treatment to minimize the chance of recurrence. So the main focus of the initial consultation is, is why, why they’re here. You know, what is the risk without further treatment, and what is the risk with further treatment. What is the toxicity of the treatment. So, it’s pretty treatment related. And, you know, I ask them a family history. Most often, there is a negative family history, so they don’t really pursue it. But if there’s a high risk family history, then, uh, these patients usually are clued in already. They would ask, you know, “What is the risk for my, uh, you know, my offspring, or my siblings?” Those type of things. Um, and that’s, you know, usually I leave it to the hereditary cancer people to work that out. [emphasis added]

(Interview with Radiation Oncologist #2, 9 June, 2000)

As a rule, providing information about genetic risk was seen to be the role of the HCP, while the management of clinical risk in families was seen to be the role of the gastroenterologist or a family practitioner.

Patients or inexpert general practitioners would be potentially unsure mechanisms for maintaining the standard of clinical surveillance of HNPCC. This would be especially alarming in light of the radiation oncologist’s suggestion that the speed of “polyp to carcinoma can be shorter in the HNPCC patient” (Interview with a Radiation
Oncologist #1, 9 June, 2000). If family members are not being adequately informed and are at risk for developing cancer while oncologists are relying on a unsure referral mechanism, then this would appear to represent a gap in standards of medical service for families at risk for HNPCC.

Clinical Narratives: Understandings of HNPCC

The interviews indicated that clinical knowledge about HNPCC is sketchy. All the clinicians interviewed were asked about the clinical differences between HNPCC and sporadic colorectal cancer. Most of the oncologists reported that there is no clinical difference between HNPCC and CRC with the exception of its age of onset. The following interview excerpt suggests a lack of knowledge of any differences between HNPCC and CRC:

**Interviewer**: Are you aware of whether there's a clinical difference between HNPCC in its manifestation and colorectal cancer? Sporadic colorectal cancer?

**Radiation Oncologist**: No, I'm not.

(Interview with Radiation Oncologist, 8 June, 2000)

The following excerpt also suggests that medical practitioners do not distinguish between HNPCC and CRC clinically:

**Interviewer**: Are there differences in the clinical manifestations of HNPCC and sporadic colon rectal cancer?

**Radiation Oncologist**: They tend to be a bit younger. Um, at least that's what's reported. But we see sporadic young patients as well.

**Interviewer**: In terms of, uh ... from a radiation oncologist perspective, looking at the cancer, the site of cancer ...

**Radiation Oncologist**: No. Even from our, from my point of view they, they, they don't really get treated any differently. [emphasis added]

(Interview with Radiation Oncologist #1, 9 June, 2000)
The response from oncologists regarding the difference between HNPCC and sporadic CRC became predictably the same in most cases:

**Interviewer:** So, just a very specific point, then. When someone presents, say, to you ...

**Medical Oncologist:** Mm hm.

**Interviewer:** Um, with colorectal cancer ...

**Medical Oncologist:** Mm hm.

**Interviewer:** It isn’t necessarily treated differently. The cancer itself.

**Medical Oncologist:** Right.

**Interviewer:** Between HNPCC and sporadic.

**Medical Oncologist:** Right.

**Interviewer:** Okay.

**Medical Oncologist:** Not at all.

**Interviewer:** Not at all.

**Medical Oncologist:** Yeah.

**Interviewer:** Essentially, it’s a colon cancer.

**Medical Oncologist:** Yeah.

(Interview with Medical Oncologist, 23 June, 2000)

Nearly every interview with the oncologists confirmed the existence of a far-reaching belief in the oncology culture that there is no difference between the two other than family history and age of onset:

**Interviewer:** Can you go, “Well, that looks like HNPCC.”

**Radiation Oncologist:** No. There is nothing ...

**Interviewer:** Basically you’re saying ...
Radiation Oncologist: That we kind of ... no. Nothing that I can say, “Well, this is more likely an HNPCC case” If you flush out the age and the, uh, family history.

(Interview with Radiation Oncologist #2, 9 June, 2000)

Yet, the similarity between the two cancers was not as definite according to some oncologists:

Interviewer: Uh, are there ... uh, is there a different clinical manifestation of HNPCC, relative to sporadic colon cancer? Given the family history?

Surgical Oncologist: Uh, yes, it’s my understanding that the, uh, uh, distribution of the precursor polyps is a bit different. Uh, that, uh, it’s predominantly, uh, right sided. Um, and this is a little unusual. And the polyps, uh, I think, are a little more [...]. A little flatter, and a little more abnormal in their morphological appearance. Uh, and they’re certainly quite, uh prevalent. Although not nearly, uh, as prevalent as in, uh, familial adenomous polyposis.

(Interview with Surgical Oncologist, 9 May, 2000)

However, in practice, it appears that CRC and HNPCC are treated the same in the oncology culture. Both are colon cancers and both receive surgery, radiation and/or chemotherapy as the primary treatment regime by oncologists.

The knowledge that oncologists had about the genetics of HNPCC was quite variable. A number of oncology specialists were not clear about genetics of HNPCC:

Interviewer: What do you know about predictive testing for HNPCC?

Radiation Oncologist: Uh, n ... I don’t know. Um, well I ... [pause] Um, I, I suppose I’d, I, I thought I’d heard of the analogy of, um, of breast cancer. Is, uh, sort of first degree relatives, and that sort of thing. Um, but I’m not sure of the strength of that association, or what, uh, things, um, would actually, uh, define it as a, uh, or the criteria for, for saying that an individual has HNPCC. Um, or, and I’m not aware whether there are specific markers for, for that, as opposed to for rectal colon cancers.

(Interview with a Radiation Oncologist, 8 June, 2000)

This particular oncologist is not aware of whether genetic mutations for HNPCC have been identified.
All of the oncologists interviewed were specialists in treating cancer and all of them had experience treating colon cancer. All of the clinicians were queried about their knowledge of HNPCC as well as their assessment of the level of awareness about HNPCC in the wider medical community. This line of questioning was aimed at determining the expected standard of knowledge in the interview group as well as in wider medical community:

**Interviewer:** What, what’s your sense of, uh, um, referrals that you get from general practitioners, um, if, if you do in fact take referrals from general practitioners, or other medical doctors. What’s your sense of their knowledge base around, uh, HNPCC? Is it ...

**Surgical Oncologist:** Um, family doctors, um, I mean, because they just deal with everything, I mean, they probably would be less, uh, educated, to use that word, on HNPCC. They probably would have an awareness that there are familial colon cancers around, alright? But, you know I, I don’t know whether they would know the Amsterdam Criterion to bring

**Interviewer:** Okay.

**Surgical Oncologist:** Uh, general surgeons should, gastroenterologists should. And oncology people should. [emphasis added]

(Interview with Surgical Oncologist, 26 April, 2000)

It appears that the specialists believe that their colleagues are expected to know about HNPCC but that general practitioners are not.

The outer limit of the knowledge for oncologists was relatively easy to identify when the questions strayed from sporadic colon cancer to more specific queries about hereditary colorectal cancer. The knowledge of the oncologists that were interviewed with respect to HNPCC was variable. Some were very familiar with this disease and could list the Amsterdam Criteria for its diagnosis. Others did not know much about it all:
Interviewer: Can you tell me a little bit about your understanding of hereditary, uh, nonpolyposis colorectal cancer?

Radiation Oncologist: Uh, very little. Um, [throat clear] I, uh, have heard of the, uh, hereditary, uh, association. Um, I suppose I’ve heard more of the association with, uh, multiple polyps [presumably FAP cancer] Um, I’m not, uh, fully aware of the, uh ... any markers for, uh ... that may be a variable for that. Uh, the only other thing I can say is in about the year I’ve been with the G-I group, I have only ... have seen one patient who had another family member [throat clear] with a, a colonic cancer. Um, so it’s not something that kind of ... we had any clinical, um, uh, clinical experience of. And, and that, that is, I preface that, I [throat clear] is that I’ve been with the G-I tumor group for, uh, uh, just a short time. And I do a little less than my other colleagues because I actually do a lot of teaching. Which cuts down some of my G-I things. So, my experience isn’t perhaps as representative as, as those that have had a longer ... and seen more patients in time.

(Interview with a Radiation Oncologist, 8 June, 2000)

Other oncologists were aware of the Amsterdam Criteria for diagnosing HNPCC but had not utilized these criteria in their practice. Consider the following example:

Interviewer: So, basically, um, we’re now taping and I just wanted to ask you, uh, just once again, about, uh whether you’ve seen any patients with HNPCC. You don’t, in your experience, that you’re aware of. Is that right?

Surgical Oncologist: I do not remember any patient that I have diagnosed the syndrome in, based on the Amsterdam Criteria.

(Interview with a Surgical Oncologist, 26 April, 2000)

Although this particular surgeon had treated hundreds of patients with colon cancer, the individual was not immediately aware of having ever treated a patient with HNPCC or, more specifically, having treated anyone who had met the specific Amsterdam Criteria. When asked again later in the interview, the surgeon performed mental calculation of epidemiological incidence of HNPCC and concluded that it was likely that they had treated someone with HNPCC. However, for the surgeon, HNPCC is no different from sporadic colon cancer in terms of their perception of their role in the treatment and management of cancer.
The following interview excerpt shows that some oncologists are not very knowledgeable about HNPCC:

**Interviewer:** Are there any particular strategies that you employ to help patients cope with a family cancer syndrome like HNPCC?

**Radiation Oncologist:** No. Um, I see relatively few of them that, um, that are actually, uh, in there. And, and I've always assumed that it's part of what the Hereditary Cancer Program counseling people are doing. Um, I, you know, I, I would tell them that, that, or, I do tell them that they have a higher risk, but that it's usually not inevitable. I mean, even with the, the BR, the breast cancer genes, I mean, it's sort of eighty percent of them will get cancer. Certainly not a hundred. And, uh, lower, I think, with the, uh, HNPCC ones. So there's a tendency for, uh, you know ... to tell them that there is ... the risk is increased, but, you know, it's not inevitable.

(Interview with a Radiation Oncologist, 9 June, 2000)

This passage shows an inaccurate knowledge about the penetrance for HNPCC. The practitioner presumes that it is lower than 80 percent. In fact, the penetrance of HNPCC is 80 percent or higher. This is to say that someone with a genetic mutation for HNPCC has at least an 80 percent likelihood of manifesting colon cancer in their life. Contrary to the oncologist's interpretation, this level of penetrance carries with it a sense of inevitability for most family members. The oncologist also believes that it is the responsibility of the HCP to assume the care of families at risk for HNPCC. In actuality, the HCP does not perceive itself as more than a research program and it does not consider HNPCC families to be its direct responsibility.

Many oncologists did not know much about the genetics of HNPCC. Consider the following passage from an interview with an medical specialist:

**Interviewer:** Can you tell me a little bit about your understanding of HNPCC?

**Radiation Oncologist:** Um, it's a genetically, um, inherited syndrome. Um, where there is a very high risk of patients developing cancer of the colon and rectum at a young age. There's usually, um, a family history of mul, of mut, of multiple, uh, relatives at a young age that gets these cancers. I don't believe the
actual gene, if there is a single gene, has been identified. It’s probably a ... this is probably diagnosed as a f... um, because they work by these Amsterdam Criteria, right? So it’s a bit like diagnosing these rheumatology diseases. You know, you have so many of these criterias, then you fit into it. But in that basket of patients, you, you know, not one of them ... not everybody would be the same, probably. I would think they all have some different genetic changes. [emphasis added]

(Interview with a Radiation Oncologist #2, 9 June, 2000)

The excerpt shows that the oncologist is not aware that several genes responsible for HNPCC have been identified and also suggests that genetics does not have a large presence in the culture of oncology at least as it pertains to understandings of HNPCC.

It is not typically the role of the surgeon to diagnose HNPCC or sporadic colon cancers in many cases. Furthermore, the two cancers, HNPCC and sporadic colon cancer, are seen to be the same from a surgical point of view:

Surgical Oncologist: It is the family history that establishes the diagnosis.

Interviewer: Mm hm.

Surgical Oncologist: I’m, I get referred patients with cancer of the colon.

Interviewer: Uh-huh.

Surgical Oncologist: And the presenting symptoms of cancer of the colon are the same whether it’s a sporadic or a genetic, uh, induced cancer.

(Interview with Surgical Oncologist, 26 April, 2000)

The assumption being made by surgical oncologist is that by the time that they encounter the patient, the diagnosis has presumably already been made and that the family history that would designate it as genetic would have been taken. Furthermore, the surgeon asserts that the presenting symptoms between HNPCC and sporadic colorectal cancer are indistinguishable. The two questions that linger are whether it is true that a diagnosis of HNPCC would have been made before a surgeon encounters a patient with HNPCC and,
if so, who made the diagnosis: a general practitioner, a gastroenterologist, a genetics counseling professional or whom?

In the following excerpt, a surgeon suggests that there is a colon cancer registry at the BC Cancer Agency.

**Interviewer:** So that the number even there, would be suspect, statistically. I’m just interested in, uh, getting a sense of, uh, of that group, and, and, and ...that meet the Amsterdam Criteria. Which itself is, is suspect ...

**Surgeon:** Yeah.

**Interviewer:** As well, because they’re not necessarily clinically ...

**Surgeon:** Yeah.

**Interviewer:** uh, viable.

**Surgeon:** Yeah.

**Interviewer:** Uh, they’re more research, uh, uh, useful for research and, and, based, as you know, on more European data. But ...

**Surgeon:** I mean, you could go to the Cancer Agency, the BC Cancer Agency, and they have a registry of all patients with colon cancer in the province. u, my understanding is that all reports, you know, of the surgery, of the, the, the specimens that are removed from these patients, actually end up in the Cancer Agency.

(Interview with a Surgical Oncologist, 26 April, 2000)

However, there isn’t actually a colon cancer registry that records HNPCC in BC.

Overall, when oncologists were asked more specific questions about clinical surveillance protocols or whether they had treated someone with HNPCC many could not answer these questions with confidence. Some reacted defensively by questioning the relevance, clinically, of distinguishing HNPCC from sporadic colon cancer.

An interview with a expert pathologist in studying HNPPC revealed that there are different protocols for HNPCC and CRC for surveillance (Interview with a Pathologist,
26 September, 2000). However, the interviews with the oncologists for this study did not reveal a firm understanding of the differences between sporadic and hereditary colon cancer. There appears to be a tremendous variance in the knowledge base of oncologists in the medical culture regarding HNPCC, its management and its treatment.

**Incidence of HNPCC in BC**

Many of the oncologists interviewed could not estimate the incidence of HNPCC in BC and most were unaware of whether they themselves had ever treated someone for HNPCC:

**Interviewer:** Um, have you treated, uh, people with HNPCC?

**Medical Oncologist:** I’m sure I have, but I’m, I’m sure I, I don’t ... I haven’t isolated those patients. Um, I don’t think patients are informed of the condition, and, certainly, we haven’t, uh, in the last couple of years, isolated those patients to, uh go on to any type of testing.

(Interview with Medical Oncologist, 23 June, 2000)

The following excerpt supports the observation that most of the oncologists interviewed were not quite sure if they’d treated someone with HNPCC:

**Interviewer:** Have you ever treated someone with HNPCC?

**Medical Oncologist:** Mm ... No. [Laugh] There’s a fast answer. I don’t think so, no.

(Interview with Medical Oncologist, 5 July, 2000)

Most of the oncologists interviewed had not distinguished their treatment of HNPCC and sporadic colon cancer. Certainly, the majority had not kept track of patients likely to have had HNPCC.

However, while the knowledge base of medical practitioners about HNPCC incidence was shaky, there were some oncologists who were aware of the incidence of
HNPCC. The following interview excerpt illustrates that there are oncologists that believe that HNPCC is quite prevalent in the province of BC:

**Interviewer:** Um, yet my sense is that there are about ... should be ... easily fifty to a hundred families.

**Radiation Oncologist:** That ...

**Interviewer:** In the province.

**Radiation Oncologist:** Correct. Um, I mean, we see 2,500 individuals with colon cancer each year. One estimates that, at a conservative estimate, five percent of those are related to inherited, um, mutations. Then you’re looking at 125 individuals who might have a mutation. And, um, I mean, our rough estimate was that there has to be between fifty and a hundred families, um, with mutations. In BC. Um, I think that between medical genetics and the hereditary cancer program, we’ve probably seen, uh, between twenty-five and fifty families. That have been identified.

(Interview with Radiation Oncologist, 12 May, 2000)

This estimate suggests that there are several hundred families living with HNPCC in British Columbia.

**Colonoscopies and Screening Protocols**

The clinical narratives support the report from families that there is inconsistent colonoscopy screening in the province. The interview with the following oncologist offers some support for the idea that screening is haphazardly offered:

**Radiation Oncologist:** I, I think the biggest, um, benefit [of genetic testing] would be to identify individuals in the family who don’t have the family mutation. Because, I think right now, screening is occurring haphazardly in the community. Depending on the index of suspicion of the gastroenterologist, or the, or the surgeon. In offering colonoscopies to at risk individuals. So I think that if we could offer testing, um, and then only screen those who have a mutation, we would probably decrease by half the number of screening colonoscopies that are being done. Um, I ... it seems to me that, um, the families who are being screened are having the col, colonoscopies done every two or three years. Whereas I think they should probably be done every one to two years. So I think that if you’ve got a mutation, we should do them more regularly, and if you don’t have a mutation, we shouldn’t do them at all. Um, so I, I, I ... there may not any cost savings, but I
think the real benefit would be to identify those who don’t have the family mutation.

(Interview with a Radiation Oncologist, 12 May, 2000)

If colonoscopies are offered based on the “index of suspicion” of individual clinicians regarding risk for HNPCC, then there would be a tremendous variation in colonoscopy surveillance because of the variation in knowledge about HNPCC in the physician community.

The interviews with oncologists revealed that there is inconsistent knowledge about screening protocols for HNPCC in the medical culture. Consider the following excerpt from an interview with a radiation oncologist:

**Radiation Oncologist:** [name] dictating, one, two, three, four. You were asking about, um, screening?

**Interviewer:** Yeah. And, and surveillance of colon cancer.

**Radiation Oncologist:** Um, eh, so, surveillance. By that do you mean follow-up of people that have been treated? And, the, um, the, the recommendation at the moment of colonoscopy every two years, um, and uh, and an unclear recommendation as far as I can see about following CMCA. Um, and, uh, I don’t think we do fecal occult tests for follow up, uh, surveillance. Um, at the moment I am uncertain as to how rigorous the follow-up colonoscopy is done. Um, I think there’s a range of surgeons around the province, and, uh, in part, and in part I’m not sure how well we’ve got that message out. Uh, in terms of, um, screening, um, the latest I heard about the haemical test is it’s um, it’s marginal, because, uh, the number of, um, colonoscopies you do and the number of perforations you are going to get from that number of colonoscopies for the number of cases you might pick up, um, and I don’t know of any evidence, uh, comparing screened and unscreened populations. And, um, I think that’s got to be done, really, before you can, uh, put in a, an expensive screening technique. And, and that may be true for the follow-up colonoscopies. Um, they are based on, uh, the theory or prediction from our known, know, knowledge of the natural history. W... that events will occur, and you may pick it up by a colonoscopy. Whether it actually picks up something that translates into a cure for the patient, uh, is, is the question that needs to be answered. Or, I need to find the answer. [emphasis added]
The interview also shows that the oncologist is unaware of studies that examine the
efficacy of screening for sporadic colon cancer. They exist. In fact, an important
longitudinal study comparing screened and unscreened populations has been highlighted
in the College Quarterly, the official publication for the College of Physicians and
Surgeons of British Columbia.

The haphazard employment of colonoscopy screening in at risk families may be
due to systemic factors:

Radiation Oncologist: Yeah. Um, as I understand from the, um, recent G-I
meeting that they had in Australia, um, if you know that there is a mutation in the
family or in an individual, then they should have an annual colonoscopy. And if
they're just a, a person from ... with modified Amsterdam Criteria, then they
should probably have it every two years. But, I think to screen people every three
to five years is not, um, very sensible screening. The interval is too long. I
understand from gastroenterologists that they're not paid. There's no fee
item for screening colonoscopies. So, they can only do a colonoscopy if they
suspect pathology. And so that's, I think, um ... there has to be a shift in the way
the government pays gastroenterologists. Um, for doing procedures. And that's
something that the Hereditary Cancer Program will probably need to look into.
And I don't know how, um ... what's being written down on, on, on the, the
billing card for the screening colonoscopies that are being done. You know,
maybe people are writing down 'bleeding,' or 'polyps,' or, um, some other item
as an indication for, for the colonoscopy. [emphasis added]

(Interview with a Radiation Oncologist, 12 May, 2000)

In other words, if the clinician does not expect to find an actual tumor, then they cannot
charge for the colonoscopy. This observation would indicate that the structure of fee
schedule in BC affects the culture of medical practice. Furthermore, the standard of care
for families at risk for HNPCC appears to be put in jeopardy by this structural
arrangement.

Clinical Narratives about Risks to Personhood

Some oncologists were aware of the unique negative social elements associated
with colorectal cancer surrounding the site of the cancer:
Interviewer: Are there issues that you are aware of, with respect to stigma and colon cancer, that are different from other cancers?

Radiation Oncologist: I think that the reason that there is so little advocacy for colon cancer is the stigma associated with it. It just ... breast cancer advocacy took off ni ... about 1990, 1991, in Canada. And it just became, um, a much easier thing to stand up in a crowd and say, “I’ve had breast cancer. And we should have more money for breast cancer research.” One could ... in meeting and in support groups and things, one could all ... feel, sort of, the palpable sympathy amongst large groups of women. I, I just think it’s so much more difficult for somebody who’s been diagnosed with colon cancer to stand up in a crowd of strangers, you know, and say, “I’ve had colon cancer.” And I, and I ... this is my own opinion. I mean, I haven’t read this anywhere. I just think it’s because we’re, we’re not comfortable talking about bowels, and bowel cancer, and bowel movements, in public. It’s, it’s kind of, not very pleasant. And, um, so I, so I think that’s probably why there aren’t advocacy groups that, that, you know, sprung up ten years ago. I mean, I’m pleased to see, now, that other groups are, are becoming advocates for themselves, like ovarian cancer group, and a colon cancer group was just formed last year. Um, to try and get some money for research. [emphasis added]

(Interviewer with Radiation Oncologist, 12 May, 2000)

This was the only oncologist that appeared to be aware of the existence of a colon cancer support group. The support group had four meetings and then collapsed.

Some oncologists did not appear to be aware of any unique stigma associated with HNPCC or colon cancer:

Interviewer: Oh, I have, actually, one final question, I realize. Is there any particular issue around stigma in colon cancer, that patients experience? That’s different from other cancers? That you’re aware of?

Radiation Oncologist: No, not that I’m aware of.

(Interview with Radiation Oncologist #2, 9 June, 2000)

Other oncologists did not appear to have considered the impact of stigma in colon cancer before the interview but, upon reflection, thought further:

Interviewer: Mm hm. Are there any issues around stigma and colon cancer? That you ...

Medical Oncologist: I don’t think so.
Interviewer: That you think are unique.

Medical Oncologist: Uh, oh, um, [pause] Well, I think, I think you get into issues of ... I mean, I think colostomies ... I mean, colostomy bags, and there's a stigma of having a colostomy bag if you're female, and, you know, a, and, you know, attractive and ... So I think there's a stigma of that. I don't, I don't think so. I mean, obviously, you know, colon is the digestive tract, and if you have colorectal, you know, you're getting rectal exams all the time. Rectal surgery. You can lose your sphincter. So there's a stigma regarding complications of the treatment. But I don't think there's a stigma of having the cancer.

Interviewer: So, there's a stigma around colostomies.

Medical Oncologist: I think so. And, and, and it's, you know, it's the same with, um, I mean, we treat a lot of people with rectal cancer, and with, um ... I mean, they get radiation to their rectal sphincter, so they become incontinent, and there's a whole stigma in society regarding those patients. People with colon cancer, if they're missing a large part of their bowel, have problems with bowel gas, and that's another, sort of, stigma. But, um, I don't think ... it's not like, you know, if, if you have, if you're HIV positive, and you get an HIV cancer, and that sort of stigmatized. It's colorectal cancer not that type of cancer where there's much stigma around having it. It's not like lung cancer and smoking. [emphasis added]

(Interview with Medical Oncologist, 23 June, 2000)

This oncologist makes reference to a number of different unique elements of stigma associated with colon cancer including: the site of the cancer (bowel gas and the implied embarrassment of rectal exams), possible incontinence, the colostomy bag and yet the physician concludes that there is not much stigma associated with it. It is interesting to note that the oncologist seems to think that there is only stigma associated with the colostomy bag if the patient is female. This assertion is not supported by the data collected in the family interviews in this study. The lack of awareness of the negative social elements associated with colon cancer by the oncologists was shocking relative to the threats to personhood posed by cancer that were discussed by patients and family. This may be due to the fact that medical treatment is mainly confined to the removal of
cancer tumors. Oncologists do not appear to concern themselves with the social or family context of disease. A number of medical doctors noted that their patients feared colostomies but these oncologists seemed to see this more as an unfortunate outcome following treatment or cancer (similar to death), rather than as an issue related to personhood.

Virtually none of the oncologists interviewed demonstrated any sense that there might be unique stigma associated with the genetic component of HNPCC. Most of them mentioned that patients had fear of receiving a colostomy bag but they seemed to think that this was a fear of a complication (such as death). Most oncologists did not appear to be aware of issues pertaining to the possibility of social death or threats to personhood. There was, however, one notable exception in the interviews with oncologists. One clinician, a medical oncologist, demonstrated knowledge about elements of stigma that were very specific to HNPCC:

**Interviewer:** Is there a difference, in your experience, in treating a family with a family cancer syndrome like HNPCC and an individual?

**Medical Oncologist:** Well, I guess if the family is very aware that, uhm, you know father had cancer and their mother had cancer, I've got cancer, you know, and so do my brother and sister, it tends to be more emotionally upsetting to them and I guess what their major concern is, uh, most people not so much for themselves but then oh my goodness what is this going to do to my children, what have I passed on that's a worry. Probably in accordance with the possibility of guilt becomes the family, they really get concerned, and what should the children do and these sorts of things but part of the treatment of the individual's cancer is no different as such in fact once you set aside that particular issue. [emphasis added]

(Interview with Medical Oncologist, 7 April, 2000)

This medical oncologist, in sharp contrast to nearly all the other oncologists interviewed, demonstrates an awareness of genetic guilt (shame and guilt associated with “passing
on” a genetic mutation to one’s children). This same clinician also described specific stigma associated with the site of colon cancer:

**Medical Oncologist:** Ya, well your bowel movements. Nobody likes to talk about, you know, your rectum or bowel movements. It’s probably less, the greatest stigma I think tends to be around concern, always, is around cancer of the rectum, whether they need colostomy and that’s the biggest worry.37 Now, if there’s no worry or concern about having a colostomy, then I would think that, at least in my experience, stigma tends to be not a lot different than other, let’s say abdominal and other forms of cancer, you don’t really see and it’s not at the present time although there is dietary information suggesting that diet is related to the infection of bowel cancer it doesn’t have the same stigma attached to the production, you know the etiological issues such as lung cancer38 where smoking, there goes a guy with lung cancer, he smoked himself into this or cervical cancer, which is virally induced, you know, it’s transmitted sexually. You don’t have that with colon cancer, so, but with rectal cancer it’s around the colostomy. People are worried about, uh, how acceptable they’ll be with a colostomy to their immediate, uh, to their spouse or other members of the family and we try and give them into contact someone who’s had a colostomy and with the ostomy nurses right away so that they can realize that life goes on very well but that’s a big problem.

This same medical practitioner also raised the issue of risks to insurance and employment brought about by stigma associated with genetic susceptibility to illness:

**Interviewer:** If the testing were available here, uh, in what way would that change your job? Or would it?

**Medical Oncologist:** Uhm, probably not. I don’t think so. Other than making sure that there was, I mean, obviously, everybody’s discouraged with the fact that we don’t have more funding for more counselors and to deal with the Hereditary Cancer Program. If that’s the proper route we’re all in favour of it. Having said that, I think that’s still the best mechanism for them to go get full information, to get all the pluses and minuses of the testing so that they can make a really informed decision. I really very much, I mean I would be very opposed

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37 This is confirmed in the interviews with patients and families. There appears to be more stigma associated with a change in the way that waste is evacuated (that is a colostomy) than any other issue, even the stigma around operations or discussions relating to the colon or rectum is far surpassed by the stigma of having a different mechanism for waste evacuation. It appears that people would rather risk death than to know for certain that they will have a colostomy and be assured of avoiding death due to colon cancer. Here, the treatment course and plan is affected dramatically by cultural variables, that is, stigma around changing the site of waste evacuation.

38 Here the oncologist is making reference to the cultural blame that might be ascribed to patient for other disorders such as lung cancer purportedly caused by smoking.
personally to referring a patient for testing if they've not had proper counselling. I think that’s quite, you know, this should not be on at all because they don’t all in cases know what they’re getting into. In cases of the rest of the family, you know, what are the theoretical risks to employment and, you know, insurance and all those kinds of things and nobody should go for testing until they’ve gone for counselling. A bit worried about some of the things that go on in the United States for that very reason.

This oncologist was unique amongst those interviewed. Interestingly, this particular oncologist was not associated with the Hereditary Cancer Program.

In general, the clinical narratives did not reveal much knowledge about the negative social aspects specific to colon cancer or to HNPCC. Often, it appeared as though this might have been the first time that the oncologists had thought about the issue. Some clinicians believe that there is an increased stigma with colon cancer due to the site of the cancer, the possibility of colostomy and cultural issues about evacuation of waste. Others believe that colon cancer was no different to any other cancer. Cancer, for many of the oncologists interviewed, is cancer. Cancer has a homogenous negative side to it. Still others feel that colon cancer had less socially damaging aspects associated with it. They cite three reasons: the survival rate can be relatively high, people don’t see the cancer (it is hidden) and the functioning of the body can proceed relatively normally. Virtually none of the clinicians demonstrated any knowledge of negative side to the hereditary or genetic component of HNPCC.

With respect to support groups for people living with HNPCC or CRC, the oncologists seem to be relatively unaware of possible patient psychosocial supports. As a rule, they do not know why there is not a support group. Many believe that there is such a group. With respect to stigma and psychosocial support issues pertaining to HNPCC

39 Interestingly, this oncologist understands that there is a definite difference between genetic testing and genetic counselling and that these are intended by system designers to go hand in hand.
and CRC, the oncologists interviewed appear to limit their analysis of colon cancer to clinical issues and do not incorporate social variables.

**Clinician Knowledge of Prophylaxis and the Threat to Practical Consciousness Posed by the Colectomy and the Colostomy Bag**

One of the most consistently reported sources of stigma regarding HNPCC from families related to the possibility of receiving a colostomy. Most of the oncologists interviewed recognized that the colostomy was a source of great fear and shame for family members:

**Interviewer:** Are there any, um, common fears that patients have, that come and see you? With colon cancer?

**Radiation Oncologist:** Um, preoperatively, they’re worried they’re going to end up with a colostomy. Um, postoperatively ... and, and the uncertainty as to what the disease is going to be like. Because at that stage, it’s a, it’s often not quite clear how extensive the disease is. Uh, postoperatively, uh, you know, they want, they don’t want it to come back. They’re worried, sometimes, about, um, sexual function, or, or those sort of things that ... some of the complications of surgery and, and or radiotherapy. They’re obviously, presumably, worried about dying. But they often don’t express that.

(Interview with a Radiation Oncologist, 9 June, 2000)

Some oncologists appeared to downplay or minimize the stigma associated with colon cancer:

**Interviewer:** Just uh on a different uh vein I am wondering if you can tell me a little about stigma and colon cancer and what um what experience you have in in dealing with patients around the issue of prophylactic surgery and and stigma...

**Surgical Oncologist:** Yeh um the my the biggest area that I am involved with in that is breast cancer which of course we do have breast cancer families with with defined high risk and uh I’ve have done a number of prophylactic mastectomies with immediate breast reconstruction and and um uh stigma well I I don’t know I think the the thing that that motivates uh these women is is just fear because they had so many in their family who had cancer of the breast and so many of them have die of it that you know they couldn’t care less [chuckle] if they had their breast back in fact they talk me into it sometimes I mean you why wouldn’t you just go with mammography and screening and that sort of thing and they say I well you know I I dream about having breast cancer every night of the
This clinician appears to be arguing that colostomy is not actually a very stigmatizing issue and that fear of cancer is a more powerful force in the lives of patients than their uneasiness about stigma about the site of the cancer. The interviews with family members in this study did not provide widespread support for this clinician’s assertions. It appears that the possibility for a colostomy bag is of mammoth significance to patients and people at risk for HNPCC.

Some of the family members interviewed suggested that they would rather risk a less efficacious surgery (taking out less of the colon) than receive a colostomy. The question of whether the stigma of colostomies could influence patients’ decisions regarding treatment was explored with the oncologists. The issue received mixed responses from the clinicians. Some felt it important to assert that their treatment choice could never be influenced by patient preferences. Others, argued that this was unlikely because the surgeon and the patient share the same goal (to avoid a colostomy).
Others weren’t so sure about the autonomy of treatment from stigma and suggested that it was definitely possible for patients to opt for a less efficacious treatment based on the stigma of a colostomy:

**Interviewer:** Um, do you think it’s possible that worries about stigma and worries about that issue could essentially result in people choosing a less efficacious treatment plan?

**Radiation Oncologist:** Ab, absolutely. And I think that when one ... the time for doing a prophylactic colectomy is probably when somebody is in their thirties. Which is really when someone is in the prime of their life. Um, might be still seeking new relationships. Um and it’s a very, very difficult, um, thing to have done. That, I mean, a ... I, I’m sure having a colostomy at any time in one’s life is not an easy decision. Um, but perhaps when one is sixty years old. You know, when you’ve, and you’ve been in a stable relationship for a long time, um, that it’s much less, um, of a psychological worry than when you are very young. Um, and, and just in terms of intimacy, in terms of sexual relationships and so on, I’m sure it’s very embarrassing.

**Interviewer:** It’s an interesting example of possibly seeing stigma affect life changes.

**Radiation Oncologist:** Mm hm.

**Interviewer:** Or, in a more clinical sense, I guess ...

**Radiation Oncologist:** Mm hm.

**Interviewer:** Life expectancy.

**Radiation Oncologist:** Mm hm. It ... I mean, I ... you know, I, I would think that [sigh] um, somebody having a colostomy for prophylaxis would have to be in a very stable relationship. Um, with a long-term partner. I mean, I think it’s a completely different situation if you’re twenty-five years old and you’ve had colon cancer, and you’ve had to had, and you’ve had to have a colostomy. Um, to treat your cancer. Um, because I think that that’s information one might disclose differently, um, to um, partners that one might meet on a social, sort of, basis. And, and somebody you go out with. Um, but I think to, to make a decision to have it for, um, prevention, I, I, I think is, is far more difficult.

(Interview with a Radiation Oncologist, 12 May, 2000)

The oncologist also comments on the notion of prophylactic surgery in HNPCC. With a few exceptions, the clinical narratives suggest that the possibility of prophylactic surgery
in the case of HNPCC does not appear to have become a part of the clinical culture. This is in marked contrast to the other form of hereditary colon cancer, FAP, where prophylactic surgery is regularly employed.

Questions about prophylactic surgery and colostomy were of paramount importance to many of the patients who were interviewed but the importance of these issues for the oncologists varied immensely in the interviews. Often, it appeared that the consideration of whether to perform a prophylactic surgery in the case of an individual at high risk for HNPCC had been first considered by oncologists when asked in the interview. For others, the issue was one on which they had clear opinions:

**Interviewer:** ... So, then, uh, in that, in case, uh, would it be fair to say that the, uh, the, the role of the surgeon doesn’t necessarily change that much whether or not it’s an HNPCC or whether it’s a, a sporadic?

**Surgical Oncologist:** Uh, It does change a little bit. Because, uh, if the pers, if the patient presents with no history of a familial polyposis, right, the extent of the surgical resection changes with HNPCC...uh, you should think about doing it a little bit more extensively, right? Because you know there’s a genetic predisposition for recurrent cancer so that, uh, uh, surveillance after the surgery is made a little bit easier and perhaps the risk is a little bit less for the patient if you remove more of the colon at the original surgery, right?

**Interviewer:** Okay.

**Surgical Oncologist:** If I knew that the patient had HNPCC, then, uh, it’s possible that, particularly in women, you would also think about doing something else like a hysterectomy or something else that would also be high risk of becoming cancerous if the patient was at the right age to be giving up that organ. [emphasis added]

(Interview with Surgical Oncologist, 26 April, 2000)

This surgeon would consider a prophylactic hysterectomy (or something else that might become cancerous) with HNPCC. It is interesting as well to note that the surgeon also describes that more of the colon might be taken out in the case of a patient with HNPCC.
The question that a clinician might choose a more aggressive surgery in the case of HNPCC was something that family members at risk for HNPCC also wondered about. In particular, families were interested in this issue for two reasons. Firstly, echoing the clinician's reasoning they wondered about taking out more rather than less colon in order to avoid recurrence. Secondly, at risk family members also thought about opting for less aggressive surgery in order to avoid at all costs a colostomy even if this meant a higher chance for the recurrence of cancer. This second concern was one against which an oncologist reacted strongly and appeared mildly irritated with the interviewer for implying the possibility of social variables influencing invariable clinical judgment:

**Interviewer**: Just on an issue, uh, around stigma and colon cancer, um, that I've been just starting to get a sense of is, is that one of the things that some patients have said, and in one case the one oncologist that I've interviewed is that patients are really concerned about, uh, having to have a colostomy bag.

**Surgical Oncologist**: Uh-huh. They

**Interviewer**: And just on that note around, um, essentially, sort of, um, somewhat of a proactive surgery or a prophylactic surgery, if you take out a little bit of extra, um, uh, of the intestine for example, or the bowel, um, I'm wondering, just since I've been interviewing some, um, some patients, do you think it's possible that some patients would rather take out less of the bowel in order to avoid having a colostomy bag and ...and where it might not even be, where it might even be less curative to do that? Or? Do you follow my question?

**Surgical Oncologist**: Um, if I'm treating a cancer, the cancer has to be adequately treated period [the period here is delivered with strong emphasis by the respondent].

**Interviewer**: Uh-hum.

**Surgical Oncologist**: With or without a colostomy. Alright?

**Interviewer**: Uh huh.

**Surgical Oncologist**: It's not very often nowadays that we have to make a permanent colostomy. For colon cancer. For the actual cancer. The cancer that
requires a form of colostomy really is within a very short distance of the anal sphincter muscle ...

Interviewer: Mm hm,

Surgical Oncologist: At the bottom. Otherwise you can preserve that sphincter and still reconstruct the intestine, okay?

Interviewer: Okay.

Surgical Oncologist: There's not many patients that require a permanent colostomy for colon cancer. Uh, it's only those that, that have the cancer right at the very bottom of the, of the sphincter. Okay?

Interviewer: Okay. [emphasis added]

(Interview with Surgical Oncologist, 26 April, 2000)

When the clinician was queried about patients opting for less aggressive surgeries to avoid a colostomy the surgeon wished to show that this decision was the surgeon's and not the patient's. Furthermore, the decision about extent of surgery was made on the basis of clinical judgment and was not subject to the vagaries of patient preferences or worries about stigma. Ultimately, however, the practice of prophylaxis or the consideration of this intervention has not consistently penetrated the clinical culture of oncology in the treatment of HNPCC in British Columbia.

There is not an indigenous reality with respect to medicine. Medicine is a culture, and as such, it is subject to changes in the climate of implicit and accepted values of its members. The evidence-based and scientific approaches are languages utilized by clinicians to convey their culture; they do not represent an indisputable reality or higher order of factual data. Evidence in support of this observation is seen in the example of prophylactic surgery for breast cancer. In the course of this study, I have observed the merits and drawbacks of this intervention hotly debated amongst clinicians. Yet, while the undisputed merits of prophylactic surgery are not widely accepted throughout the
culture of medicine many clinicians believe that there is a clear clinical answer for this issue. The following excerpt shows how a particular clinician believes that prophylactic mastectomies prevent breast cancer:

**Interviewer:** What is your sense of physician’s knowledge of [....] generally, like GPs and such, of hereditary, um, cancers like HNPCC?

**Surgical Oncologist:** Uh, very, uh, I think very minimal. Very minimal. Uh, they’re aware of things, but I don’t think, uh, you know, GPs are really up on it. I mean, I know for myself. I try ...I look for it a fair amount, and still. So I try and, and, and remember and stuff. But it’s really ...you don’t, you just don’t, you usually don’t see it on a regular basis, so it’s very hard to say, uh, how familiar with all the applications and ins and outs of it, you know, I think ...

**Interviewer:** And just one clarification on that. In what way could genetic testing save lives? You mentioned it could potentially save lives. With that information.

**Surgical Oncologist:** Oh, well, in a ... for instance, uh, for breast cancer. Uh, you know, that, uh, prophylactic mastectomies will definitely, uh, prevent breast cancer. Not a hundred percent, but close to it. And, uh, the same would go for colon cancer. So it could possibly draw attention to, uh, I mean, you know, patients who are positive could potentially have more frequent and earlier screenings. Hopefully they check out. And, uh, uh, either get cancers at an early stage or remove them in [ ... ] or deal with [ ... ] polyps. [emphasis added]

(Interview with a Surgical Oncologist, 9 May, 2000)

The clinician also believes that prophylactic surgery in HNPCC would prevent colon cancer. In contrast, the following clinician provides a less optimistic view of prophylactic surgery:

**Radiation Oncologist:** Ab, absolutely. I, I ... my only concern is that we don’t overestimate the benefits of surgery. I think that clinicians, I think, can influence the choices their patients make. And I think it’s important not to be paternalistic. And, so, what I try to do is guard against clinicians saying, “You must have your colon removed.” Or, “You must have your breasts removed. To do, to decrease your risk. Um, because you can decrease your risk by ninety percent.” I think that there are many issues that go into making a decision regarding prophylactic surgery. And I think we should only present the medical information, as we understand it today. And tell patients what the pros and the cons are. And not present a one-sided view. I think that, in terms of prophylactic mastectomies, that a lot of the benefits have been overestimated.
And the reason for that is, I think, that there were a lot of women who weren’t at the highest risk, who were at moderate risk, who, because of fear of breast cancer, went and had what I probably, what I believe to be unnecessary surgery. So, I think we, we should continue to keep a very open mind about which individuals might benefit from surgery, and evaluate that data constantly. And, um, I think we should fully discuss the pros and cons of surgery with patients, and let them make up their own mind about which, um, path they want to do. But I think we should guard against saying that, you know, “There is irrefutable proof that if you had this surgery, you would live longer.” Un, until we have that information, um, that’s not a viewpoint we should give to patients. [emphasis added]

(Interview with a Radiation Oncologist, 12 May, 2000)

In contrast to the surgical oncologist presented beforehand, this clinician is much more cautious with respect to the benefits of prophylactic surgery in breast or colon cancer.

**Institutional and Systemic Arrangement of Health Care**

The clinical narratives appeared to show that the standard of care in BC, at least with respect to HNPCC, is ordered by institutional and systemic arrangements. In the case of HNPCC, if a genetic testing service does not exist where an oncologist can make a referral, then in many ways HNPCC is not a part of clinical reality. This point of view is affirmed by a radiation oncologist:

**Interviewer:** What are patients being told right now about, uh ... HNPCC families that are likely to have a mutation for HNPCC? Based on the Amsterdam Criteria, or a modified version?

**Radiation Oncologist:** Um, f, for a long while, the, the gastroenterologists have ... just told them that they were at increased risk. Um, but because genetic ... the, the laboratory testing in fact has not been available in BC, um, people haven’t taken it further than that with families. So, they haven’t said that testing is available, um, elsewhere. Or might become available. In fact, families have just been advised that, yes, you know, colon cancer seems to occur commonly in your family and is probably due to inherited risk. And then the discussion is ended at that point.

**Interviewer:** Has it ... at that point likely mentioned the words HNPCC, or is it just, “You have a strong family history”? In your view?

**Radiation Oncologist:** [Breath intake]
Interviewer: People are actually discussing ...

Radiation Oncologist: I ...

Interviewer: HNPCC with people.

Radiation Oncologist: I think it’s unlikely, um, that HNPCC is being discussed with families. Because I think the, the, the knowledge, um, might not be ... is certainly not available to family physicians. Um, gastroenterologists and gastric surgeons, um, might be able to discuss it. Um, in more detail. Because I, I mean, I, I remember going through medical school and certainly learning about Lynch Syndrome. I mean, we knew it was one of those genetic syndromes out there. So, the knowledge is, has been out there, vaguely, for a long while.

(Interview with Radiation Oncologist, 12 May, 2000)

The clinician suggests that because laboratory testing is not available, it is likely that the clinical management of families is being excluded from the orbit of medical practice. By suggesting that families are not likely being told that they have HNPCC, this interview excerpt raises questions about disclosure of cancer and HNPCC diagnoses. These questions will be discussed in the subsequent section.

The fact that limited genetics counseling is available for families with HNPCC does not appear to reliably stimulate oncologists to follow this disease. Many interviewed did not actually know whether they had ever treated someone with HNPCC. It may be that the availability of a testing program would increase the level of clinical interest in following HNPCC. The following interview suggests that oncologists recognize the need to follow families with HNPCC:

Radiation Oncologist: ... I mean, I think the, the set-up of the other counsellors, um, is good at the moment. Um, because they can, can take that on and, and follow up with that at another time. Um, and again, I think in, in the future, what I expect to do as an oncologist is know about that. Because they can talk to them about the treatment and the prognosis, I surely ought to know about the risk factors for their family. And again, I think it’s uh, um, I think it’s something that [pause] needs to be addressed, uh, in a recognized group. Um,
and that at the moment we have uh ... and a recognized group of patients who are in ... and at the moment we have a, a program beginning that, that can address that. [emphasis added]

(Interview with a Radiation Oncologist, 8 June, 2000)

The clinician’s interview raises an interesting question: what would it take to recognize the group? It is almost as if HNPCC does not exist without a testing program and specific resources dedicated to its detection, surveillance and treatment. At the very least, it is not currently being uniformly tracked and its risk in families is not being consistently clinically managed.

As a rule, oncologists reported that they focus their time with patients on the very specific management of disease. A number of the oncologists interviewed felt that patients do not retain very much information from medical sessions so they omit information that is complex. The following interview excerpt illustrates this point:

**Radiation Oncologist:** ...If, um, they ask me a prognosis ... uh sorry, I should say, if I think, uh, the, the treatment has a chance of cure, I will state that first. And say, “The treatment is aimed at and expected to cure.” And, uh, of course, that’s never a hundred percent. If they ask, um, or I try and ex ... have to explain the prognosis, um, I try never to say, “The five year survival is x percent.” Um, because, um, some of the medical profession don’t actually understand what that means. Um, patients certainly don’t. Patients will, I think, very qui ... frequently pick up the time that you mention, and say, “That’s how much I have got to live.” So, if I said, for instance, where there is cancer of the bowel, that, um, uh, say, “In any cancer of the bowel, eighty percent of patients were alive five years,” I think it’s quite common that that patient would say that they’ve been given five years to live. Uh so, I always try and say, “If I saw ten patients like you, if there were ten in this room, only five would be alive, or eight would be alive, or two, in so many years.” And that I can’t, for you as an individual, say what’s going to happen. But that’s the risk. Uh, like if you go in an aeroplane, the risk of that crashing is that number out of a thousand flights, or five thousand flights. Uh. One has a, a minor problem. [emphasis added]

(Interview with a Radiation Oncologist, 8 June, 2000)

This clinician is so sure of patients inability to retain and understand clinical information that they do not provide statistics about long term survival rates.
The following excerpt from an interview with a radiation oncologist suggests that providing information about genetics (i.e. HNPCC) is the job of someone else and that typical clinicians do not have the time to provide more than “mechanical management” of disease:

**Interviewer:** What kinds of things would you discuss with the patient? With colon cancer?

**Radiation Oncologist:** [Breath intake]

**Interviewer:** In light of that ... the way that you’ve described that [pause] role as it’s practiced here?

**Radiation Oncologist:** Um, on the whole, um, I don’t discuss enough. Uh, we have about an hour for a patient interview. Um, and ... I don’t know whether it’s just the ... uh, current ... I think it’s more than the, the kind of, um, [pause] expansion of knowledge, or the availability of, uh, information to people. It’s, uh, that we are being much more suitable in, in explaining what’s happening to patients. Uh, and I think, uh, in the past here, and certainly in the past in Britain, there was, um, uh, a general acceptance that, uh, when the doctor said, “You’re going to have an operation,” you said, “Thank you very much.” And there are still patients who are quite prepared [throat clear] and it’s their wish that you’re the expert. If they develop a suitable rapport with you, they say, “You tell me what to do, doc.” And they may even say, “I really don’t want to know the details.” Um, but they will, they will hand over that [throat clear]. Uh, and I think some of them will do that freely. That, that’s that really is what they wish. Um, most patients need to know more than that. Uh, some of them need to know an enormous amount. Um, even if you had more time in a given session, they ... I doubt any patient could absorb most of what they feel they want to know in one sitting. And we certainly have no allowance for subsequent sittings or explanations. And, uh, to come back perhaps to what is more pertinent for you, this is just trying to tell them about what’s gonna happen next week, and the week after. About what I can do for ... the mechanics of doing for them. Um, this doesn’t touch on their mental welfare. Really, I suppose answering their questions uh, and giving explanations helps to a degree, but, uh, uh, we don’t touch some of the other stuff; uh, really.

And in, in terms of counseling beyond that, um, uh, that’s difficult. I actually came across, eh, the first patient for quite some time who I think may need, um, uh, some guidance, or their family may need some guidance, because, uh, she is admittedly one of fifteen children. Um, but she does have quite a strong history of, um, breast cancer and lung cancer in the family. And, um, my [throat clear] situation is that I actually spend all my time, uh, trying to adequately answer questions and explain uh, uh, the, a relatively finite area of
mechanical management. Uh, and this person, you know, once I introduced it later, um, uh, I would refer on to, uh, the hereditary group for counseling...

[emphasis added]

(8 June, 2000)

The clinician suggests that the fee structure of the system does not allow for extra sessions for providing information (more explanations such as HNPCC) or for addressing the "mental welfare" of patients (presumably the clinician is referring to counseling here). The institutional and systemic arrangement of health care is such that oncologists are not funded to do counseling or to provide information about genetic disease even when it is genetic disease that they are treating. This responsibility for addressing the "mental welfare" of patients and for providing genetics information about HNPCC was universally thought by the oncologists to be the responsibility of the HCP.

Many of the family members interviewed in this study appeared to be struggling with profound issues such as concern about the possibility of death due to their illness:

Interviewer: Do most of the people ... just the way you're describing that .. have some sense of death being present in their lives? Or is it usually ...

Oncology Nurse: Oh, I would think so. Yes. Yeah.

Interviewer: Okay.

Oncology Nurse: Uh, and again, some, some people talk about it openly, and others don't.

Interviewer: So essentially, the way you see it from your experience, is that death is present somehow in their lives. The possibility of it.

Oncology Nurse: Mm hm.

Interviewer: They choose to talk about it in different ways.

Oncology Nurse: Yeah. Yeah.

Interviewer: Or not to talk about it.
Oncology Nurse: Yeah. Yeah.

Interviewer: Or to deal with it in different ways.

Oncology Nurse: Yeah. I don’t think anyone can have a diagnosis of cancer and not think about death.

(Interview with Oncology Nurse, 18 October, 2000)

The excerpt below echoes the observation that oncologists are aware of concern people faced with cancer have about the possibility of death:

Interviewer: What is the biggest fear of, of patients, in your experience?

Radiation Oncologist: Death.

Interviewer: With colon cancer. Death?

Radiation Oncologist: Every patient that comes into your office thinks they’re going to die, until you tell them they’re not. I was taught that early in medical school. A patient comes in with a nose bleed, they might think they’re going to die, until you tell them they’re not. Any, any illness, the reaction is, it’s a threat to life. I mean, there happen to be other immediate concerns, like all the toxicities of treatment. All the fears of the treatment, as well. But, death. Mortality.

(Interview with a Radiation Oncologist, 8 June, 2000)

The same medical practitioner comments below on how the health system does not allow for enough remunerated time to provide more than the most basic information about medical procedures:

Interviewer: Do you discuss, ever discuss, uh, death?

Radiation Oncologist: Yes. Um, I only discuss, discuss death when the patient asks. Um, um, and I ... by that, I mean, uh, [sigh] really in answer to the patient saying, “Is, isn’t this a painful terminal disease?” Or, “How will I die?” Um, it’s brought up in terms of prognosis, that, you know, only, only two, uh, two out of ten will, will have died by the five years. Um, but I, I talk about death in terms of, uh, eh, what’s the commonest risk. And, so, with bowel cancer, uh, the commonest risk may be hepatic metastases, uh, and local recurrence. And, um, we describe that, uh, in the terms of the clinical illness. Uh, that may occur. That, uh, if the liver is damaged, uh, it interferes with the chemistry of the body. It interferes with their eating. Uh, and it, it is a, a progressive deteriorating illness. Um, often I have to try and reassure them that, uh, cancer is not inevitably
a painful death. There, there is pain, if you like, associated with illness, or
discomfort with illness. Distress. But not necessarily pain.

Um, I am ... [telephone ring] beyond that, um, I don’t [ring] I don’t very
often, um, [ring] have the opportunity or am requested to talk about death in the
context [ring] of the individual patient. Um, uh, that um, what it means to them,
what their concerns are for their family beforehand, uh, that, um, that’s rare that
patients will talk to me about that. And it’s, it’s rare that, that I am in a position
of bringing that up. I don’t know whether I should more often. I try and offer
patients the opportunity as much as possible to ask questions, talk about their
worries or concerns, um, but I may see these patients for a very small portion of
their, um, of their disease. I see them for an hour, I probably talk to them
for perhaps half an hour in the first session, see them on treatment. Uh, and
really I’m looking at very specific things to make sure the treatment’s all
right. And there’s some opportunity for discussion, and then see them in a
short follow up clinic. And then not see them. [emphasis added]

(Interview with Radiation Oncologist, 8 June, 2000)

The clinician conceptualizes the role of radiation oncologist in terms of their relationship
to a portion of the disease process in a patient.

**Disclosure of Cancer**

Medical anthropologists have noted geographic differences in the culture of oncology, in particular with respect to the practice of disclosure of cancer diagnoses (Gordon and Paci, 1997). In some regions in the world, patients are simply not told that they have cancer even though the clinician has diagnosed a cancer, members of the immediate family are aware of the diagnosis and the patient eventually dies of the disease. The clinical narratives gathered in this study reveal that the practice of not disclosing a cancer diagnosis to a patient occurred in the relatively recent past in BC as well:

**Interviewer:** Okay um does the presence of of a strong family history um for colon cancer affect the role of a surgeon typically or does typically in keeping with that one patient um and it does your role expand with that family ...

**Surgical Oncologist:** Oh it doesn't expand it ugh you know I think any time you have a patient with cancer you're always dealing with the family anyway ugh with this there's the added concern that the family members you know the the blood
relatives in the family would also you know might come under your [light chuckle] under your knife at some time or another if they they prove to have some abnormality. So sure there's a there's some some expansion but we're always dealing uh you know we seldom deal with uh let me put it this way we seldom deal in isolation with a patient with cancer. You're always having effects of the family the family is always there anyway nowadays. When I was training you know um the stigma of of cancer was such that a lot of people say don't tell mom what she has I mean you can't believe that but that's what happened and so we were instructed by families not to tell mom or dad what the diagnosis was which was clearly an absurdity but so we come [chuckle] a long way in that regard.

(Interview with Surgical Oncologist, 3 May, 2000)

Although the question is aimed at examining the extent to which the physician sees the family as an object of clinical responsibility, the respondent interprets the question in a different direction and appears to understand the family as a barrier to treating the individual patient. This interpretation leads to an unintended discovery as the clinician describes the practice of not disclosing a cancer diagnosis in the not too distant past of his practice. Another clinician interviewed in this study suggested that this practice may still occur in today:

Interviewer: Just as an interesting aside, you’re probably well aware of this, but, there’s some literature in the medical anthropology world that talks about how some oncologists don’t dis ... actually disclose cancer diagnosis ...

Medical Oncologist: Mm hm.

Interviewer: In some parts of the world.

Medical Oncologist: Yeah. That is interesting, and I, I think, as a ...

Interviewer: Except to family members ...

Medical Oncologist: Yeah.

Interviewer: But not to the patient.

Medical Oncologist: Yeah, and ... but that’s still very common in some cultures. That, um, the Chinese community, um, I’m trying to think what other communities that that’s happened to me. Um ...
The clinician describes how disclosure of cancer diagnosis does not always occur and that this practice is a choice that should be respected. In this example, the clinician is definitely expanding the focus of their treatment beyond the individual patient to include the family dynamics. Presuming that the clinician is providing treatment to the individual with the cancer diagnosis, this flies in the face of more customary ideas about informed consent in individual patients. However, the practice of not disclosing diagnosis was not confined to these limited examples. It appears to be practiced widely in the culture of oncology when it comes to HNPCC.

**Disclosure of HNPCC diagnosis**

The oncologists interviewed, as a rule, stated that they would not and did not disclose a diagnosis of HNPCC to their patients, even when they suspected it:

**Radiation Oncologist:** ...Uh, and this person, you know, once I introduced it later, um, uh, I would refer on to, uh, the hereditary group for counseling. Um, this patient ... it uh, uh, is a, a, an interesting, um, individual, where the management of her disease is frightening to her. And I specifically elected not to raise the problem that this may actually have an impact on your children and, and uh, and, and siblings, at that stage. Because, um, she was actually overwhelmed, uh, to a degree by the information of that. I think it’s another example where [throat clear] you need, actually, several sessions to be ... to approach what we think is ideal. In some patients. Uh, in ... perhaps in most patients, even beyond that... [emphasis added]
(Interview with a Radiation Oncologist, 8 June, 2000)

In the above example, the medical doctor describes deliberately choosing not to tell the patient about risk of HNPCC to her and her children. The following interview supports the observation that families are not being told about HNPCC by oncologists:

**Interviewer:** Do you, do you discuss, actually discuss HNPCC with patients? Or do you discuss strong family history?

**Radiation Oncologist:** Um, it depends what they’ve got. Um [pause, sigh] I don’t go HN... I don’t mention HNPCC by word. Definitely not. Because it’s the sort of jargon that’s confusing for them. For people. So, I... if, if I am talking about it, I, I say that we’re, you know, you can identify a group of patients that have a hereditary predisposition to colon and other cancers. So, I mean, I’ve talked a bit like that. And that your family history is strong, and you should, we should get you in touch with the Hereditary Cancer Program, just because it’s going to be important for your relatives.

(Interview with Radiation Oncologist #1, 9 June, 2000)

The finding that oncologists do not disclose a diagnosis of HNPCC to patients was widespread throughout the interviews with oncologists:

**Interviewer:** Just a couple of final questions. One, do you actually discuss or have you discussed with patients, HNPCC? And called it that?

**Radiation Oncologist:** No. Well, I mean, I tell them that, you know, like the, like I said, the ones that have a very strong family history, I say, “There’s probably a hereditary component to this.” And then I send them off to the, uh, hereditary cancer people I don’t really spend a lot of time talking about it at all.

(Interview with Radiation Oncologist #2, 9 June, 2000)

Although there were exceptions, it appears that the standard of practice in the culture of oncology is not to disclose a diagnosis of HNPCC to patients but to leave this task to the HCP:

**Interviewer:** So, essentially, um, of the people that you’ve treated that might ...

**Medical Oncologist:** Mm hm.
Interviewer: Out of that large group, that might actually have HNPCC, um, these people wouldn’t actually be told that they have HNPCC. It would just be that you would identify a strong family history and refer them to ...

Medical Oncologist: Exactly.

Interviewer: The Hereditary Cancer Program.

Medical Oncologist: Exactly. Yeah.

Interviewer: Okay.

Medical Oncologist: And I, I mean, I had done that already.

Interviewer: Mm hm.

Medical Oncologist: Um, there’s about a, I guess eight months to a year waiting list. Um, you know, to see the genetic people. They’re more than counselors. They’re made up of an, an entire group, and, um, I think there’s a radiation oncologist on that group, but they’re people that are interested and, and knowledgeable in that field. [emphasis added]

(Interview with a Medical Oncologist, 23 June, 2000)

This means that in practice patients will have been treated for a disease but will not be given the official diagnosis until sometime after the treatment. The delay between treatment and disclosure diagnosis depends on the time taken to obtain an appointment at the HCP which could take anywhere from six to eighteen months (assuming that the patient follows through on the referral). By not disclosing the diagnosis of HNPCC, this may signal a departure by oncologists from traditional bio-ethical principles that firmly establish the idea of informed decision making and needlessly delaying the inevitable process of research on HNPCC by families.

Oncologists would certainly talk with their colleagues about HNPCC, but would not, as a rule, disclose the suspected diagnosis with patients or families. There were a number of reasons provided for this lack of disclosure such as the belief by oncologists that it was not their responsibility (or their area of expertise) to diagnose HNPCC. What
this means in practice is that families are not told about HNPCC until they meet with the HCP which may be anywhere from six months to several years once the referral has been made. This means that families are left to rely on their own sense about an inherited disease in their family. The families, who are hungry for information, appear to be left in the dark by the practice of not disclosing the suspected diagnosis of HNPCC.

**Sharing Information: Different Narratives**

Clinicians employ different narratives for patients and colleagues. This applies to both the sharing of medical information as well as genetic information. The clinical cases presented in the Gastrointestinal Tumor Group were primarily narratives for colleagues. They contained highly technical information, candid assessments of prognosis, and consideration of personal factors in the lives of patients. They typically begin with a description of personal factors about a particular patient, such as: “Mr. Smith is a 48 year old male, a former longshoreman with a wife and three children”. They also comment on personal factors that they believe to be clinically relevant. For example, in one GI Tumor Group case conference, the group was examining a case about a man who had a number of medical problems including a failing liver. When asked about the possibility of a liver transplant, the presenting physician quickly noted that this individual had previously been the President of a local Legion and was therefore an unsuitable candidate for a liver transplant. The group concurred and moved on to the next case. Presumably, the significance of the patient’s involvement in the local Legion (a drinking establishment) is that alcohol use associated with this role counts against his
candidacy for a liver transplant. This example appears to provide an example of the soteriological components of the clinical culture as seen in the GI case conferences.

The same clinician, however, would likely discuss HNPCC as part of a narrative to a different audience, that of fellow colleagues at the GI Tumor Group:

**Interviewer:** If... just coming back to an earlier question, if you were discussing, um, with a patient... and this is obviously a hypothetical question. Discussing, um, a patient’s diagnosis and their treatment course, who was likely to have HNPCC...

**Medical Oncologist:** Mm hm.

**Interviewer:** And you’re thinking, okay I’m going to refer them to the Hereditary Cancer Program, but you’re, you’re telling them that they have a strong family history that looks like it might be one of these family cancer syndromes, would you... if you were presenting that to, say, your colleagues at the G-I tumor group or something...

**Medical Oncologist:** Mm hm.

**Interviewer:** Would you discuss HNPCC with them? Would you say, “And it looks like it might be HNPCC, to me.”

**Medical Oncologist:** Yeah, I think that that’s something that, um, would be of interest to the group, and that would probably come up. The other question I would have in my mind, was, would be, is this somebody who needed to be followed, um, not by the family practitioner, but should they be followed here at the Agency. Should my follow-up be somehow different for this patient than for other patients. And, um, as I’ve not encoun... I’ve not encountered that yet, I probably would want to present it, and see what my colleagues thought about that [emphasis added].

(Interview with a Medical Oncologist, 5 July, 2000)

This illustrates clinicians provide different narratives for different audiences. The Medical Oncologist would likely discuss HNPCC with expert clinicians but would probably not discuss it with patients. It may be possible that patients are not perceived by oncologists to have enough cultural (and linguistic) capital to receive information about

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40 Good (1996) asserts that medical encounters between patients and physicians contain a soteriological component (principles of salvation and morality).
HNPCC. It may also be the case that physicians are acting in accordance with a paternalistic orientation where they seek to avoid heightening the sense of uncertainty and anxiety of the patient by disclosing their suspicion of genetic susceptibility.

**Family History and Diagnosis**

The roles and responsibilities of oncologists are constrained by institutional arrangements (in the BCCA for example) as well as by the disciplinary conventions of their field. Of note here, there are two carefully defined areas in the culture of oncology, that is, the taking of the family history and the diagnosis of cancer itself, that are pertinent to understand the handling of HNPCC. The surgical oncologist, as a rule, does not take family histories or make the original diagnosis of cancer:

**Interviewer:** Do family histories tend to be taken by, uh, the general practitioner? Or, would the family history be ... at what point ... who would actually tend to take the family history for something like that? Had a strong, uh, family history for colon cancer?

**Surgical Oncologist:** Well, the GP, uh, the general practitioner would. And then, we usually ask as well. But, to tell you the truth, what usually happens is if they have a strong family history, they know it and they're volunteering it. Uh, I mean, that's ... out in the public domain, that's one of the common things that people ask right away, if someone has cancer. No matter what kind. They say, "Well, why have I got this? Is it in my family, or who...?" If someone has cancer. And so they ask around their relatives. Usually they know that before they come and see you.

(Interview with Surgical Oncologist, 9 May, 2000)

A detailed family history is presumed to have been taken before the surgeon encounters the patient and at the time of their meeting a diagnosis will have already been established. As a result, the surgeon's interaction with the patient relates primarily to a surgical intervention that follows fairly restricted clinical guidelines. Consider the following segment from an interview with a surgical oncologist:

**Interviewer:** Have you ever treated someone with HNPCC before?
Respondent: As far as I am aware no.

Interviewer: cough

Respondent: “I’m sure I must have [chuckle] but I don’t [chuckle] have a specific person in mind. There is sort of I guess there are patients that are even less well defined that are, that have, a familial sort of predisposition. It says that if you have a relative with colon cancer you have two and a half roughly two and a half times, uh, likelihood of getting colon cancer that is not sporadic and again that’s kind of a gray zone group and I am sure that there will be some, some, of those people will be HNPCC when they’re looked at as a family and some of them will be sporadic um but anytime you take a history in a patient with with colon complaints you ask for a family history of colon cancer and so that, that, group of patients you might see as being as slightly higher risk. The surgeon gets the patients who have the diagnosis already so we don’t see a lot of people as a general rule that that are being worked up we see them at the obstruction or something like that. But most of the patients that I would see in my office would be people who have been worked up, diagnosis made or highly suspected and then we go from there with a management plan [emphasis added]”

(Interview with a Surgical Oncologist, 26 April, 2000)

The surgical oncologist, then, is observing that family histories are normally taken by another clinician and that this is where a family profile indicating the possibility of a mutation for HNPCC would be detected. Furthermore, another clinician typically makes the diagnosis of colorectal cancer at a date prior to the patients’ meeting with the surgeon. In this sense, the surgeon’s responsibilities are being narrowly circumscribed to include proceeding with a management plan for the presenting cancer, but not to involve either the diagnosis of colon cancer or the detection of a strong family history indicating HNPCC. Discussion of the genetic component of the illness in HNPCC, therefore, theoretically falls under someone else’s umbrella of responsibility such as that of the individual who takes the family history or who makes the initial diagnosis.
The diagnosis of the HNPCC remains somewhat of a mystery. It is clear that patients are diagnosed with colon cancer but what is unclear is whether the genetic version of the disease, HNPCC, is diagnosed consistently:

**Interviewer:** So, then, how is HNPCC diagnosed in practice? Or is it?

**Surgical Oncologist:** Um ...

**Interviewer:** At present.

**Surgical Oncologist:** At present, it's, uh ... *we're probably missing some.* Uh, especially, especially if you use the modified criteria, we may be missing some. Because, I don't think many of us actually go specifically asking about other, um, cancer. And other involved cancers are now recognized as essentially part of the syndrome. Uh, we probably usually ask about, uh, ovarian and, and maybe endometrial. But the others, we probably don't hear ... much rarer cancers, and the patient may not think of a relative, or have, you know, not known what their relatives died of. So, we may be missing some in that way. Uh, and if there, if there's a strong family history, we probably, uh, would pick up on it. I mean, I have run across the odd case, um, actually, where there have been, you know, relatives. And all we've done at the moment, is, uh, advise them is to get, uh, screening done. Get a screening colonoscopy done at an early age. **But I haven't, uh, haven't actually sought them out** [that is: attempted to diagnose].

(Interview with Surgical Oncologist, 9 May, 2000)

The diagnosis of the HNPCC as distinct from sporadic colorectal cancer is variable. In some cases, it appears that patients are simply told that they have colon cancer and the genetic component does not appear to be featured in conversations with medical practitioners. In other cases, patients are definitely told that their family appears to have the features of HNPCC. In still other situations, strong family histories are discussed but HNPCC is never mentioned directly. Patients are instead told that they are likely to have 'cancer family syndrome'. Some patients may not even be told this information about their condition. As was seen in the above excerpt from an interview with a surgeon, many oncologists are not aware of whether they have even treated a person with HNPCC even though they are statistically highly likely to have treated numerous patients with this
condition based on epidemiological estimates published through the provincial cancer agency.

For some time I was wondering whether a gastroenterologist was the clinician who would talk to patients and family members more directly about HNPCC. Since they were the clinicians who were the experts on colonscopies, which is the most effective clinical surveillance mechanism for HNPCC and sporadic colorectal cancer, it seemed to follow that they might know a lot about HNPCC. Although some general practitioners perform colonoscopies, the gastroenterologist is the specialist that typically performs this procedure (Interview with a Gastroenterologist, May 2001). However, an interview with a gastroenterologist revealed that they do not usually diagnose or discuss HNPCC with patients:

Gastroenterologist: ... In order to make that diagnosis, you’d have to have the right criteria for it. It has to affect at least two generations. Uh, and, you know both the members of that, in those, those two generations, um, and at least one member at a young age. Like, this can start in the 50’s. And, and that makes... that puts that particular family into a, a... highly suspect. And then you can do the genetic work up. Which is [...]. **You have to do that through a specialized, uh, uh, place, the Cancer Agency.** Uh, has now got a program there, with a geneticist who can work that out. And the, the, the test for the [...] is very much. You know, [...]. They’re beginning to identify [...].

(Interview with a Gastroenterologist, May 2001)

The specialized place that the gastroenterologist is referring to is presumably the Hereditary Cancer Program. He is similar in his observations to all the other clinicians who were interviewed that the expertise, resources and therefore responsibility for identifying and diagnosing HNPCC rests with the HCP.

I also surmised that gastroenterologists might be able to clear up the variability in reports that I had heard about the most appropriate screening protocol for HNPCC. There was a lingering question for me: do people with strong family histories likely to have a
mutation for HNPCC need more frequent screening than the protocols for the general population that are normally recommended every 5 years after middle age? A gastroenterologist interviewed seemed to imply that the issue was not clear:

**Gastroenterologist:** And, uh, now this has been expanded to other cancers. So I've got, uh, patients, for example, who are young. And they, they, they know, they, they, they have been identified as having the genetic, uh, problem associated with familial malignancy, uh to the colon. And, uh, um, in one case, uh, uh, it, it's a, it's a...two sisters. And, and, and they've got a strong family history of uh, of sporadic cancer. And these are all, uh...the one, one girl is in her 20s and the other girl is in her 30s. So these are very young people. And they get screened every year. Because they are...they still have their colon in place and they, you know, they, they’re not forming enough that we can’t remove them on a frequent basis. **And the recommended screening for them is every year.**

But, uh, usually you follow people every...with, genetic, uh, who you suspect have a genetic basis for polyp formation, you follow them two or three years. **If you don’t find polyps you might, you know, as I, as I say [...] you do it less. If you’re finding polyps, and as they are getting older, you do it more often.** Because you don’t want to get this rapid progression if you can catch it early. You know. If it’s somebody who, who [...] develops cancers [...] Or if you miss the polyp on, on one, uh which is two years down the road will become a malignancy...

(Interview with a Gastroenterologist, May 2001)

While he notes that colonoscopies are necessary every year for people likely to have HNPCC, he goes on to state that each case may be individual and demand a different screening protocol. The screening protocol for an individual appears to be quite variable and to depend on an assessment of clinical risk for polyps and malignancy in that particular patient. Based on this report, it is understandable why patients receive different messages about screening protocols from different clinicians. What families wonder about is the speed at which cancer progresses in HNPCC relative to the progress of sporadic cancer. Many families and patients worry that HNPCC cancer progresses quicker than sporadic CRC and that this requires more stringent clinical vigilance with respect to surveillance of polyps. Some patients interviewed reported that they had had a
colonoscopy relatively recently that was "clear" and then suddenly they are diagnosed with colorectal cancer. This may be due to the fact that a polyp was missed in the colonoscopy the possibility of which is alluded to by the gastroenterologist in the above excerpt. However, there was not a consistent answer to this question from the oncologists interviewed, that is, does HNPCC advance more rapidly than sporadic cancer? One conclusion emerged from interviews with both families and oncologists, although colonoscopies are the “gold standard” for clinical surveillance, they are not perfect in either their application or accuracy. Screening by colonoscopy is not an exact science.

As well, one issue that is not always known by general practitioners is the guide mentioned by numerous family members in the interview (as well as by some oncologists) that family members should be tested ten years younger than the age of the most recent case of cancer in their family. Family members commonly reported that they had been told by their family physician that they were too young for colonoscopy screening regardless of the age of someone else in their family who had experienced CRC. This seems to point to a possible gap in knowledge in the wider physician community and an incorrect belief that colon cancer is always an older person’s disease.

A great deal of information stands to be gained or lost on the basis of the quality and thoroughness of taking of the family history. A clinician interviewed for this study suggested that the quality of family histories taken by clinicians may be quite variable (Huntsman 2000). Since the family history is, in the absence of genetic testing for HNPCC in BC, the only way to identify the likelihood of a mutation for HNPCC in a family, variance in family history taking is cause for concern for families who may be at
risk for this cancer. As a result, the clinician suggested that a study needs to be completed that examines the efficacy of taking a thorough family history in detecting genetic susceptibility to illness and, ultimately, decreasing mortality due to HNPCC that could have been detected earlier with increased surveillance. It is not clear at this point how many families are likely to have a mutation for HNPCC in BC because these families are not being consistently tracked by individual clinicians or by a central colon cancer registry.

Most of the oncologists interviewed perceived their primary responsibility is to focus on the treatment of cancer that has already been diagnosed. The informal or formal counseling of families with respect to a family cancer syndrome or their risk for hereditary cancer is not, as a rule, believed by oncologists to be either their responsibility or within the domain of their expertise. It follows, then, that the responsibility for discussing the hereditary component of the illness, in particular HNPCC, appears to be considered the responsibility of someone else, such as the Hereditary Cancer Program.

The susceptibility for HNPCC as a disease that has not yet been manifested falls into an ambiguous category for the oncologists. This ambiguous category is considered to be the responsibility of someone else, such as the Hereditary Cancer Program, the general practitioner, or the patient themselves. In the experience of the patient, with the waiting period for genetics counseling having been as long as one year and a half, consistent diagnosis of, clinical monitoring of and education about HNPCC appears sometimes to be lacking. In fact, for patients living in rural areas without the financial means for travel, the possibility of discussion of genetics by a trained professional may be essentially non-existent. This issue continues to lurk in the shadows of the health care
system as it appears that some patients and families living with HNPCC are inadvertently overlooked or lost. The question that began in the initial part of this study remains at its conclusion: how many families with HNPCC are there in BC, where are they, and who is monitoring these families? A partial answer emerged in the interviews with families and patients: clinicians are not reliably following these families and they are not practicing preventative medicine: the families themselves are.

The professionals interviewed in this study regard the HCP as a part of the health system that is responsible for genetics counseling for HNPCC and they refer according to this perception. The HCP is perceived as responsible for providing genetic information, more precise diagnosis, access to waiting lists for genetics testing, making appropriate referrals to specialists and for making recommendations for clinical screening. Yet, the HCP is not a medical service. It is a research initiative. It does not have the resources to address the needs of families with HNPCC throughout the province of BC. This represents a major concern with respect to the standard of care for people at risk for and affected by HNPCC.

Perceptions of Genetics Counseling and Testing

All the oncologists interviewed were asked about the impact of genetic testing for HNPCC on their role as medical practitioners. Most reported that it would not affect their role very dramatically:

Interviewer: But, uh, just, uh, one final question then. Essentially, the genetic testing, um, for HNPCC, wouldn’t really affect your day to day work as a radiation oncologist.

Radiation Oncologist: I don’t think ... like I said, unless we really redefine the mandate. If it’s the way it’s going now, I don’t think it would. I don’t think it would.
Interviewer: You're seeing people with colon cancer, essentially.

Radiation Oncologist: Exactly. And the odd preoperative case, but those are still very treatment focussed. Um, not seeing patients with no cancer diagnosis. And you're talking about, you know, counselling, prophylactic colectomy, those type of things.

(Interview with Radiation Oncologist #2, 9 June, 2000)

Again, the role of the oncologist appears to mainly focus on the treatment of cancer:

Radiation Oncologist: So you're talking about guys like ... there's an index case, and then their family came along and all had predictive testing? And then some are found to have a high risk gene? But they don't have a cancer? And you're talking about whether they should have prophylactic colectomy? Is that what you're talking about? I don't think it would affect my practice. I mean, this is mainly a surgical issue. I mean, it would affect it in a sense that, because ... the way this place is structured, which is provincial tumor group, and the provincial tumor group, you know, is multidisciplinary, so we have to discuss some of these issues. Uh, you know, with our surgical colleagues and, and, in terms of setting provincial guidelines, and things like that. But in terms of day to day practice on the G-I patients I see, it wouldn't because, I, you know, they wouldn't be really coming here to talk about prophylactic colectomy with me. At least, I wouldn't think. Unless we redefine our mandate.

Interviewer: Mm hm. So, essentially, um, patients, in particular HNPCC patients who come into contact with you, are likely already receiving counselling and services somewhere else, or are going to. Such as through, um, medical oncology, or through the Hereditary Cancer Program. And you're essentially, um, providing, um, treatment for a particular site.

Radiation Oncologist: Are you talking about the, uh, the ones with a family history, or the ones without a family history?

Interviewer: With family history.

Radiation Oncologist: With the fam, with family history. The counseling, uh, the medical oncologist, I don't think, is very different. I mean, we're very treatment focussed. [emphasis added]

(Interview with Radiation Oncologist #2, 9 June, 2000)

Interestingly, the issue of prophylactic surgery was not brought up in the initial question. The medical practitioner appeared to be struggling to understand the line of questioning about whether genetics might affect the role of an oncologist. The oncologist has a
difficulty imagining a role that doesn’t involve the treatment of cancer without surgery, chemotherapy or radiation. Early detection and risk management in families at risk for HNPCC is not a part of the culture of oncology. The only risk management that the oncologist could imagine would be a prophylactic colectomy. Generally, oncologists stated that genetic testing would not have a large impact on their role. This seems to be due to the fact that they understand their role as primarily clinical and that they distinguish genetics separately. Thus, it appears that genetic and medical culture are distinct from one another.

Other oncologists also suggested that one of the results of introducing genetic testing for HNPCC in BC would be to bring about prophylactic surgery:

**Interviewer:** Do you think that genetic testing if it were available locally in the discussion for HNPCC that it would affect the role of the surgeon?

**Surgical Oncologist:** Well uh you know I think if you have a patient with a bunch of polyps and you knew that they had HNPCC then yeh you you'll be fraught with with questions of what you know what to do. You obviously want to clear all the polyps out of the colon as a cancerologist can see these people as I say and and they would continue to to lop the little polyps out of there because as long as there are no polyps there is not likely to be any cancer um if they had a patient who had the characteristics of started to you know seem to be coming back quite frequently the polyps continues I think in that patient it would inform a decision if you knew that they had a a genetic marker for colon cancer I think it would inform a decision for prophylactic surgery yeh it definitely would I mean we've taken three years I mean ever since I was trained we've always taken the colon out of individuals with polyposis cancer syndrome I mean it it's not a huge leap of faith that uh that and they haven't been tested genetically because the because the uh you know it's such an obvious diagnosis when you see a colon with all these sort of polyps but if you see people who have a number of let's say ten or dozen polyps you know you it it start to wonder about prophylactic removal of the colon yeh so it would affect if if we knew that that individual with the dozen of polyps did or didn't have HNPCC then I think it would definitely affect what we would do. [emphasis added]

(Interview with Surgical Oncologist, 3 May, 2000)
However, at present in the absence of genetic testing in BC, prophylactic surgery does not appear to have become a part of the standard of practice for treating individuals at risk for HNPCC.

A number of oncologists were quite critical of the usefulness of genetic testing:

**Interviewer:** If the genetics, uh, genetic testing program for HNPCC were available here, um, in what way would it affect your work? Or would it?

**Radiation Oncologist:** Um, [pause] it, uh, it would affect my role in that I would like to see it in the form of a study. In terms of ... when you do the genetics test, what can you do with it? And when you’ve done that, what’s the effect of doing that? I mean, just because we can test for it, em ... I mean, it’s a bit like finding lung cancer, at the moment. Unfortunately, the answer mainly is “Gee, whiz.”

(Interview with a Radiation Oncologist, 8 June, 2000)

Essentially, the clinician is arguing that the provision of genetic information isn’t very helpful to the patient because nothing can be done for them clinically. The same clinician goes on to question the overall efficacy of screening for colon cancer:

**Interviewer:** Your sense is that that hasn’t been adequately studied as of yet with ...

**Radiation Oncologist:** Well ...

**Interviewer:** Colon cancer?

**Radiation Oncologist:** That’s my ignorance. And um, it’s a bit like sun screen. They’re only just finding out that the sun screen that we’ve been using probably hasn’t changed the incidence of skin cancer at all. I mean, it’s a good idea ...

**Interviewer:** [Laugh]

**Radiation Oncologist:** It was a good idea, and I thoroughly applaud the idea. You know, we’ve got something that blocks sun. The I ... the UV rays don’t get through. Do it. But test it to see if what you think it does, actually works.

(Interview with Radiation Oncologist, 8 June, 2000)

This interview excerpt illustrates that a widespread reverence of genetic technology has not yet overrun the clinical culture.
This chapter has shown that the cultures of medicine and genetics are distinct and that the therapeutic plots of oncologists do not include the diagnosis of HNPCC. Medical practitioners do not appear to have much knowledge about disease outside of the clinical setting. For them, disease exists in the hospital and their object is disease, not patients and certainly not families. The roles of genetics professionals and medical practitioners are different and they are institutionally consecrated.

Disease as relegated to the body still remains as a construction of the medical field in the treatment of cancer. The professionals time and time again attested to the fact that they simply treat disease, that is, a tumor or cancer. With respect to HNPCC, the majority of medical practitioners have not yet widened their clinical domain to include the family. The understandings of family members affected by HNPCC, in contrast, appeared much more sophisticated when it came to illness.

This research has shown that families who are susceptible to HNPCC resist this dualistic construction by the medical world. The compartmentalization of disease like HNPCC in the clinical biomedical realm was an artificial one and the families had come to understand that social fact. In the experience of the patients and families, it seems that the bifurcation of the mind and body is an artificial process for academic purposes. People experience the body and the mind at the same time. Furthermore, they experience cultural and self-construction of personhood simultaneously. The separation of these variables is an artifact of the academic world. Culture, individual experience and illness all intersect in the construction of the person. Families affected by HNPCC had entered reflective period in their lives as part of healing where they contemplated the interplay between the body, culture and self in the construction of personhood.
This chapter demonstrates that most of the oncologists interviewed do not, as a rule, diagnose HNPCC and that they do not distinguish between CRC and HNPCC in their treatment practice. Their roles are institutionally defined: they do not diagnose HNPCC or take full family histories and surgical oncologists perform surgery while medical oncologists use chemicals to treat tumors and radiation oncologists irradiate tumors. The oncologists appear to have inconsistent knowledge about HNPCC and the interviews confirm the reports that colonoscopies may be inconsistently applied. While some oncologists were aware of the unique negative social elements about CRC (fear of colostomy), most were not aware and did not distinguish between CRC and HNPCC in terms of negative social issues. Virtually none of the oncologists mentioned the genetic side of the cancer having a social impact and the oncologists did not appear to have much knowledge of life outside of the treatment realm. For instance, most did not know whether a support group for CRC existed. However, the most surprising finding in the clinical narratives pertains to the issue of disclosure of diagnosis of HNPCC. Most oncologists explicitly stated that they would not disclose a diagnosis that indicates the possibility of HNPCC. This means that at the time of the writing of this dissertation, it appears to be standard practice in oncology not to disclose a suspected diagnosis of HNPCC. The interviews also confirmed that oncologists have different narratives for different audiences. Some would, for example, share a suspicion of HNPCC with colleagues, but not with the patient in question. The oncologists interviewed here appear to focus on the treatment of disease that is present. They do not focus on the prevention of disease in families suspected to have a genetic susceptibility for HNPCC. The role of addressing prevention, early detection and surveillance of high-risk people who are not
yet stricken with a disease falls somewhere outside their clinical realm. The next chapter offers a possible hypothesis for who takes on responsibility for education, early detection and prevention in families. The final section also offers some possible conclusions about the rival world of patients with its basis in healing emplotment and the construction of personhood.
CHAPTER SEVEN: HEALING VS TREATING

"How high is the sky. How deep is the ocean. How many roses are sprinkled with dew?"  
(How Deep is the Ocean: Eta James)

This study has outlined the strategies that families employ in healing emplotment to fortify the protective cocoon of their person as they confront the threats of HNPCC. Therapeutic emplotment by clinicians and genetics professionals is only a small part of the larger process of healing emplotment for family members, a process that foregrounds emotional capital over all other forms of cultural capital. In this study we have seen individuals confront the dangers of genetic shame and guilt to shore up their practical consciousness. They reflexively author their person and utilize the tools of clinical genetics and medicine so that they can face fateful moments brought about by genetic susceptibility to disease.

A person is an autobiographer who constantly engages their personhood as the cumulative subject of an ongoing life story (Gillett 2002). Diseases have the ability to alter personhood. This is especially evident with diseases where an individual’s ability to narrate their personhood is seriously compromised, such as those illnesses that disable narrative functioning early or late in life (Gillett 2002; Nelson 2002). Experience with disease highlights the importance for people to maintain a consistent sense of their person. The people at risk for HNPCC interviewed here were not compromised in their ability to be autobiographers. Their narratives show that they have a rich “heritage of understandings” about their disease and its impact upon the story of their personhood (Gillett 2002: 27). It is argued here that they employ healing emplotment as active stewards over the many selves that comprise their life stories and their narratives demonstrate that they are particularly deep readers of the events that narrate their lives.
People are not simply psychological beings. They are flesh and blood; they eat, they sleep and sometimes they get sick. Everyone dies eventually and, as the words of a song by Kris Kristofferson noted, life is a promise that no one keeps. Death is the ultimate external condition to personhood. However, people are not simply biological either. People wonder how far is the distance to the moon, how high is the sky and they wonder who they are and why they have cancer or why they are at increased risk for it. A defining aspect of humanity is to seek out a purpose for events and for ourselves. The main share of the illness experience studied here does not really occur in clinics or in hospitals. The experiences of people in clinical settings are tiny snapshots in the full course of a family’s experience with hereditary colon cancer. Hereditary colon cancer happens to people who do not live in clinics and the wake of their illness flows into peoples’ entire lives and is reflected in their healing narratives.

Illness and therapeutic narratives occur as part of a larger healing narrative about a person. The experience of illness is not bounded within the individual body. Its influence is beyond the individual and it has a kind of living memory that lasts beyond even death. When a mother dies, the memory of this illness lives on in her daughter, her son, her husband, her sister and in her family. The social mark of this illness becomes a part of who these people are and it heralds the interconnectedness of persons. Illness is social and can influence our social roles as well. The head of the company is no longer the Chief Executive Officer. The teacher is no longer teaching. The policewoman is no longer policing. The mother is no longer mothering. The experience and impact of serious illness like cancer is weathered in the social world and its mark is written in the narratives that describe who individuals are as persons. Who people are is not bound by
their bodies and they do not simply begin and end at the edge of their skin. They are mothers, fathers, sisters, brothers and lovers and everyone is a son or a daughter. They are fundamentally socially defined. And so too is hereditary cancer in its experience, in its meaning, and in its very purpose for people knowing themselves.

Families at risk for HNPCC are very experienced with cancer. They are experts. These families are not simply empty vessels seeking to be filled with medical knowledge. They have had many generations of experience with cancer in their families and they have all weathered the loss of close relatives. Consider the example of one person affected with cancer who was 30 years of age when interviewed and whose father and grandmother had both had the same cancer. Her understanding of her cancer in her family and of herself as a person is elaborate. It appears in many cases that the reason these seasoned families seek out clinicians and genetic counselors is not simply to obtain clinical service but to bolster their strategies for healing and personal growth. This research suggests that the process of healing is very connected to the careful stewardship by these family members over their personhood. Healing is assumed here to be distinct from treatment, although treatment itself may be included as a stop along the roadway towards the active creation of personhood.

In developing a theoretical framework for this study, I have tried to move beyond binary or oppositional approaches that have hitherto been based on either “constructionist theories that emphasize the production of subjects [or] seemingly voluntarist accounts that emphasize what subjects make” (Ortner 1996: 20). In keeping with this reasoning, I have avoided simply trying to demonstrate that genetic susceptibility to illness is, in part, socially constructed: the “autoproof of social constructionism” (Strathern 1995: 5).
Chapter Six on Clinical Narratives attempted to show that the field of clinical genetics is not very influential on the practice of medicine with respect to HNPCC. Many of the oncologists were able to demonstrate a superficial knowledge of the genetics of HNPCC. This might be taken to mean that they share some of the culture of genetics but it does not appear to affect their practice of medicine with HNPCC. This chapter and chapter three on institutional narratives indicate that oncologists are constrained by institutional arrangements, such as their roles within tumor groups in the provincial cancer agency, the availability of medical procedures or tests and the availability of programs to which they can refer patients. To develop a metaphor from Bourdieu (1999), they cut their coat of medical practice according to the cloth that is available. There are, as has been observed by a number of the oncologists interviewed, realities that exist outside of the networks of negotiated meaning of professionals. Individual oncologists do not appear to have much control over the organization of tumor groups, the availability of medical geneticists or the number of gastroenterologists to perform colonoscopes in BC. As Hannerz (1992: 17-18) has observed regarding the relationship between social and cultural variables:

“There are, as I see it, realities outside culture with which people must also interact, whether their grasp of them through their culture is perfect or imperfect. To elaborate: persons may be culturally constructed, but (usually) not out of thin air; there are also flesh-and-blood human beings to which the constructions are attached, and the number of such human beings, taken all together or divided into categories, can make a difference for cultural process. Power, similarly, may indeed be culturally defined; and much of the time symbolic references to it are made to stand in for the real thing, but in the end the ability to use force counts, and can be used effectively to back up one of competing definitions”.

The relationship between structural variables and semantic networks is complex and is a debate that I do not intend to complete within the bounds of this dissertation. However, I
wish to highlight the influence of institutional conditions and the health care context in which clinicians operate. For the purposes of the analysis here, I share the interactionist stance taken by Hannerz (1992). Oncologists cannot, at the individual practitioner level, in any effective way determine how the oncology roles are organized in the B.C. Cancer Agency. For example, a medical oncologist cannot decide that they will provide both the medications and the radiation for their patient even if this would improve the continuity of care and reflect the practice from their original training. Similarly, a general practitioner cannot easily influence the number of gastroenterologists or colonoscopes necessary for early detection of colorectal cancer. However, in order to point to a possible area for improvement in health services for families living with HNPCC, I will twist Bourdieu’s metaphor in a slightly different direction: while clinicians cut their medical clothes according to the institutional cloth available to them, they do, nonetheless, cut them. In this way, I wish to point out that while the individual physician is constrained by the system, it could be pointed out that they as a group are the system. While they are apparently captains of their clinical destiny, they are captains in circumstances over which they have no institutional control in terms of what programs are available and how they are paid in the medical service plan. This study has several practical applications for clinicians and policy makers in the fields of health. The standard of care for families at risk for HNPCC could be improved and standardized by:

- Encouraging physicians to focus on families as well as patients with respect to HNPCC. This could be done by improving the consistency of family history taking and by encouraging physicians to write an open letter for family members regarding HNPCC.
- Provincial education needs to occur with clinicians regarding the diagnosis of HNPCC. A discussion needs to occur regarding whose ethical responsibility it is to disclose a suspected diagnosis of HNPCC. This is especially important because the HNPCC syndrome can also lead to a
number of other cancers (endometrial, ovarian, bladder, breast, kidney, larynx, pancreas, stomach, small bowel, and ureter) beyond colon cancer that all need to be monitored (Blackburn and Giardiello 1992; Li 1995).

- The development of a provincial education program for health promotion and early detection for people at risk for HNPCC (i.e. family history, colonoscopy, clinical monitoring for other cancers).
- Provincial guidelines need to be developed and standardized in clinical practice for the surveillance of HNPCC.
- The Hereditary Cancer Program needs to be awarded the funding required to perform genetic testing for HNPCC so that it can fulfill the responsibilities that it is presently expected to fill by the medical community. It is hypothesized that once the testing service is available, then oncologists will begin to consistently identify and refer people at risk for HNPCC. In conjunction with colonoscopy, this could reduce the risk for colorectal cancer by 50%, prevent deaths due to colorectal cancer and decrease the “overall mortality by 65% HNPCC families” (Jarvinen, et al. 2000: 829)
- The interviews with people genetically at risk for HNPCC suggest that the distinction between counseling and risk assessment in genetics counseling needs to be further examined with respect to patient expectations.

The understandings of families with respect to colorectal cancer appear heavily influenced by “machineries of meaning” that fall, to a large part, outside of conventional medical interactions (Hannerz 1992: 26). These technical forms of sharing understandings for families at risk for HNPCC include the world wide web, the media, journal data bases such as medline and e-mail correspondence between relatives and friends. While this study has been restricted to people who appear eager to engage genetic, medical and academic professionals about the disease, the interviews suggest that it is unlikely that an untouched family with a relatively blank slate of knowledge about inherited susceptibility to HNPCC exists in BC. Even those family members described by the interview subjects who were not interested in seeking genetic knowledge about HNPCC in no way lived in a social vacuum with respect to information available to them through a diverse array of formal and informal sources.
The fields of clinical genetics and medicine may be cultures, representing smaller zones of culture, that is, "smaller units of collectively carried meaning within wider cultures" (Hannerz 1992: 37). Arguably, a culture consists of a unit as small as two individuals and there are hot spots of meaning production:

"The sound and fury of cultural production may well be particularly great on some sites within the social structure. Yet it is not obvious, as role repertoires differ, that everybody in a complex society is involved with these sites in the same way, or at all" (Hannerz 1992: 66).

Similarly, the fields of clinical genetics and medicine are treated in this study as cultures in that they represent particular webs of understanding that are consistently shared by the members of their professional group. These semantic networks are arguably constantly shifting. Furthermore, this study has shown that being a member of one or the other, that is, a medical practitioner or a medical geneticist, indicates a contrasted understanding of families at risk for HNPCC. This is also true of contextual involvement in the wider culture:

"Furthermore, not all situations are equally important in the construction of a perspective. We spend less time in some than in others, and attach different weight to them. If certain kinds of situations are thus perspectively peripheral, so to speak, they would have less impact on the variability of perspectives. Being a mother or a factory worker should influence one's personal meaning system more than being a sometime bus passenger..." (Hannerz 1992: 67).

Being a person living in the downtown eastside of Vancouver with serious addictions, AIDS and hepatitis influences a person's personal meaning system more than being a now and again coffee drinker. Social position and experience with respect to HNPCC also leaves a powerful impression on meaning construction. While medical practitioners

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41 In an attempt to address issues of scale with respect to culture, Hannerz (1992) breaks categories of culture into four overall settings: forms of life, market, state and movements. As a full discussion of these frameworks is not possible within the bounds of this paper, the interested reader is directed to the original work for an elaborate discussion.
may be part of the health care field, their primary membership in either the clinical genetics or medical culture\(^\text{42}\) dramatically affects their understanding of HNPCC. In clinical genetics, families are pivotal, while in medicine patients are central and families are not the focus.

The bottommost level of shared understandings that are tied to specific settings might be referred to as microcultures (Hannerz 1992). For instance, the G.I. Tumor Group, the Medical Oncology Group, the Radiation Oncology Group, the Surgical Oncology Group or the Hereditary Cancer Program Steering Committee might all be considered microcultures tied to the specific setting of a hospital or Cancer Agency. One of the potential problems with analysing and writing up the results of the present study is that the data might be taken out of the context of oncologists treating families faced with CRC and over generalized to higher points in the cultural cosmos than is warranted. In this sense, a microculture is not automatically a building block of the wider cultural world. Notwithstanding, the narratives of the oncologists and families interviewed in this study show that they shared experiences and meanings with members of their respective groups. Clinical genetics and medicine do exist as semantic universes, that is, as cultures and this arguably has an effect on the standard of care for families suspected to be genetically susceptible to HNPCC.

The medical practitioners interviewed in this study were not immune to the impact of the clinical genetics field with respect to HNPCC. They appeared to have adopted some of the values of this culture at least in so far as most could demonstrate basic understanding of HNPCC and many genuflected to the importance of the

\(^{42}\) While it appears that the clinicians interviewed in this study primarily exist in either medicine or clinical genetics many professionals such as those in the HCP may exist in some senses in both culture areas.
Hereditary Cancer Program. However, it appears that the structure of health care needs to include formal resources for managing families with HNPCC before the practice of medicine is to fully adopt the understandings of clinical genetics regarding families at risk for hereditary nonpolyposis colon cancer. More specifically, oncologists manage genetic understandings of HNPCC from within a medical world that does not provide a structural reality for the disease (there is no funding to follow it, detect it or prevent it). “People, that is, manage meanings from where they are in the social structure” (Hannerz 1992: 65). Oncologists, as people, are no exception.

What is healing and what is treatment? Healing is a process of personal growth and understanding about the relationship between one’s self, body and society. In many ways, the healing process and the process of negotiating personhood are one and the same. This healing process entered into as part of family members’ examination of the impact of HNPCC appears to bring about, as one participant in this study said, a profound sense of self for people. Treatment, in contrast, is typically a more specific intervention performed by clinicians or other professionals. The therapeutic emplotment of oncologists typically addresses one of four distinct sectors of medical intervention:

- Radiation
- Chemotherapy
- Surgery
- Palliation

The therapeutic narratives of oncologists focus on these four possible treatment themes. In practice, the focus of these oncologists is very specific. It is on the treatment of disease in the body. The therapeutic plot does not focus on peoples’ psychology, the whole person and certainly not the family. For oncologists, healing refers to very specific body processes related to the eradication of cancer tumors. In contrast to healing
employment of individual patients and family members who talk about their selves in society, the therapeutic employment of oncologists highlights radiation, chemotherapy and surgery. Oncologists have a specific narrative realm that shapes their understandings and actions that shapes their interactions towards medical treatment. This therapeutic narrative focuses on tumors and is comprised of tangible medical techniques (e.g. surgery) or referrals to other professionals or specialists such as genetic counselors.

Participants in the genetic counseling environment have different agendas. For counselors, the main point of counseling is to offer individuals a risk assessment and education about genetic conditions. In contrast, the client already perceives his or her risk as high before arriving at the counseling session and expects that the principal aim of the interaction is to identify an appropriate course of action. Similarly, interviews with people receiving radiation therapy revealed that prognosis is the most important concern for patients, followed by interest in disease process, finally followed by their regard for treatment side effects, options, and basic information (DelVecchio-Good 1991). Clients, in the genetic counseling setting, tend to perceive the communication of risk information as merely an introductory phase that precedes a more meaningful discussion of methods for risk reduction. In fact, risk assessment, a major component of the genetic counseling agenda, is typically difficult for clients to either understand or recall (Richards, et al. 1995). The interviews in this study with people at risk for HNPCC show that the struggle between the psychological aspects of genetic counseling and its role in the provision of

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43 Clinicians and patients have qualitatively distinct understandings of risk (Gifford 1986). While the focus for investigation in epidemiology is the population, the subject matter for the clinician is the individual patient. An assessment of risk does not permit a confident forecasting of disease outcome for a particular individual. However, disease outcome may be perceived by the patient as the most important issue.
bio-technical information continues to reflect a need for a fundamental reformation of the discipline in general (Kenen and Smith 1995).

Not only are cultural schemata about inheritance incompatible with scientific Mendelian views of genetics, they may serve different purposes, such as the construction of personal or family identity, the building of family history or the extension of kinship networks (Richards 1993; 1996; 1997). It appears from the interviews with people genetically at risk for HNPCC that their ideas about inheritance and the ideas they hear about in the genetic session co-exist in their overall understanding. For example, the interviews with people at risk for HNPCC show that technical medical and genetic information around a condition can peacefully co-exist with ideas that would not be accepted by clinicians such as the belief that the way that two family members splay their toothbrush indicates that they are both likely to develop same hereditary cancer.

It was unexpected to discover the relative lack of influence of the culture of clinical genetics on the culture of medicine in the case of HNPCC. Genetics does not appear to be a large part of the culture of oncology in the treatment of HNPCC. In fact, it is not clear that oncologists even intentionally treat HNPCC. They, by and large, consider HNPCC to be the same as sporadic colon cancer in clinical terms. It was telling to observe that many could not say whether they had ever treated someone with HNPCC. While certainly most oncologists interviewed could define HNPCC relative to sporadic colorectal cancer, the distinction between the two forms of cancer appears to be considered to be mostly an academic clarification. The oncologists interviewed in this study did not consider the provision of information about heredity to be part of their role or expertise, at least in so far as they would not consider discussing it with their patients.
The oncologists appeared to evaluate the role of genetics in HNPCC in terms of its clinical application. Therefore, it appears that oncologists infer that because there is not a genetic test available for HNPCC, then genetics is not very significant clinically. As a rule, oncologists focus on patients who have abnormal or suspicious tissue that could be cancer. They do not deal with risk or prevention of disease except in the case where it has already occurred and they are trying to prevent its re-occurrence.

With respect to HNPCC, then, the clinical culture does not focus on the treatment of potential disease (disease that has not yet manifested) nor is it customary in this culture to practice preventive medicine. The issue of which clinician takes on the responsibility for addressing risk, prevention, and surveillance in families at high risk for HNPCC emerged as a research question in the early stages of this research. It is a question that still remains and it points to a potential weakness in the system that needs to be addressed. It appears logical that the HCP should have the funding required to identify, assess and ensure a clinical surveillance plan is in place for families at risk for HNPCC and to educate the wider population of physicians about HNPCC.

The contrasting perspective of patients and oncologists regarding their interactions was seen in their narratives. Oncologists talked primarily about the treatment of disease while patients, people at risk for hereditary disease and their family members, focused on a process that I have described as part of healing emplotment: their understanding of themselves and the impact of disease on their lifeworld as it pertains to the construction of their person. The oncologist and the patient come with different narrative agendas, that is, a different sense of where the interaction begins and ends. For the oncologist, it is a finite interaction with a clear purpose, that is, an attempt to
eradicate a cancer tumor. For the genetics professional, it is to provide genetics information and a risk assessment. In practice, the oncologist attempts to confine their interactions into a format that can be documented as part of a chart or medical record. As part of a therapeutic narrative, clinicians organize their interactions on the basis of four variables: Symptoms, Observation, Assessment, Plan (S.O.A.P.) as part of the standardized format for recording their treatment of patients into a hospital chart. Any variables outside of this document realm are seen as extraneous to the provision of evidence-based medical treatment, as lacking in objectivity, and as background noise. Many of the variables that are not part of therapeutic emplotment by oncologists, such as those with emotional capital seen in the narratives of people genetically at risk for HNPCC, are the very ones that are crucial to the process of healing emplotment.

A question that sprung out of the research, then, was ‘who deals with HNPCC in British Columbia?’ Is there a clinical body or type of medical practitioner who focuses on the early detection, monitoring and education about this disease? Presumably, part of this responsibility might be undertaken by general practitioners. However, the knowledge of HNPCC in the population of general practitioners is likely to be at best patchy, given the variable level of knowledge in the specialists interviewed in this study who specifically treat colon cancer. In fact, many families with HNPCC may not have a family practitioner and may instead make use of walk-in clinics. Many of the locum practitioners do not consistently take detailed family histories, given that these walk-in clinics are not considered responsible as a source for continuous medical care but rather one-time stops for their patrons. Given the importance of family history taking for identifying family cancer syndromes such as HNPCC, the consistent use of this medical
procedure needs to be widely promoted. Given the alarming finding that family histories do not appear to be universally taken by all physicians, this should be a priority for continuing medical education and quality control (Acheson, et al. 2000).

For family members with a family practitioner, the resources available for use by the GP for early detection of HNPCC are scant at best. The most effective clinical surveillance technique for detecting HNPCC, colonoscopy, is difficult to obtain. There are long waiting lists for this procedure and many communities do not have the equipment necessary to perform colonoscopies. This makes it unlikely that families likely to be genetically susceptible to HNPCC are obtaining reliable clinical surveillance. This problem of access to preventative surveillance is further exacerbated by the fact that the focus of the clinical treatment is on disease, not the possibility of disease and on individuals and not the families. Surveillance for HNPCC would be most effective in high-risk families and it could save lives (Jarvinen, et al. 2000).

Does the Hereditary Cancer Program address the needs of families who are genetically susceptible to HNPCC in BC? The short answer is no. Although the clinicians and stakeholders in the HCP would like to include HNPCC as a provincial focus in their program, they do not at present because of a lack of resources. They do, however, clarify risk and identify families (who are referred by physicians) likely to have a genetic susceptibility to HNPCC as part of a research program. The HCP has expertise in HNPCC, and they address some families on a case by case basis, but the program does not have adequate resources to address the clinical and research needs of families with HNPCC in the entire province unless the central point of the program were to be moved away from breast cancer. Many oncologists interviewed in this study made reference to
the HCP as the one with the knowledge, expertise and resources to deal with families with hereditary cancer. In fact, while the HCP does have the foremost expertise regarding HPNCC in the province, it is not a treatment program. It is a research program with barely enough resources to meet the needs of its current focus: hereditary breast and ovarian cancers. The main allocation of its limited resources to date has been on hereditary breast cancer. The overworked genetic counselors have long waiting lists for their clients and they have repeatedly stated that before taking on responsibilities for other hereditary diseases in a programmatic manner, they need more resources. The HCP is the expert group in the province of BC, but due to limited resources, HNPCC is not a priority. This may change in the future, but during this research the preponderance of energy from the HCP was invested in hereditary breast cancer. Unlike some provinces such as Ontario with more funding for services (research and clinical) for families with hereditary disease, families at risk for HNPCC are simply not being consistently followed by a formal system in British Columbia.

Another fundamental issue that arose from this research pertained to the question of why families seek out genetics counseling. Besides a more precise risk estimate, why do people at risk for HNPCC seek out genetics counseling? Even with respect to risk, they already know that they are at higher risk than the general population-based on their lived experience. One reason may be that the families were seeking actual counseling, that is, some type of guided discussion regarding strategies for understanding and coping with their experiences. Certainly, many of those interviewed made note that they did not receive any counseling and that the name genetics counseling led them to infer that they would receive counseling of some sort. This seems to imply, at some level, that the
families feel that they might benefit from counseling. Families do not receive genetics testing yet either. If participants do not receive counseling or testing, then why do they seek out this service? The narratives of those interviewed suggest that their seeking of genetic services is part of their overall healing strategies. While there is not a formal group in the medical system that focuses on the needs of families with HNPCC, there is one group of people taking on the responsibility, informally, for health promotion, risk management and clinical surveillance of HNPCC: the families themselves. The seeking of genetics services by families with HNPCC is part of taking on that charge.

What is the relationship of healing to personhood? They appear to be inextricably related in the process of healing emplotment. The creation of personhood and healing are a process of negotiation of personal and cultural construction. For the patient or family member, interactions with clinicians are part of a larger process of meaning construction that focuses on an attempt to determine why this event has occurred, what level of control the individual has over their own health, and, ultimately, an attempt to assess the direction and purpose of their life. Each aspect of the clinician-patient interaction is assessed for meaning by the patient or family member and, further, the patient may sometimes attribute meaning to parts of the interaction that may escape the attention of the clinician. For those clinicians who confine their interactions to providing a neutral clinical intervention or imparting medical/genetic knowledge, the ascription of meaning by their patients may be a process about which they have little or no awareness. For those who are aware of it, the symbolic and social side of medicine is referred to in the professional vernacular as the art of medicine.
For patients experiencing HNPCC, almost all interactions are meaning laden and they are fit into a complex semantic network that goes beyond constructing an illness narrative to the narrative construction of personhood that is a key part of the healing process. The clinical or genetic information or intervention appears to fit into a larger web of meaning as part of the healing process and the process of negotiating personhood. The lay-perspective is not simple, it is not without medical knowledge but is instead comprised of an elaborate symbolic web that includes medical and genetic information, the experience of illness, ideas about inheritance and a process that culminates with a negotiation of social identity and an exploration for sources that generate a sense of agency and meaning.

This study has shown that medical doctors have different narratives for different audiences. Their narratives differ depending on whether they are talking to patients, family members or medical doctors. Their narratives may also change depending on whether they are talking to students, and they likely vary for different types of students (graduate versus undergraduate, social science rather than medical). In the interviews with oncologists, their narratives appeared to be socially sensitive in that they were performed differently and with different themes for different audiences. Far from being purely scientific and acontextual, they were highly socially sensitive and context specific. Practitioners' narratives spoke to their institutionally constrained roles (treating tumors) and they noted that there are different narratives for patients than for colleagues (e.g. disclosure of suspected diagnosis of HNPCC). Clinicians consider the accepted standard of care (this is code for a consideration of the assessment by one's peers) whenever engaging in a medical act or clinical intervention. As physicians narratively organize
their actions, one issue that they sometimes consider is the hypothetical appraisal by the College of Physicians and Surgeons, the ultimate peer audience for medical culture (the licensing and disciplinary body with the ability to take away one’s license for bad medical practice).

While the narratives of the oncologists had a social purpose, so too did the narratives of the family members affected by a genetic susceptibility to HNPCC. They appeared to have a narrative function for organizing and understanding the experience of illness and its impact upon the lifeworld of those interviewed. However, the narratives were more than social, they appeared to be producing a representation of experience, sculpting an understanding and they, in some ways, seemed to point towards the future. They seemed to organize reality for people amongst the multiplicity of conceivable realities. They were filled with possibility; they implied a number of possible endpoints to the narrative of healing. The interactions of families with clinicians were a part of a grander process of healing emplotment. For people genetically at risk for HNPCC, the therapeutic emplotment of the clinicians was incorporated into a larger process of healing emplotment.

Narratives were initially utilized in this study as a way to dig at the understandings and experience of families with cancer, but they revealed something more: they provided a glance into the process of healing and the creation of personhood as part of this cultural proceeding. The narratives of families were more than records of experience and understanding, they were filled with social purpose and intentionality and they illustrated that people actively comment on their experience, their role, and their personhood as an intersection between the experience of disease in their bodies and the
impact of that experience on their social tenure. People were not victims of illness or passive recipients of expert knowledge or technology. The individuals interviewed here were strong and healthy authors who were actively creating representations of themselves and their families in the light of their experience. The narratives were not simply immutable oral records that recounted a linear experience of a disease, the genetic roots of that disease and the interesting folk notions about illness. I initially went to dig at the experience, to tug at people’s understandings relative to those of clinicians, to compare two cultures: the lay and the clinical and possibly the genetic. Yes, I found them to be distinct, but underneath I saw a social process of seeking healing and creating personhood that extended far beyond my expectations.

People had a purpose, they had taken the reins of their lives, they had defined themselves and they had created themselves, they narrated their personhood as part of a healing narrative. They marshaled control over key variables in order to maintain authorship over their identity in the social world:

- Increased reflexivity and active authorship of the person to maintain narrative continuity and to address the threat of genetic shame and guilt
- Shoring up the protective cocoon and emotional inoculation by colonizing the future: by maintaining control over the clinical interventions in their bodies (surgery, radiation, chemotherapy) and by supervision over the tests studying their bodies (genetics, CT Scans, X-rays, colonoscopies, sigmoidoscopies, isotope tests)
- Seeking genetic knowledge to enhance practical consciousness
- Transcending material capital by seeking emotional capital and pursuing pure relationships
- Seeking of emotional capital
- Addressing fateful moments through health promotion and education in the family

Once people had addressed the interruption in their life trajectory caused by the health problem or the potential of it, they kept on, they continued on their way into a larger process of narrating themselves, their past, their present and their future. Once they had
addressed the fundamental threat to their personhood brought about by serious disease, they had developed a set of conceptual skills for understanding themselves, their social world and the sought out answers of humanity: what is the meaning of their life?

Perhaps the most surprising aspect of this study was that the most interesting aspects of this foray into medical anthropology was not seen through a rich description of the culture of medicine or genetics, nor was it found in a description of cancer or the proximity to the real experience of cancer in the everyday lives of people. The most fascinating and engaging aspect of this study was the chance to observe the process of people asking why and what does it mean to be a person. Why has this happened to them and what impact might it have on their lives, their pursuit of the meaning of it all to them, their person? The people genetically at risk for HNPCC appeared to be dipping into a busy social whirlpool where they are constructed by social forces and where they simultaneously constructed themselves. In this sense, the narratives collected (or, more accurately, experienced) had more than social purpose, that is, for negotiating the way through the social network by engaging in a conversation with other participants utilizing linguistic symbols. Here, narratives were used to create people, to create persons, to negotiate personhood. People began to take hold of the reins of the where, who, what, why and how of their experience, not just with illness or medical therapy but in the process of healing. Further still they began to define their purpose and the meaning of their life itself. People knowingly entered into the fields of anthropology, sociology, psychology, medicine and genetics and at this hub they carved out their person at its whirling centre. At this hub they mapped out possible directions for their lives and who they are, were and will be.
Social Meaning of a Door Knob

This study has shown that the public’s assessment of their interactions with the medical system is not made simply on the basis of an evaluation of pure clinical service. These interactions for the patient and family member are not neutral; they are heavily laden with values and contain manifold cultural expectations based on a mandate for healing. Take for example the case of the family mentioned in chapter five that travels a great distance in search of a consultation from a specialist regarding a second diagnosis of cancer. The specialist, during their entire meeting, stood at the entrance to the room with his hand on the door knob (while they were sitting). To the couple, the fact that the clinician held onto the doorknob seemed to mean that he was rushed and that he did not care about their health. The fact that they had to go to the clinician in a remote part of the hospital rather than to his office also seemed to communicate something important. It felt disrespectful of them. The fact that the clinician held the doorknob rather than, say, sitting down or providing eye contact communicated more than clinical information to the couple. Although the level of care offered by the clinician may very likely have met the expected standard of care, the couple went away feeling extremely unfulfilled. Is it that they are simply unrealistic in their expectations or is it possible that the clinician could modify the style of his interaction to meet more than what was simply clinically required? No doubt if the clinician were aware of this disappointment, he might be surprised. However, the two are engaging in two different types of emplotment: the clinicians and that of the patients and families. Healing emplotment and therapeutic emplotment have two different plots and themes and, as a result, two different sets of
expectations for the medical encounter. In one, treatment is an endpoint, while in the other, treatment is only one aspect of a larger goal: healing.

There are many examples from peoples’ narratives that show that they do not evaluate their interactions with medical practitioners in terms of therapeutic emplotment. In healing emplotment, whether a clinician demonstrates caring and respect is very relevant for many patients when they evaluate these interactions. For patients, it appears that these issues are not just qualitative variables that doctors need to be aware of in order to have optimum ‘bed side manners’. Although these expectations may not immediately appear to fit into a therapeutic plot that values evidence-based scientific medicine, for many patients, how successful the clinician is in helping to make them feel cared for and respected as part of their healing is a large part of their expectations for good clinical care. For many patients, this is medicine. In contrast, the focus on the clinical sequence of events as it pertains to treatment of disease is part of the cultural bedrock of medicine.

I attempted to draw a diagram of personhood, but each time I did so I discovered a number of contradictions that seemed to defy any attempts to create a fixed map of its important elements. It appears that variables of personhood crisscross with one another more like ocean currents flowing into one another in different ways and at different times than like clearly delineated territories. Perhaps an analogy will be helpful. Attempting to observe and describe the process of personhood is like trying to describe an old house that doesn’t fit into clear-cut categories of a design professional:

“...old houses, with their successive annexes and all the objects, partially discordant but fundamentally in harmony with them, that have accumulated in them in the course of time, to apartments designed from end to end in accordance with an aesthetic concept imposed all at once from outside by an interior designer” (Bourdieu 1999: 13).
People don’t understand their personhood according to neat theoretical categories. However, there are still themes that are perceptible. I have attempted in this dissertation to explore the syndrome of HNPCC as a guest in the well-worn homes of peoples’ understandings rather than to act as a distant theoretical interior designer. Essentially, I have striven to obtain a “familiarity” with their understandings, a type of “solidarity beyond cultural differences” (Bourdieu 1999: 14-15). The stories that they have shared with me have hopefully helped me to develop a less theoretical idea of what it is to live with genetic susceptibility to HNPCC just as an anthropologist might attempt to advance a less ethereal notion of what it is to be a mountain peasant (Bourdieu 1999).

Human beings are survivors; part of being a human is to attempt to successfully navigate through our experiences of our selves to be a person in society. When we pass through the gateway of challenging experiences such as cancer, we expect and hope to heal, and to advance towards a fulfilling life. The narratives of the people interviewed here give some insight into the hope-filled strategies that people utilize to create agency, to evade danger to their personhood, to heal and to define themselves in ways that they can live with.

In a healing narrative, many things are possible. People consecrate roles rather than institutions, if only for a fateful moment. People genetically at risk for HNPCC can have more power than clinicians over their own lives. Pure relationships can be more important than the acquisition of commodities. Emotional capital can be more valuable than material capital. In a healing narrative, relationships are the most significant and the most meaningful in life planning. And, in the emplotment of healing, how we live is replaced by how should we live in our story.
The “practice of personhood” is a deeply social process: it is an “interpersonal achievement” (Nelson 2002: 35). Yet while patients and doctors evaluate one another they seldom engage in a dialogue about each other’s place in the other’s story (Frank 2002). The healing emplotment framework employed in this dissertation holds that personhood is a critical part of the narratives of people genetically at risk for HNPCC. By focusing on the importance of healing emplotment for people living with the risk for illness, it might be possible to promote a dialogue between physicians and patients. For example, could such an approach encourage the physician whose hand was on the doorknob during the entire consultation with the couple facing cancer to envision their account about him (his role in their story) and would the story that they tell about their experience in his office trouble him? Simply put: if he was able to see himself as a character in their story, then it would. If he were not able to see his part in their story and instead only saw their tumor and his medical treatment of it, then it would not. A theoretical approach that focuses on healing emplotment encourages us to see beyond illness and therapies to the people who live these experiences.

**Limitations of My Study**

The subjects in this study were a purposeful selection and not random sample. Given that this was a qualitative study aimed at exploring a new area and identifying its webs of meaning, it was designed to explore in-depth the accounts of a smaller number of subjects than would be necessary in a quantitative study that might identify associations between demographic and other factors and variations among individuals’ and families’ experiences of living at risk for HNPCC. The participants were predominantly women, which is consistent with both their use of health services and participation in other studies.
of this type. All the family participants in the research were Euro-Canadian and there were no visible minorities in the interview sample of people at risk for the HNPCC syndrome. This accurately reflects the ethnic distribution of the patients requesting consultations or those who are referred to the Hereditary Cancer Program. Cultural variations in individuals’ and families’ understandings of hereditary cancers are an interesting avenue for future research that may help to explain their limited participation in the Hereditary Cancer Program.

The way that I interpreted my informants’ perspectives was affected by the tenets of my discipline, I, too, am engaged in a type of meaning-making and knowledge production where my work is evaluated and judged against the values of an academic community. Therefore, I, too, am a “positioned subject” (Rosaldo 1996 (1989)). The very act of writing will dramatically transform the experiences and understandings of the people that I am studying. My role as a student in the discipline of anthropology has likely influenced the boundaries that I have placed around the events that I am studying. As well, the creation of the dissertation is not a neutral exercise for me. It is aimed at establishing my own status as an expert (Saris 1995). The analytical categories that I utilize and the issues focused on in this study have been influenced by the academy to which I subscribe. While utilizing the tenets of interpretive anthropology which assume that social actors symbolically construct their semantic worlds, I also intend to take note of recent anthropological criticism that notes that “ethnographies, no less than any other form of creative writing, are texts that privilege the perspective of their authors” (Erickson and Murphy 1998: 12). It is my ultimate hope that my social position as a Ph.D. student in anthropology has still allowed me to produce a convincing picture that
provides a momentary view into the compelling insights shared by people from their experiences with hereditary illness.

**Application and General Significance**

In summary, I hope that this investigation has been important for the following reasons:

- It has built on work on illness narratives and therapeutic emplotment in medical anthropology to develop the concept of healing emplotment that has at its core the ongoing management of personhood.

- It has contributed to research on the understandings of lay-perspectives of inherited illness and their relationship to clinical genetics and medicine. It has challenged the social construction of lay-perspective as independent from and contrasted from medical points of view.

- It has identified a need to develop more consistent application of standards of care for clinical surveillance of HNPCC through colonoscopy.

- It has identified a gap in the standard of care for families affected by HNPCC especially in relation to disclosure of a suspected diagnosis of HNPCC. It raises some ethical issues that may need to be discussed by key groups including: the BC Cancer Agency, the College of Physicians and Surgeons, the BC Medical Association and the Ministry of Health.

- It raised some questions about the current relationship between the culture of clinical genetics and the culture of medicine in BC in terms of clinical practice with respect to managing families at genetically at risk for the HNPCC syndrome. It has provided information on the institutional arrangement of oncology services in terms of the focus on tumors rather than families.

- It has highlighted the role of family members in health promotion and identified a possible area where families might require assistance in this role.

In the end, this study has highlighted the centrality of personhood as part of the ongoing process of healing for people managing the fateful moments of genetic susceptibility to disease.

**Ethical Considerations**

In this research, I attempted to be self-reflexive with respect to my role, not only in the production of anthropological knowledge but also to my influence over the social
field of study (Harries-Jones 1990; 1991). Initially, I was concerned that many of the individuals who would be interviewed in the study might not know very much about the genetic syndrome that they might carry. I was always very careful about subtly influencing their perspectives or motivations as I asked them about their perspectives about a possible familial cancer syndrome in their family. In particular, I was cautious not to raise concerns in the families that did not exist before my interaction such as worries about barriers to health insurance, risk to children, threats to employment as a result of risk for genetic susceptibility to illness. As part of my interactions with patients and families, a number asked me for information on genetics, treatment or prognosis. I was careful not to provide advice about suggested courses of action with respect to the pursuit of genetic information or medical interventions. I was always very clear about my role as a non-clinical researcher and deferred to the expertise of clinicians.

All aspects of this study were examined and approved by U.B.C. Research Ethics Board in addition to the Research Ethics committee of the B.C. Cancer Agency. I obtained written informed consent from every participant in the study prior to their being interviewed. As well, I have taken steps to ensure that the data collected in this study are secure and that confidentiality is preserved for the participants in this research.
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## APPENDICES

### APPENDIX I. Estimated Incidence and Mortality Rates for Cancer per 100,000

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<td>Mortality Rate Per 100,000</td>
<td>Incidence Per 100,000</td>
<td>Mortality Rate Per 100,000</td>
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(Adapted from the National Cancer Institute of Canada: *Canadian Cancer Statistics 1997*)

* Estimated Rates
APPENDIX II: GENERAL RESEARCH QUESTIONS

I. Interviews with individuals diagnosed with colorectal cancer (likely to be HNPCC)

A. Life history/ background: Please tell me about:
   • Your family history and background
   • Relationship status, children
   • Where your family lives, how frequently do you have contact with them (in person or by some other means: e.g. telephone)
   • Educational background
   • Occupation, employment status
   • Social activities
   • Friendship group: how often do you have contact with them?
   • What is a typical day (or week) like for you?
   • Your overall health, previous or present health problems

B. Family history/ experiences and knowledge of colon cancer:
   • Tell me about your experiences with colorectal cancer. Has it affected your life or that of other members of your family? If so, how so? (e.g. identity, sense of control, volition, agency)
   • When did you first learn that you were at risk for or had colon cancer?
   • Is there a family history of colon cancer? Please describe, in your own words, what this means? What have you been told about the heredity of colon cancer (e.g. inheritance, genetics, science, specific mechanisms of inheritance)?
   • Please describe, in your own words, your understanding of and ideas about the causes of colon cancer?
   • What do you understand about your risk status and your family risk status?
   • Did you have any prior knowledge of colon cancer? Was this connected to your family history of colon cancer?
   • Where did you learn about colon cancer (e.g. GP, family member, media, friends)
   • Can you describe how colon cancer has affected relationships with your spouse or partner, friends, siblings and other relatives? (e.g. family identity)
   • Can you tell me what factors have influenced the decisions which you have made with respect to your illness and treatment?
   • Can you tell me about any stigma which you have experienced with respect to colon cancer? (include worries as well as actual experiences of stigma)
C. Sharing Information about colon cancer and risk status

- Who knows about your colon cancer? who does not? why? (e.g. family, friends, colleagues, family doctor)
- Who knows about your family risk for HNPCC? who does not? why?
- What are your strategies for coping with colon cancer and family risk for HNPCC?

D. Predictive Testing for HNPCC

- Have you ever heard of genetic testing for HNPCC?
- What have you heard of genetic testing for HNPCC? What do you know about it?
- Where have you received information about genetic testing for HNPCC?
- If it were available in BC, then would you pursue genetic testing for HNPCC?
- What ideas or factors would influence your decision to (or not) to have genetic testing for HNPCC? (e.g. family or social relations) What benefits would the testing have? What draw-backs?
- Would you involve other family members in your decision to be involved in the genetic testing process? Who would you tell about your results? Who wouldn’t you tell? Why?
- Would you encourage other family members to be involved in the genetic testing process? Why or why not?
- How do you imagine that genetic testing might affect you and your family?
- How would you utilize the information received from a genetic test for HNPCC? (e.g. reproductive decisions, career choices, lifestyle, plans)
- Would the discovery of a genetic mutation for colon cancer in your family change your understanding or perception of your colon cancer? How so?

E. Experiences in the clinic, counseling and the research

- Have you been to a clinic, such as the BC Cancer Agency? What were your impressions? Did you come on your own?
- Did you learn anything new there?
- Are there any important areas or experiences which we should discuss which we haven’t covered in the interview?
- What do you think is most important about your experience of colon cancer?
- Is there anything that we have discussed in the interview which you would not want shared with your family members?
- Is there anything that you would like to add?
II. **Interviews with individuals not diagnosed with colorectal cancer but at high risk for the HNPCC mutation (family members)**

A. **Life history/ background: Please tell me about:**

- Your family history and background
- Relationship status, children
- Where your family lives, how frequently do you have contact with them (in person or by some other means: e.g. telephone)
- Educational background
- Occupation, employment status
- Social activities
- Friendship group: how often do you have contact with them?
- What is a typical day (or week) like for you?
- Your overall health, previous or present health problems

B. **Family history/ experiences and knowledge of colon cancer:**

- Tell me about your family’s experiences with colorectal cancer. Has it affected your life? If so, how so? (e.g. family identity, sense of control, volition, agency)
- Is there a family history of colon cancer? Please describe, in your own words, what this means? (e.g. inheritance, genetics, science, specific mechanisms of inheritance)
- When did you first learn that someone in your family had colon cancer and that your family may be at higher risk for this cancer? How was it described to you (family cancer syndrome, HNPCC)?
- Please describe, in your own words, your understanding of and ideas about the causes of colon cancer in your family?
- What do you understand about your risk status and your family risk status?
- Did you have any prior knowledge of colon cancer? Was this connected to your family history of colon cancer?
- Where did you learn about colon cancer (e.g. GP, family member, media, friends)
- Has the presence of colon cancer in your family has affected relationships between family members? (e.g. family relations or family identity)
- Can you tell me what factors have influenced the decisions which you have made with respect to your illness and treatment?
- Can you tell me about any stigma which your family has experienced or worried about with respect to colon cancer?

C. **Sharing Information about colon cancer and risk status**

1. Who knows about colon cancer in your family? who does not? why? (e.g. family, friends, colleagues, family doctor)
2. Who knows about your family risk for HNPCC? who does not? why?
3. What are your strategies for coping with colon cancer and family risk for HNPCC?

D. **Predictive Testing for HNPCC**
1. Have you ever heard of genetic testing for HNPCC?
2. What have you heard of genetic testing for HNPCC? What do you know about it?
3. Where have you received information about genetic testing for HNPCC?
4. If it were available in BC, then would you pursue genetic testing for HNPCC?
5. What ideas or factors would influence your decision to (or not) to have genetic testing for HNPCC? (e.g. family or social relations) What benefits would the testing have? What draw-backs?
6. Would you involve other family members in your decision to be involved in the genetic testing process? Who would you tell about your results? Who wouldn’t you tell? Why?
7. Would you encourage other family members to be involved in the genetic testing process? Why or why not?
8. How do you imagine that genetic testing might affect you and your family?
9. How would you utilize the information received from a genetic test for HNPCC? (e.g. reproductive decisions, career choices, lifestyle, plans)
10. Would the discovery of a genetic mutation for colon cancer in your family change your understanding or perception of your colon cancer? How so?

E. Experiences in the clinic, counseling and the research

1. Have you been to a clinic, such as the BC Cancer Agency? What were your impressions? Did you come on your own?
2. Did you learn anything new there?
3. Are there any important areas or experiences which we should discuss which we haven’t covered in the interview?
4. What do you think is most important about your experience of colon cancer?
5. Is there anything that we have discussed in the interview which you would not want shared with your family members?
6. Is there anything that you would like to add?
III. Interviews with professionals: (e.g. oncologists, GPs, surgeons, radiologists, nurse educators, genetic counselors)

A. Overview
1. Your professional background
2. Educational background

B. Hereditary Non-Polyposis Colorectal Cancer
1. Tell me about your understanding of hereditary colorectal colorectal cancer.
2. When did you first learn that about HNPCC? Where did you learn about HNPCC?
3. Have you treated many people with HNPCC?
4. Please describe your understanding of and ideas about the causes of HNPCC?
5. What do you tell patients with family cancer syndromes about HNPCC?
6. What are the differences between HNPCC and sporadic colon cancer? (e.g. illness, treatment, prognosis)
7. Can you tell me about any stigma which patients experience with respect to colon cancer? (include worries as well as actual experiences of stigma) Is it different for hereditary colon cancer?

C. Sharing Information about colon cancer and risk status
1. Who do you tell in a family about hereditary colon cancer? Who don’t you tell? (e.g. patient, immediate family members, spouse). How is this decided?
2. Does your professional responsibility range beyond the patient in order to include the family in the case of genetic colon cancer?
3. What barriers exist (if any) to patient and family understanding of hereditary colon cancer? How do well do patients and family members understand genetics, risk, prognosis, treatment options?
4. What strategies do employ in order to help families cope with family cancer syndromes like HNPCC (e.g. surveillance, counseling, education, testing, referral to other agencies)?

D. Predictive Testing for HNPCC
1. Have you ever heard of genetic testing for HNPCC? What do you know about it?
2. Where did you learn about genetic illness (e.g. formal education, media, journal articles, professional correspondence, post-graduate education)?
3. Where have you received information about genetic testing for HNPCC?
4. If it were available in BC, then would you suggest that your patients pursue genetic testing for HNPCC? What do you tell patients about genetic testing for HNPCC (given that it is not available here but is in other places such as Ontario or the United States?).
5. What ideas or factors would influence your decision to (or not) suggest that patients pursue genetic testing for HNPCC? What, in your view, are the benefits of predictive testing for HNPCC? What are the draw-backs?

6. What, in your view, are the possible impacts of genetic testing for HNPCC upon patients and families?

7. How would you, as a professional, utilize the information received from a genetic test for HNPCC? (e.g. to help patients to make reproductive decisions, career choices, lifestyle, plans)

8. Would the availability of genetic testing for HNPCC affect you as a professional? If so, how so?

9. Is there anything that you would like to add?
### Digital Rectal Exam
In this exam, a physician inserts their gloved finger into the rectum of the patient to search for irregularities or polyps. It is usually combined with other screening methods. This test is completed in a physician’s office.

### Fecal Occult Blood Testing
This testing procedure, that is completed by taking a stool sample collected at home or in a physician’s office from a patient, results in a 15 to 33% reduction in colon cancer mortality according to controlled investigations (Burt 2000). A series of stool samples are inspected for blood in this test. This technique is relatively effective in locating large lesions in the colon but is not as effective in finding smaller ones. This technique is a lab test and is widely available and can be administered by a general practitioner without referral to a specialist. When a general practitioner can administer a test, this means that there is not a waiting period to see a specialist such as a gastroenterologist. There is no risk to the patient associated with this test. The cost of the procedure is covered by medical services plan of BC.

### Barium Enema
This technique refers to a special x-ray that is taken after a barium solution (sometimes combined with air) is inserted into the bowel so that it can be more effectively scanned for problems by a radiologist (Canadian Cancer Society 2002). No systematic studies have been completed of the efficacy of barium enema in colon cancer screening. However, this technique is generally understood to be less effective in detecting colon cancer and lesions.

### Sigmoidoscopy
This is a rigid scope that is inserted into the entrance the rectum and lower part of the colon. This is the traditional method for detecting colon cancer. It is more effective than the fecal occult blood test with a 59 to 80% reduction in mortality due to colon cancers (Burt 2000). General practitioners can perform this test in their office. This risk is minimal to the patient with this test. The cost of the procedure is covered by the medical services plan.

### Flexible Sigmoidoscopy
The flexible sigmoidoscopy is similar to the traditional sigmoidoscopy except that its end is flexible and can see more angles and further into the colon than its forerunner. The sigmoidoscopy focuses on the bottom third of the large intestine including the rectum and the sigmoid colon. This means that it is more versatile and successful in detecting lesions. It can also be used by general practitioners. The cost of the procedure is covered by the medical services plan.

### Colonoscopy
The colonoscopy is the gold standard in terms of detecting lesions in the colon. In the case of HNPCC, it has been shown in a 15 year trial to cut the risk of CRC by 50 per cent, to prevent deaths due to colorectal cancer and lower overall mortality in families affected by HNPCC by 65 percent (Jarvinen, et al. 2000). It is a flexible scope that is longer than the sigmoidoscopy so that the entire colon can be seen during examination. It is connected to a video monitor so that the physician can carefully examine the colon. It detects lesions that cannot be reached by the relatively short sigmoidoscopy. Although general practitioners can be trained to administer this test, it is typically completed by a specialist, a gastroenterologist. It is a more dangerous procedure and the patient has to be partially sedated for the test. There is a shortage of both gastroenterologists as well as the instruments needed to complete the test, the colonoscope. This means that there is a long waiting list (several months) for the procedure. There is a minimal risk to the patient in terms of perforations to the colon due to the procedure (these can result in death). The cost of the procedure is not covered by the medical services plan unless it is clinically indicated. This means that it cannot be used for screening purposes. It is the most expensive procedure of the screening techniques.

### Virtual Colonoscopy
This technique involves pumping air into the colon before utilizing a specific type of CT scan, either a helical or spiral CT, to scan the colon. It is considered to be more accurate than a barium enema but not as effective as an actual colonoscopy in detecting smaller polyps (American Cancer Society 2002). The advantage to the virtual colonoscopy is that it does not carry the risk of perforation associated with colonoscopy (approximately 1 in 1500).
Understandings of Cancer Genetics: The Case of Hereditary Colon Cancer

In this case, the second interview will occur before you or your relative receive the results of a predictive test and the second will take place three months to one year after the results are known. You will be interviewed at your convenience in your home, or if you prefer, at the University of BC or BC Cancer Agency. Each interview will last approximately one and a half hours (total of four and a half hours over the course of a year). This research is part of the research requirements for graduate research: a Ph.D. in anthropology at UBC.

In the first interview, you will be asked to describe your experience with and understanding of hereditary colon cancer, your attitude towards the possibility of predictive testing for this disorder, and the impact of this disease upon you and your family. If testing is available, we would like to schedule second and third interviews in order to ask you to describe the impact of genetic information and the results of a predictive test on you, other people in your family being tested, your relationships, and your family as a whole. We hope that the information which you provide will help us to understand family member's concerns about predictive testing and the effects of genetics information upon families. We also hope that it will help us to further assess and improve counseling available to individuals who receive predictive testing and their families.

The interview will be tape recorded only if you agree. You may request that the names of any individual deleted from the tape during or after the recording is made. Information provided during the interviews will be kept confidential. No information will be provided to others (including family members) or used in publications which will identify you without specific, written consent. If you feel that there is more that you would like to say, then a second interview will be scheduled. Your identity as a subject in this study will be kept confidential. Records in the Principal Investigator's possession will be coded to hide the subject's identity; kept in a locked filing cabinet and under password protection on a computer hard drive in a secure office.

This study is sponsored by the Social Science and Humanities Research Council of Canada. You may withdraw from any part of the study at any time. If you decide not to participate or withdraw, your decision will not adversely affect you or your family member's present or future participation in the Hereditary Cancer Program or any clinical care you or they receive at the BCCA. Your rights to privacy are protected and guaranteed by the Freedom of Information and Protection of Privacy Act of British Columbia. This act lays down safeguards respecting your privacy and also gives you the right to access, and if need be, correct any errors in your personal information. Further details about the act are available on request.