

Development of a Method of Analysis for Identifying an  
Individual Patient's Perspective in Video-recorded Oncology Consultations

by

Sara Healing  
B.A., University of Victoria, 2007

A Thesis Submitted in Partial Fulfillment  
of the Requirements for the Degree of

MASTER OF SCIENCE

in the Department of Psychology

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## **Supervisory Committee**

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**ABSTRACT**

Patient-centred care has become an important model for health-care delivery, especially in cancer care. The implementation of this model includes patient-centred communication between the clinician and his or her patient. However, most research on patient-centred communication focuses on the clinicians' initiative: what clinicians should do and what information they should seek to elicit from patients. It is equally important to recognize what each individual patient can contribute about his or her unique perspective on the disease, its treatment, and the effects on what is important to this patient. This thesis reports the development of a system for analyzing over 1500 utterances made by patients in eight video-recorded oncology consultations at the British Columbia Cancer Agency, Vancouver Island Centre. The analysis distinguishes between biomedical information that the patient can provide and *patient-centred information*, which contributes the individual patient's unique perspective on any aspect of his or her illness or treatment. The resulting analysis system includes detailed operational definitions with examples, a decision tree, and .eaf files in ELAN software for viewing and for recording decisions. Two psychometric tests demonstrated that the system is replicable: high inter-analyst reliability (90% agreement between independent analysts) on a random sample of the data set and cross-validation to the remainder of the data set. A supplemental idiographic analysis of each consultation illustrates the important role that patient-centred information played in these consultations. This system could be an important tool for teaching clinicians to recognize the individual information that patients can provide and its relevance to their care.

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## ACKNOWLEDGMENTS

I would like to thank Dr. Janet Bavelas, Dr. Jennifer Gerwing, and Christine Tomori for their guidance and support. This thesis would not have been possible without Dr. Bavelas's invaluable direction, dedication, and unwavering support.

I would also like to thank Dr. Grant MacLean, Jennifer Finck, and Dr. Peter Kirk for providing the clinical direction for this project.

It is a pleasure to thank the multidisciplinary team at the Pain and Symptom Management/Palliative Care Clinic and the management at the BCCA for allowing me to do my research at their agency and for supporting my work. A special thanks to Brenda LaPrairie and Jennifer Finck, both wonderful nurses at the BCCA, for being so dedicated to my project and helping me to recruit the patients for my study.

A special thanks to Ruth Sawbridge for taking such care in transcribing the consultations.

Finally, a deep thanks to my dad, David Healing, for the hours spent learning Elan and my analysis system, and to my family and partner for each of their encouragement and support.

This thesis was supported by a traineeship from a Canadian Institutes of Health Research —New Emerging Team grant (Overcoming barriers to communication in end-of-life and palliative care) to the Vancouver Island Health Authority; and a Development Catalyst grant to Dr. Grant MacLean and Jennifer Finck, R.N., from the Vancouver Island Research Advisory and Development Committee at the British Columbia Cancer Agency, Vancouver Island Centre.

**DEDICATION**

I dedicate this thesis to all of the patients who were willing to take part in my study at this challenging time in their lives and to my friend Ashley Brear, who died of Hodgkins Lymphoma in 2006. Her ability to be open about her life and to describe her unique experiences as she went through her cancer treatment made me realize the importance and value in capturing each individual patient's perspective.

## **CHAPTER ONE**

### **INTRODUCTION, LITERATURE, AND GOALS**

The purpose of this thesis is to develop an analysis system that can identify and distinguish between the different kinds of information that patients contribute in consultations with their clinicians. Specifically, this analysis system should be able to identify patient utterances that contribute information about the individual patient's perspective.

#### **Background**

Prior to collecting the data for this study, I did a practicum at the British Columbia Cancer Agency, Vancouver Island Center (BCCA-VIC). My particular focus was on the often-cited ideals of patient-centred care and shared decision-making. I was familiar with the definitions of patient-centred care and communication, as well as shared decision-making, but I wondered what these would look like in practice. More specifically, when the oncologist and patient are having a patient-centred conversation, what are they doing and saying? During this practicum, I was fortunate to be able to sit in on consultations with oncologists and their patients and families and to observe their conversations. One of the first things I noticed was that my perceptions of whether a conversation was patient-centred or not seemed to have more to do with what kind of information the patient was providing to the physician than with what the physician was doing. This was intriguing because most of the literature about patient-centred care has been concerned with what the clinician is doing, for example, the types of questions the clinician asks. I could not recall any articles that characterized patient-centred communication as the information that the patient was contributing. During my

observations of oncologists and patients interacting, I also became interested in the process by which they made decisions together. I knew that another ideal in cancer care at this agency was to achieve shared decision-making between the patient and the oncologist. However, how would one know that a decision was shared? It became clear in my observations that, in order for a decision to be shared, it was necessary that both the physician and the patient contributed information relevant to the decision. I had a good idea of the kinds of information from the physician that would be essential to the decision-making process (e.g., diagnosis, types of treatments available, side effects of treatments, statistics, prognosis information), but I wondered what kinds of information would be considered relevant *patient* information in a shared decision-making context. This led to the conclusion that, in order to be able to fully conceptualize patient-centred communication or shared decision-making, I would need to know more about the different kinds of information that patients contribute and how I could recognize information that contributed a particular individual patient's perspective. These musings helped narrow down the research questions that I needed to answer:

1. Within a consultation, a patient will contribute many kinds of information; what are these different kinds?
2. What precise features distinguish between the different kinds of information?
3. In order for a consultation to be considered patient-centred, a patient must contribute his or her own individual perspective. What are the characteristics of patient contributions that include the individual patient's perspective?

These questions guided the literature review for this thesis.

### **Notes on Terminology**

The literature on patient-centred care often focuses quite broadly on optimizing communication processes between the patients, family, and health care delivery teams--not just the patient-physician dyad. Thus, using terms that are more general is more reflective of the state of the literature as a whole. A monograph commissioned by the National Cancer Institute and authored by Epstein and Street (2007) conveyed this broad focus by using the term “patient” to refer to both the patient and his or her family and using the term “clinician” to refer to all professionals who provide care to patients within the cancer care context, not just to physicians. I use the same terms and meanings throughout the literature review that follows, which also focuses on cancer care settings.

### **Patient-Centred Care**

Effective patient-centred care is an important aspect of health care delivery (McCormack et al., 2011). It is even more crucial in cancer care settings, where most patients have to deal with stress, uncertainty, complex information, and life-altering medical decisions (Epstein & Street, 2007). Patients diagnosed with cancer usually have little knowledge about the cancer care system and must navigate their way through numerous consultations with different specialists, surgeons, oncologists, and nurses, most of whom they have never met before. It is also common that they start out with little knowledge about their disease and must learn about the numerous details of diagnosis, prognosis, and treatment for their particular form of cancer. Moreover, they have to understand complex information about their disease, and make difficult treatment decisions, while at the same time dealing with the stress of a life-altering, perhaps life-threatening, disease. In recent years, patient-centred care has become more and more

accepted as the ideal care delivery model in cancer settings because of the reported benefit to patients who receive care delivered in this manner (de Haas & Koedoot, 2003; Kahn, Schneider, Malin, Adams, & Epstein, 2007; Stewart, 2001).

### **Defining Patient-Centred Care**

In the past 40 years, an extensive body of literature has emerged advocating a “patient-centred” approach to health care. Yet despite the popularity of the concept, there has been little consensus as to its meaning. Mead and Bower (2000) did an extensive literature review and pointed out that the definitions of patient-centred care have evolved over the past 40 years. For example, Balint (1969) described patient-centred medicine as “understanding the patient as a unique human being” (p.269), while Byrne and Long (1976) referred to it as a style of consulting in which the doctor uses the patient's knowledge and experience to guide the interaction. McWhinney (1989) described the patient-centred approach as one in which “the physician tries to enter the patient's world, to see the illness through the patient's eyes” (p. 35). Numerous studies have also highlighted the importance of giving information to patients and involving them in decision-making (e.g., Barry & Edgman-Levitan, 2012; Grol, de Maeseneer, Whitfield, & Mokkink, 1990; Lipkin, Quill, & Napodano, 1984; Weston, 2001; Winefield, Murrell, Clifford, & Farmer, 1996). For Laine and Davidoff (1996), patient-centred care is “closely congruent with, and responsive to patients' wants, needs and preferences” (p. 152). A report from the Institute of Medicine (2001) proposed that patient-centred means considering patients’ cultural traditions, personal preferences and values, family situations, social circumstances, and lifestyles.

Stewart (2001) presented one of the most comprehensive definitions of patient-centred care, based on evidence gathered from studies done in England, Canada, and the United States. Stewart (2001) defined *patient-centred care* as care that

(a) explores the patients' main reason for the visit, concerns, and need for information; (b) seeks an integrated understanding of the patients' world—that is, their whole person, emotional needs, and life issues; (c) finds common ground on what the problem is and mutually agrees on management; (d) enhances prevention and health promotion; and (e) enhances the continuing relationship between the patient and the doctor (p. 445).

Notice that, in this definition, patient-centred care is a set of broad goals that could be met in a variety of ways, for example, by designing a health care system so that it is more easily navigated by patients. Another way the goals of patient-centred care could be implemented is during the dialogue between clinician and patient. In fact, one of the primary ways in which patient-centred *care* is delivered is through patient-centred *communication*.

### **Focusing on Patient-Centred Communication**

The term *patient-centred communication* presupposes that certain kinds of dialogues with patients will optimize patient-centred care. Over the past decade, it has become widely accepted in both Canada and the United States that an understanding of how to optimize the communication process between patients and clinicians is essential to the goal of reducing the burden of cancer (Canadian Medical Association, 2007).

Despite this recognition of a need to understand patient-centred communication, there has been little consensus on its definition. In 2007, in order to address the need for a

definition and an understanding of how patient-centred communication can be optimized, the American National Cancer Institute commissioned a major monograph, *Patient-Centred Communication in Cancer Care: Promoting Healing and Reducing Suffering* (Epstein and Street, 2007). This 200-page report provided a critical synthesis of the existing literature on patient-centred communication, including information obtained in a symposium with a number of internationally recognized experts in the areas of communication, oncology, health care delivery, and quality of care.

The Epstein and Street (2007) monograph provided a comprehensive conceptual framework that defined the core elements of patient-centred communication in cancer care. Specifically, it defined patient-centred communication in terms of the processes and outcomes of the patient-clinician interaction:

1. Eliciting, understanding, and validating the patient's perspective (e.g. concerns, feelings, expectations)
2. Understanding the patient within his or her own psychological and social context
3. Reaching a shared understanding of the patient's problem and its treatment
4. Helping a patient share power by offering him or her meaningful involvement in choices related to his or her health (Epstein & Street, 2007, p.2)

This definition is an improvement over the earlier, more abstract definitions of patient-centred communication because it explicated the goals of patient-centred communication and implied some of the processes involved in it. In Chapter 1, Epstein and Street (2007) described in detail the kinds of behaviours that clinicians might choose to engage in, in order to be patient-centred. For example, the clinician would be “[asking] about family

and social context,” “providing clear, jargon free explanations,” and “soliciting the patient’s beliefs, values, and preferences” (p. 4). This chapter also describes some of the “active” behaviours of patients that would be patient-centred, although the behaviours described are fewer and less detailed than the descriptions of clinicians’ behaviours. Implicit in the definition of patient-centred communication, as well as in the unequal emphasis on clinician versus patient contributions, is an assumption that patient-centred communication is primarily something that clinicians do.

### **The Role of the Patient in Patient-centred Communication**

One of the key goals of patient-centred communication is to centre the communication around the *patient* and to help the *patient* to become more actively involved in the communication and decision-making processes. However, most of the studies and measures of patient-centred communication limit their assessment to the clinician’s communication, “thus implicitly assuming [that patient-centred communication] is a clinician attribute” (McCormack et al., 2011, p. 1086). Compared to the number of studies that examine what clinicians need to do in order to encourage patients to become more active in their care, there are very few studies that examine the role that patients play in patient-centred communication. In their review of the measurement of patient-centred communication in cancer care, McCormack et al. (2011) emphasized recent critiques suggesting that, in order to have a comprehensive measure of patient-centred communication, researchers must also characterize and assess patients’ communication.

Some studies have begun to address the need to understand more about the patient’s role within a patient-centred model (e.g., Epstein & Street, 2007; Ford,

Fallowfield, & Lewis, 1996; Katz, Jacobson, Veledar, & Kripalani, 2007; Street, Gordon, Ward, Krupat, & Kravitz, 2005). Ford et al. (1996) examined both physician and patient utterances (an utterance is approximately a speaking turn) in consultations that included the delivery of bad news. When patients' questions or utterances contributed psychosocial information (e.g., "information re emotional issues and lifestyle"; p. 1513), they coded these as patient-centred.

Street et al. (2005) examined how factors such as the patient's personal characteristics and the physician's communication style affected active patient participation. Their operational definition of *active patient participation* included (1) asking questions, defined as utterances in interrogative form intended to seek information and clarification ( e.g., "When should I get my next checkup?"); (2) expressions of concern, that is, utterances in which the patient expressed worry, anxiety, fear, anger, frustration ( e.g., "I'm worried about cancer given my family history"); (3) assertive responses, in which the patient expressed his or her rights, beliefs, interests, and desires as in offering an opinion, making recommendations, making a request, disagreeing, or interrupting (e.g., "I would like to see if it gets any worse before I think about surgery").

In a later review, Epstein and Street (2007) identified *active patient behaviors*, which included: "asking questions"; "communicating assertively" (including offering opinions, stating preferences, interrupting if necessary, sharing beliefs about health, and introducing topics for discussion); "expressing concerns and feelings" (e.g., expressing emotions, disclosing fears, noting frustration); and "telling one's health story in the context of one's own life" (p. 5). Several studies focused on patients' questions in particular (Street, et al., 2005; Katz, et al., 2007).

Although not explicitly framed within patient-centred communication, a review by Zimmerman, Del Piccolo, and Finset (2007) focused on one kind of patient communication. They identified 58 studies that, in their view, had examined patients' *cues* and *concerns*. Their definition for inclusion was very broad and included any observational study with a measure of patient utterances that represented "an issue that is experienced by the patient to have a certain subjective importance and a negative emotional impact" (p. 439).

**Two different focuses on patient communication.** The above studies illustrate how many researchers have begun to explore the patient's role and what the patient might do in patient-centred consultations. It is interesting to notice that these studies are examining patient communication at two different levels. One focus is on whether patients are participating actively and how they do so. For example, do the patients ask questions or interrupt the clinician? Studies about how actively patients are participating across different conditions or variables might give some overall idea of the behaviors patients engage in during conversations that are patient centred. However, they do not provide any information about what information patients contribute to the conversation, that is, what they actually talk about.

The other focus is on what topics patients talk about, for example, psychosocial issues or cues and concerns. There are a number of studies on what patients talk about, but the focus is almost entirely on psychosocial or negative emotional topics. Ford et al., (1996) proposed that "specific aspects of clinicians' basic interviewing techniques discourage patients disclosing details concerning their psychological state" (p.1511). The same assumption led Zimmerman et al. (2007) to focus their review on "patients'

emotions, worries, needs and other topics of perceived and immediate importance for the patient” (p.438). However, by emphasizing an important type of information that clinicians might otherwise neglect, these studies focus narrowly on only one topic, namely, patient's negative emotions. This topic is not representative of the wide variety of information that patients might contribute when expressing, for example, their goals, their values, their need for information, their understanding of their disease--all parts of the definition of patient-centred communication. Thus, even the studies of what patients talk about are limited to certain pre-determined categories of information. The next section will explore the assumptions that lead to this methodological approach.

### **Nomothetic versus idiographic methods**

One similarity of the studies reviewed in the above section was that the vast majority were quantitative in that they categorized and aggregated utterances in a way that let them study patients-in-general, for example, examining which physician behaviours elicited patient utterances about cues and concerns. These studies follow a typical *nomothetic* approach, which aims for what is abstract, general, or universal (Reber, Allen, & Reber, 2009, p. 512) and which permits comparisons across patients by using the same set of categories for all individual patients. Because the goal of a nomothetic approach is to learn about patients-in-general, the analysis would disregard what a particular patient had said once it was fitted into a nomothetic category. Obviously, this approach would not be helpful when the goal is to capture an individual patient's perspective.

The alternative methodological approach is *idiographic*, which aims for the concrete, the individual, or the unique (Reber et al., 2009, p. 368). Several authors have

suggested that physicians should tailor their approach to each individual patient (Hudak, Hogg-Johnson, Bombardier, McKeever, & Wright, 2004; Zandbelt, Smets, Oort, & de Haes, 2005; Institute of Medicine, 2001). When a clinician sits down with a patient to practice patient-centred communication, they will of course discuss nomothetic biomedical information, but to be able to recognize and incorporate the patient's unique perspective, the clinician must take an idiographic approach (Bleakley & Bligh, 2008). The clinician must treat, assess, and communicate with this particular patient, not with patients-in-general. An idiographic measure is designed for this individualized information; it is not designed to be aggregated across patients.

It is implicit in the ideal of patient-centred communication that each conversation between clinician and patient is unique and should be centred around that individual patient. Clinicians need to be able to gather information from a particular patient, who has a particular condition, a particular set of life circumstances, and a particular set of priorities even though each individual patient may convey this information in many different ways. I propose that it is necessary to know how each *individual patient's perspective* emerges in a conversation with a clinician. Information about abstracted categories that patients-in-general use— such as asking questions or talking about negative emotions -- is not likely to be helpful to a clinician faced with a conversation with an individual who has his or her own way of imparting information.

Specifically, a shift to focusing on the information contributed in individual patient utterances may be more helpful when considering the patient's role in patient-centred communication for several related reasons. Within a patient-centred consultation, a clinician will need to gather information from a particular patient. Invariably, the

patient will need to provide some biomedical information to the physician so that the physician can engage in diagnosis and prognosis. But if the consultation is going to be considered truly patient-centred, then the patient will also need to provide information that gives his or her individual perspective on both biomedical and other topics. Such a conversation would be patient-centred because the individual patient was able to contribute his or her perspective on all of the issues that were personally relevant. Whether this information was contributed through assertive responses, questions, or expressions of concern will not matter in this particular conversation. What will matter is that the patient provided the information and that the clinician recognized the information and incorporated it into their consultation.

It is therefore important that clinicians be able to recognize patient utterances that contribute information about each individual patient's perspective. It would be helpful to provide clinicians with an analysis of patient utterances that reveals the information that individual patients can contribute and that distinguishes between biomedical information and information that contributes to an understanding of an individual patient's perspective. More broadly, many of the goals of patient-centred communication require a knowledge exchange between patient and physician. For example, in shared decision-making, both parties must share information: the clinician offers options and describes their risks and benefits, and the patient expresses his or her preferences and values (Barry & Edgman-Levitan, 2012). In order for shared decision-making to be successful, the clinician will have to be able to recognize the patient's preferences and values within the information that the patient contributes. A knowledge of the kinds of information that individual patients provide about their preferences and values would presumably help

physicians with shared decision-making. For all of the above reasons, it would be highly desirable to teach medical students to recognize the individual patient's perspective and its importance in any practice setting. This thesis reports the development of an explicit and replicable idiographic analysis system for identifying patients' utterances that contribute information (content) about each patient's individual perspective.

## CHAPTER 2

### METHOD

This chapter includes all of the procedures required for collecting the data: ethics review, recruitment of clinicians and patients, equipment, location, the pre-and post-consultation interviews, recording the consultation, debriefing, and data preparation.

#### **Ethics Review**

Research by University of Victoria students that involves patients and clinicians at the BCCA requires ethics approval from both the University of Victoria's Human Research Ethics Board (HREB) and the Behavioural Research Ethics Board of the University of British Columbia (UBC), which reviews any research that takes place at the BCCA. UBC uses the Researcher Information Services (RISe) system for ethics applications; this system requires the completion of several steps. First, it was necessary to take a tutorial on the Tri-Council Policy Statement and to pass a test in order to receive a certificate showing that I understood the policy. The ethics application itself included a full research proposal, all of which was submitted electronically. The UVic HREB form is a 19-page paper application with a summary of the research. Both Research Ethics Boards approved this research with minimal changes.

#### **Participants: Clinicians**

The clinicians in the study were seven physicians and one nurse from a variety of departments at the British Columbia Cancer Agency, Vancouver Island Centre (BCCA-VIC). Two physicians and the nurse worked in the Pain and Symptom Management Clinic; one physician was in Medical Oncology; and four were in Radiation Oncology. The clinicians were between 40 and 65 years old. Their specialties were nursing (1),

general practice oncology (1), medical oncology (1), radiation oncology (4), and palliative medicine (1). One physician was in two different consultations.

**Recruitment and consent.** One of the members of our research team, Dr. Grant MacLean, assisted in the recruitment of physicians. He sent an e-mail to physicians at the BCCA, telling them about the study and asking them to get in touch with me if they were interested in learning more about the study. In addition, I made two formal presentations to potential participants and other employees at the BCCA-VIC in order to describe the study, answer questions, and address any concerns they might have. When a clinician expressed interest, there was a face-to-face meeting to review the consent form and answer any additional questions. Each clinician left the meeting with a consent form (Appendix A1) and an agreement to take a day to think about whether or not they wanted to participate. When they indicated that they were interested in participating in the study, they signed the consent form and arranged for me to collect it.

### **Participants: Patients**

There were eight patients and a total of six accompanying spouses. Each patient was coming to the BCCA-VIC to meet a physician or a physician-nurse team. Three patients had appointments in the Pain and Symptom Management Clinic (two were follow-up appointments, and one was a new appointment), and five patients had appointments with an oncologist. There were two female and six male patients. The patients had various types of cancer (breast cancer, ovarian cancer, lung cancer, prostate cancer, colon cancer, and melanoma) and were at different stages in their treatment. The main criterion for recruiting patients was their willingness to participate in our study, their fluency in English, and their competence to consent. Ideally, the patients would be

meeting the physician for the first time in order to minimize the possibility that they would have developed common ground that the analyst would not understand. However, three of the patients who consented had met the physician previously and this turned out not to be a problem during the analysis. The patients ranged in age from 65 to 89 years of age. Three of the patients had appointments at the Pain and Symptom Management Clinic; these three have since passed away. See Table 1 for a list of patient characteristics compiled from information gleaned from their consultations. (The ethics approval for this study did not include access to the patients' medical files.)

Six of the eight patients brought spouses with them to their appointment. Two of the male patients did not have a spouse or other family member with them. One patient's husband was present for only the second half of the consultation.

**Recruitment and consent.** The RISE recruitment process for patients had several steps. First, once a physician had agreed to participate in the study, a nurse needed to identify new patients of this physician; two nurses had volunteered to do this. Second, the nurses phoned these new patients, gave them a brief description of the study, and asked whether they would like to hear more about it. (See Appendix B1 for a copy of the recruitment script for this stage.) If a patient was interested in hearing more about the study, the nurse asked for permission to pass the patient's contact information on to me. The nurses did not keep records of how many patients declined. Third, I phoned the patients who had agreed, gave them a fuller description of the study, and answered any questions they had. (See Appendix B2 for a copy of the recruitment script for this stage.) The patients who were still interested in participating in the study at the end of the telephone conversation provided an e-mail or mailing address where they could

Table 1

*Patient Characteristics*

Group Number	Age	Type of Cancer	1 <sup>st</sup> or 2 <sup>nd</sup> Cancer Diagnosis	Spouse present	Type of Consult
1	76	Ovarian	1st: Breast 2 <sup>nd</sup> : Ovarian	Yes, husband	Medical Oncology
2	71	Breast	1 <sup>st</sup> : Breast 2 <sup>nd</sup> Breast	Yes, husband for 2 <sup>nd</sup> half of conversation	Radiation Oncology
3	69	Prostate	1st	No	Radiation Oncology
4	80?	Prostate	1st	Yes, wife	Radiation Oncology
5	87	Lymphoma	1st	Yes, wife	Pain and Symptom Management
6	74	Prostate	1st	No	Radiation Oncology
7	Unknown	Colon cancer	1st	Yes, wife	Pain and Symptom Management
8	Unknown	Melanoma	1st	Yes, wife	Pain and Symptom Management

receive the consent form. The ethics procedure required that they receive the consent form (Appendix A2) at least seven days in advance of their appointment so that they would have time to read it carefully, talk it over with family members, and consider whether or not they wanted to be part of the study. At the end of the phone conversation, I also asked that, if they did choose to be part of the study, they would come 15 minutes early for their appointment. Finally, when they arrived for the

appointment, I met the patient and any accompanying spouse in person, introduced myself again, and presented an identical consent form for the patient (Appendix A2) and any spouse (Appendix A3) to sign before conducting the pre-consultation interview.

### **Equipment**

A Cannon GL2 portable camera with Mini Digital Video Cassettes and either a Crown Sound Grabber II directional microphone or the built-in camera microphone recorded the consultations. A Samsung handheld digital audio device recorded the pre- and post consultation interviews. Broadway software ([www.b-way.com](http://www.b-way.com)) captured the recordings from the video cassettes and compressed them into MPEG format for analysis with the ELAN annotation tool (<http://tla.mpi.nl/tools/tla-tools/elan/>; Wittenburg, Brugman, Russel, Klassmann, & Sloetjes, 2006; Brugman & Russel, 2004).

### **Setting and Video Recording**

The video recording took place in several consultation rooms located in the BCCA-VIC. The camera was on a cart in the corner of the room, positioned to capture both the clinician's and patient's faces. The clinician and patient sat face to face, slightly off-centre from each other to facilitate the camera view. In the consultation with both the physician and nurse, the camera captured both of them as well as the patient. Spouses usually sat next to the patient, on the periphery, with their side to the camera. The microphone was on the counter near where the clinician and patient sat.

### **Procedure**

**Advance preparation.** An hour before the scheduled consultation, I met with a senior nurse who looked up which clinic the consultation was to take place in and took me to that area to meet the patient-care aides and any other staff who were working in the

clinic at the time. The care aides indicated the assigned consultation room, and I set up the room by positioning the chairs, cart, camera, and microphone as described above. When the patient and spouse arrived in the clinic, I met with them in the waiting area, collected the signed consent form from each patient and spouse, and answered any last-minute questions they had.

**Pre-consultation interview.** Approximately 15 minutes prior to the scheduled consultation, the patient, spouse, and I went into the consultation room for the pre-consultation interview. This brief interview served, first, as an opportunity for the patient and the patient's spouse to meet and get to know me. Second, it assessed the patient's initial goals for the consultation (e.g., "What are you meeting with Dr. X about today?" and "Do you have specific goals for this meeting?"). Appendix C gives examples of the kinds of questions in the pre-consultation interview.

**Recording the consultation.** When the physician arrived for the consultation, there were several matters for me to arrange: asking everyone to sit in their assigned chairs; checking that the camera was set up properly and making adjustments if needed; showing the participants how they could turn the camera off using the remote control, if at any point they wanted privacy; answering any last-minute technical questions; informing them that I would be in the waiting room during the consultation should they need anything; turning the camera on to start recording; and stepping out to the waiting room until the consultation was over, when I could re-enter and turn the video camera off.

**Post-consultation interview.** After the consultation, the patient and spouse remained in the consultation room for the second interview, which focused on the

patient's evaluation of the process and outcome of the consultation. This was a detailed interview to assess the following specific issues:

1. The extent to which patients felt that they had met their goals, i.e., a comparison with the goals they had listed initially. Specifically,
  - a. What topics, if any, they would have liked to discuss and did (or did not) discuss.
  - b. Which of their goals had been met; if one or more of their goals were not met, why in their opinion did this not happen.
2. Their understanding of the information provided by the physician.
3. Their impression of what the physician had understood about (i) the patient's values and goals and (ii) the patient's medical condition.
4. The decisions made in this consultation, including
  - a. What the patient believed to be the decisions made during the consultation.
  - b. What information the patient saw as relevant to each of those decisions.
  - c. The patient's overall level of satisfaction with the consultation.

Appendix C gives the full guidelines for the post-consultation interview. The actual interview varied the order of questions according to the patient's replies (e.g., sometimes patients answered a question without needing to be asked).

**Debriefing.** After the post-consultation interview, the patients learned about the purpose of the study, had an opportunity to watch the video if they wished, and filled out a Permission to View Form (see Appendix D). As the form shows, patients were able to indicate clearly the specific uses of the data for which they did and did not give

permission. For example, they were able to request that their data be used only by the named researchers but not in conference presentations. If anyone did not grant permission for the research analysis, we would destroy the data. They all understood that the video included everyone who was present and that it was impossible to erase one participant from the data. However, if anyone wished, we could obscure their identity by visual and voice alterations. However, all participants gave permission to use the videotapes for research purposes, with no alterations.

### **Data Preparation**

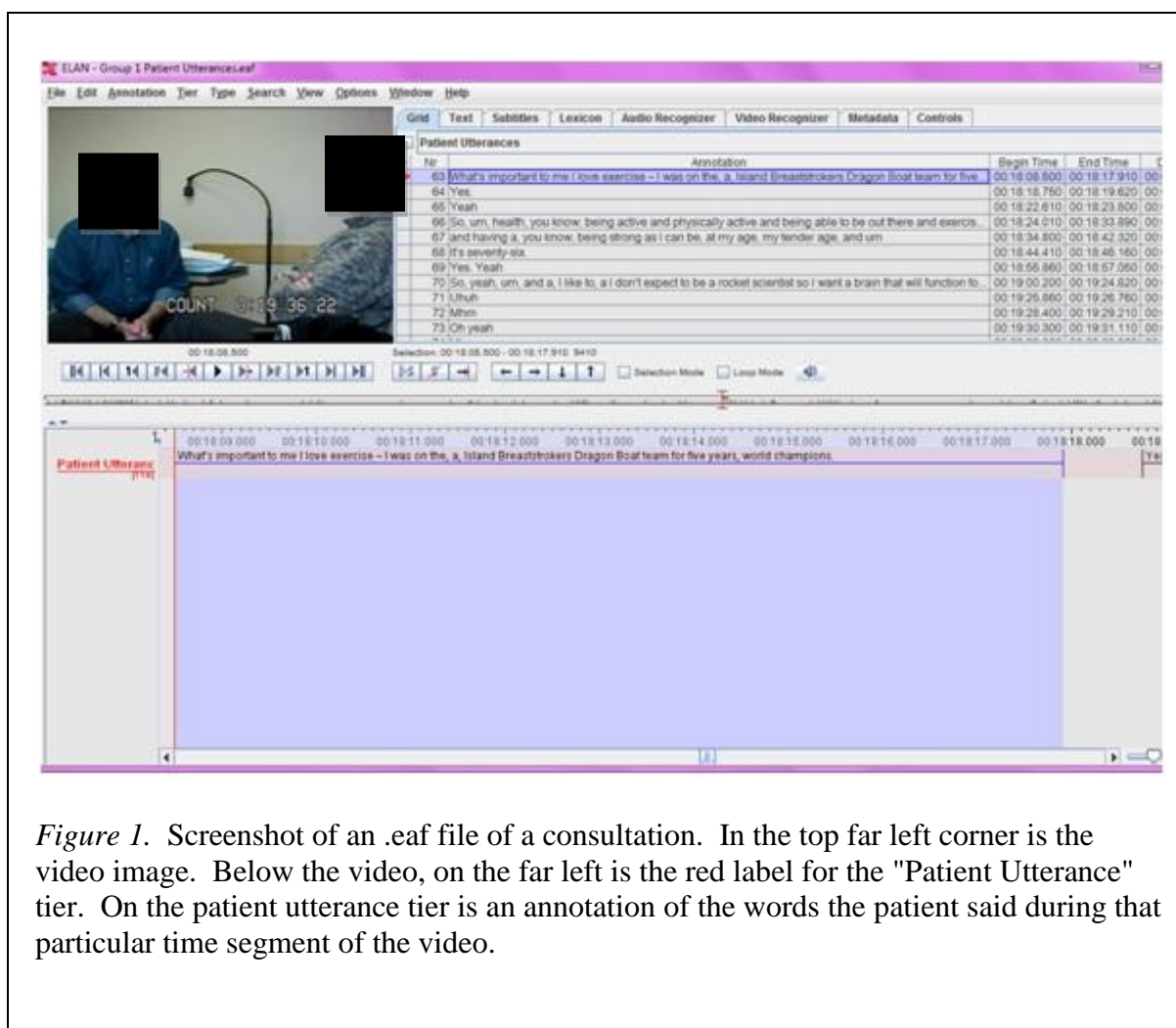
First, the videotapes of the consultations had to be digitized using Broadway Pro and converted from AVI to MPEG format. Second, an assistant transcribed each entire consultation. Third, I set up an ELAN “.eaf” file for each consultation. An .eaf file combines the MPEG video with the researcher’s *tiers* (i.e., annotation rows) for recording analysis information. An *annotation* is a note, label or transcription linked to a specific time interval in the video. Figure 1 is a screenshot of an .eaf file with a tier for patient utterances (an utterance is approximately a speaking turn) as well as an annotation of a patient utterance on the tier. In this case, the first tier of annotations was the transcription of each patient utterance, and I entered each patient utterance into this first tier.

#### Annotation required

- watching the video,
- locating each patient utterance,
- marking out the time interval for that utterance (e.g., the blue line segment in Figure 1),

- typing the assistant's transcription of the patient's words (making any corrections required) into that annotation interval.

This was a very time-consuming process but ultimately facilitated the analysis phase of the research. The result of this data preparation was an ELAN .eaf file for each consultation video that contained an annotation of every patient utterance. Later decisions about each patient utterance went on tiers below this.



*Figure 1.* Screenshot of an .eaf file of a consultation. In the top far left corner is the video image. Below the video, on the far left is the red label for the "Patient Utterance" tier. On the patient utterance tier is an annotation of the words the patient said during that particular time segment of the video.

## CHAPTER 3

### DEVELOPING AN ANALYSIS OF THE INDIVIDUAL PATIENT'S PERSPECTIVE

As outlined in the Introduction, the literature on patient-centred care includes an emphasis on patient-centred communication both as a goal and as a way for clinicians to work with patients. However, most of the guidelines in this literature focus on the behavior of clinicians, (i.e., what a clinician does or says in order to be more patient-centred) rather than on the behavior of patients. A small number of studies have examined patient behaviors, but most of these descriptions of patient behaviors are quite general (e.g., being assertive in stating opinions and preferences or expressing concerns). Such descriptions lack enough detail to be of practical use in teaching someone how to recognize and distinguish between utterances that contribute the individual patient's perspective and those that contribute other kinds of information. The main purpose of this research was to create a system of analysis for recognizing and identifying which patient utterances contribute the individual patient's perspective.

Developing a detailed analysis of patient utterances required two major stages: First, the *inductive* stage used about 30% of the data to identify the phenomena of interest and develop the analysis principles. The second stage produced *the formal analysis system*, that is, a detailed document of operational definitions, a decision tree, and the procedural details of analysis. (Chapter 4 presents the tests of reliability and cross validation.)

#### An Inductive Approach

To *induce* is “to infer from particulars” (Merriam-Webster's 11th Collegiate Dictionary, 2008, electronic version) rather than using a priori or pre-existing principles. In this research project, an inductive approach meant using a subset of the data to identify the phenomena of interest and to create rules for analysis rather than applying a pre-existing coding system or rules taken from the literature. This process took several steps, described below.

### **Identifying Different Kinds of Information in Patient Utterances**

The first step was to capture the different kinds of information that patients provided during a consultation, which involved intensive and repeated viewing of some of the patient utterances in consultations 1, 2, and 3. While watching these consultations, it became clear that patients contributed several distinct kinds of information, and these distinctions helped to form the rules of analysis. For example, patients frequently talked about their diagnosis or treatment without providing any indication of their own individual perspective. This observation led to a key distinction between information that a patient provides that is purely biomedical versus information that includes some indication of this patient's unique perspective on his or her biomedical status.

While watching the consultations, I made notes and comments about the different functions of information that the patients provided, paying particular attention to information that seemed to include the individual patient's perspective and also noting any utterance that definitely did not contain the patient's perspective. Four broad kinds of patient information emerged from these notes and comments. These corresponded to four different functions that the patient's information could serve in the consultation:

- *Patient-centred information* was information about the patients' own perspective on the illness or treatment; for example, "That's probably the thing that *scares me* the most ah, is incontinence, *I like to do* active things and *don't want* to be tied up like that."
- *Biomedical information* was information about the illness, treatment, or medical procedures without any indication of the patient's perspective; for example, "Ah no I am not on a pain killer, occasionally I take a just a regular (short pause) Tylenol, ah that's it."
- *Small talk* was information that was not directly related to the illness or the treatment, e.g., "And then I married an American and went down there. And that ended up, in divorce, and so, life went on and ah, then I met Chuck."
- *Generic listening responses* occurred when the physician was talking and the patient simply indicated that he or she was following what the physician was saying; for example, "yeah" or "mm hmm."

The videotaped data was the direct source from which I derived the four kinds of patient information, and after watching several hours of video, it seemed possible to determine which of the four kinds of information each utterance contributed.

### **Creating Formal Rules**

The next step was to create explicit, detailed rules for the aforementioned kinds of patient information. In order to do this, I began to create lists of reasons for each of my decisions. I continued to watch more of the videotaped consultations, examining each patient utterance, and deciding which kind of information it was contributing (patient-

centred information, biomedical information, small talk, or a generic listening response). For each decision, I wrote notes articulating the reason for deciding that a patient utterance was of a particular kind. For example, if a patient said “My goal is to remain active throughout my treatment,” this utterance was patient centred because the patient was talking about a goal specific to her. I would add this reason to the growing list of reasons for considering an utterance to be patient-centred information. Some reasons, such as the one in this example, occurred so frequently that they became a potential rule. Other reasons suggested new rules, made an existing rule more specific, or articulated an exception to a rule. (If a patient utterance did not contribute any of the four kinds of information, I noted the exact utterance under “Other.”)

As I went through the videos, generating rules and variations on rules for each utterance, a detailed list of potential rules emerged. This list eventually became my first draft of the operational definitions for the four kinds of patient information. It is important to note that the process of rule development was iterative. I repeatedly created a draft of the rules, tested them on more data, and when problems arose (e.g., the rules could not account for a new patient utterance in the data), I modified the rules to produce an expanded definition that would capture the new patient utterance. The end goal of this iterative process was to have a set of analysis rules that another analyst could use to recognize the distinctions between the different kinds of patient information in consultations such as these, that is to be able to replicate the analysis.

### **Formal Rules and Operational Definitions**

In the second stage of analysis, I formalized the accumulated rules into a detailed and extensive set of operational definitions for the use of an analyst. The first part was a

general overview introducing the four kinds of patient information; the second part provided detailed rules and examples. These two documents are in the two text boxes below.

### **Overview of the Rules**

In this analysis, we are interested in distinguishing between the different types of information that a patient provides. The types of information we will be distinguishing between are Generic Listener Responses, Small talk, Patient-Centred Information, and Biomedically Centred Information. The following are brief definitions of each type of information. More extensive definitions with examples can be found on the next pages.

**Generic Responses (G)** are listener responses that a patient will make to indicate to the physician that she/he is following along or paying attention. Generic responses do not provide new information but indicate that the listener is paying attention. Common generic responses are “Yeah,” “uh huh,” “mm hmm,” “okay,” or “right.”

**Small talk (S)** is light informal conversation that is used in social situations; it is the type of information you might give someone when you meet them for the first time. Examples of small talk are times when you are talking about the weather or where you were born.

**Biomedically Centred Information (BC)** is information about the illness, treatment, symptoms, or health of the patient without an explicit indication from the patient of whether and how the illness or treatment is affecting the patient’s life and without an indication of whether the illness, symptoms, or side effects are tolerable or are interfering with life activities. Biomedically Centred information often occurs within history taking; it often sounds like the patient is just reporting information that could be

found in the patient's file or chart. Another type of biomedically centred information is administrative or procedural information about the patient's care (e.g., information that the patient provides about procedures, appointments, or consultations with other physicians and specialists) without an explicit indication from the patient of whether and how those procedures or appointments affect the patient's life and without an indication of whether the illness, symptoms, or side effects are tolerable or are interfering with the patient's life activities.

**Patient-Centred Information (PC)** is information about this specific patient from the patient's perspective. There are several different types of patient-centred information. The first type of patient-centred information is any question that a patient asks or any implicit request for confirmation from the physician that the patient's understanding is correct. The second type of patient-centred information is biomedical information or medical procedural information with an explicit indication from the patient of whether and how the illness, treatment, side effects, or symptoms are either (a) affecting the patient's life, (b) interfering with the patient's life activities, or (c) tolerable to the patient. The third type of patient-centred information includes information about the patient's hopes, fears, plans, goals, resources, expectations, wants, coping methods, decisions, and preferences.

### **Full Operational Definitions**

**Generic Responses (G).** Generic responses are listener responses that a patient will make to indicate to the physician that she/he is following along or paying attention. Generic responses do not provide new information but indicate that the listener is paying

attention. Common generic responses are

- “Yeah,” “uh huh,” “mm hmm,” “okay,” or “right.”

**Small talk (S).** Small talk is light informal conversation that is used in social situations; it is the type of information you might give someone when you meet them for the first time. Patients and physicians will often start a conversation with small talk where they will talk about the weather, their accents, or where they were born. Some examples of small talk are

- “Ah, well, started off being born in Saskatoon but ended up ah, then was in the US for a while and then came up here.” (Note: Sometimes a physician will ask where a patient is from to determine if they are at an extra risk for cancer; e.g., there are certain French Canadian families at added risk for breast cancer. If you can tell from the context that the physician asked where the patient was from to gather this kind of information, please classify the patient’s answer as Biomedically Centred information.)
- “And then I married an American and went down there. And that ended up, in divorce, and so, life went on and ah, then I met Chuck.”
- “And you’re from?” (Note: In this case, the patient asks a question of the physician; because it is the type of question that you would ask someone in a social situation, it is considered small talk.)
- “I prefer to be called Pat.”

**Biomedically Centred Information (BC).** Biomedically centred information is information that the patient provides that is focused purely on biomedical information or medical procedural information without an **explicit** indication from the patient of whether

and how the illness or treatment is affecting the patient's life and without an indication of whether the illness, symptoms, or side effects are tolerable or are interfering with life activities. It is usually information about the illness, treatment of the illness, or any administrative aspects of treating or diagnosing the illness, e.g., past and future medical procedures or consultations. When the patient presents biomedical information or administrative/procedural information and you don't know how it is affecting the patient's life, what activities it interferes with, or what the patient's judgement about the information is, then it is usually biomedically centred information. It includes patient information about topics such as

- Nature and status of the disease or illness (diagnosis, prognosis):
  - “After the biopsy I went to see him and he gave me the biopsy results, and that was pretty well everything. He said, we need to make an appointment to see the oncologist in Victoria. And then I have to see him next week.”
  - “My PSA was going up and uh, sure enough, there was something there.”
  - “When I saw the doctor in April he told me that they'd found cancer cells.”
- Administrative Issues:
  - “My doctor sent me for a biopsy.”
  - “After the biopsy I went to see him and he gave me the biopsy results, and that was pretty well everything. He said, we need to make an appointment to see the oncologist in Victoria. And then I have to see him next week.”

- Likely course of disease progression (prognosis):
  - “My doctor said that this type of cancer grows slowly.”
- Medical options for treatment (treatment options, information about medications the patient is on without the patient’s evaluation of the treatment option or the medication):
  - “Ah no I am not on a pain killer, occasionally I take a just a regular Tylenol, ah that’s it.”
  - “I take a blood pressure medication and a baby aspirin.”
- Probabilities (statistics about the illness or treatment):
  - “My doctor told me that I have better chance of surviving if I get chemotherapy and radiation.”
- Other health issues (other illnesses, complications, past surgeries):
  - “I have had a couple of surgeries on my nose. One on the inside and one on the outside.”
- Side effects, without the patient’s evaluation of them:
  - “I’ve had different antibiotics and some of them have made me sick and some have not. None of them made me as sick as the penicillin.”
- Their medical history (this includes information about family history, past surgeries, tests, procedures, illnesses etc.):
  - “Um, actually I’ve got a brother who died about 3 or 4 years ago from bowel cancer. And that’s it as far as immediate family is concerned.”
- Symptom information ( i.e., whether a symptom is present without giving an evaluation of how the symptom is affecting them):

- “I’d had some a, pains going up into the jaw” or “ I haven’t had pain since I’ve had the angiogram.”
- “ Um, very frequent urination was the main reason for the TURP. Like, less than, or more frequently than every half hour or so.”
- “Um, ah, I have a good stream of urine coming out.”
- “I am sexually active and don’t have trouble getting erections.”

Notes:

(1) Do not classify patient *questions* about biomedical issues as biomedically centred information. Questions and concerns about biomedical issues are patient-centred information.

(2) Biomedical information presented by the patient to the physician for clarification is not classified as biomedical information because it is an implicit request from the patient for confirmation from the physician that he or she is understanding. E.g., “Ah, I got the impression from what I read that before the prostatectomy was the best way to go but with advances in, in both prostatectomies and radiation that now it’s kind of equal. I mean the results are good for both?” The patient’s prosody,<sup>1</sup> in this example makes it clear that he was requesting the physician’s confirmation that his understanding of what he read was correct and thus would be classified as “patient-centred information.”

(3.) If the patient provides an explicit evaluation or an explicit opinion about whether any symptom, treatment, medication, diagnosis, prognosis is tolerable or not, etc., then it is not purely biomedical information it is patient-centred information.

**Patient-Centred Information (PC).** Patient-centred information is information about the patients’ experience of their illness and disease. This information can range

from their experience of biomedical symptoms or their experience of receiving a diagnosis to the experience of making plans, hopes, or goals as a patient with an illness.

Patient-centred information includes

- Explicit evaluation of whether symptoms are tolerable or not:
  - “That *damn* resection – boy was that painful for a couple of weeks afterwards. [D. nods while writing], *and this would be worse (laughs) I’d rather avoid it.*”
- Explicit evaluation of how the illness, symptoms, treatment, or suffering are interfering with life:
  - “Yeah, and I don’t *bend over well and I don’t do a lot of things.*”
- Explicit evaluation of whether side effects are tolerable:
  - “Frequent urin-, urination has been *during the daytime* – that’s when it’s been bad for me, not at night time.”
  - “*But it was a, not a good drug at all*, I got a serious rash on my legs.”
  - “Just add to that, that I seem to ah, if, if ah drugs have a downside, or, or a counter-effect thing I seem to get them. The, the Statin drugs *are really a problem for me.*”
- Explicit evaluation of whether past treatment or past side effects were tolerable:
  - “I felt very tired after it [radiation] was all over. *It took me quite a few months to feel like I was myself again.* But otherwise I was fine. I would say 4 to 6 months before I really felt strong like I used to be.”
  - “*It’s not that I wasn’t feeling well* but it had, ah, it has two side effects, one was the, ah increased, ah (Clinician overlaps saying “hot flashes”)

(patient nods) Ah, in numbers and in, in quality.”

- Wishes (preferences) for the future as a patient, for the consultation, for the treatment:
  - “If I make it into my eighties, kickin’ and screamin’ *then that’s good.*”
  - “I’m, *I’m okay if* [my husband joins us], you know.”
  - “I’d *like him to* be here.”
- The patient’s hopes in the face of illness and *disease*:
  - “We were kinda *hoping*, in September, to go on a cruise.”
- The patient’s fears and concerns:
  - “I *don’t want* to be an invalid.”
  - “That’s probably the thing that *scares* me the most ah, is incontinence, *I like to* do active things and don’t want to be tied up like that (slight laugh).”
- The goals of the patient in the face of illness, disease, treatment:
  - “*Yeah, I would like* quality of life, and I’d kind *of like to* have another five years, you know, which is sort of reasonable I would think.”
- The patient’s plans in the context of their life as a patient.
- A patient statement that explicitly expresses their understanding of their illness, disease, treatment:
  - “But as far as the cancer’s concerned, I, I, I, really have no *understanding.*”
- How the patient is making medical decisions or the way the patient is thinking about medical decisions:

- “Um, I pretty well came here with a *totally open mind*. And I even said to my husband, I will take any, anything they recommend because, you know, from my experience [Dr. nods] having had everything that [previous doctor’s name] at the time, had suggested, and, ah, I followed everything that she did, she said, and ah, here I am, you know, 19 years and [gestures with hands] so.”
- “I would ... *what’s important*, Not everything possible, but everything necessary.”
- “Like when I, [previous doctor’s name] had explained to me, you know, that the chances of survival are 80%, I said, ‘well gee, I’ll take the 80%’. [slight laugh] When in this case, you know, it’s, it’s so minimal as far as the number of survival is concerned that I, I (shrugs) you know, *I see no need for any other treatment*. (laughs) For the time being.”
- “Yeah, Well [pointing to chart] I look at this [survival rate] more than I look at this [risk of reoccurrence]. Yeah. Because then I mean (slight laugh) my way, *my philosophy of life, is take things as they come*. Yeah, *but it’s for differences like this it’s, to me, it’s not important*.”
- The patient’s expectations for the consultation, of the physician, or of the treatment:
  - “I’ve been told that I would need radiation. Following a lumpectomy. [D. nods] But I don’t know how many or, so, I’m *hoping* to find out today ().”
  - “Expectations, um, I *want to know from you*, what you’re going to do to me.”

- The patient's opinions about their medical care:
  - "If, if I'm, if things are so bad – *I'd just as soon take a potion and exit.*"
- The patient's perceptions about their illness.
- The strategies that the patient has come up with to cope with their disease:
  - "When I am in pain I have found that lying on my stomach gives me a bit of relief."
- The patient's decisions surrounding his or her care and treatment:
  - "No, I think I'm satisfied, you know that, with all these explanations, to me, *I see no need to have any further treatment.*"
  - "Ah, *I'd like* to have some sort of um, something that might take care of the little wandering cells and stuff, you know."
  - "To me that's very clear. I understand that um, um, *and I know that I don't want it [chemotherapy].*"
- The patient's resources (support in their life; limitations):
  - "I kind of *have my own* [support group] I have half a dozen buddies at various stages of it."
  - "And since *I've got so many buddies who've been through systems and everything, ah yeah, very good support system.*"
- How the patient is conceptualizing the choices and possibilities available to him or her:
  - "If, if I'm, if things are so bad – I'd just as soon take a potion and exit."
- Patient's questions or concerns about his or her condition:
  - "What I was, a, thinking, wondering about any cells that might have

migrated, into, like, attached to a bowel or to a kidney or to a bladder or any of that kind of stuff?”

- “Anything special on nutrition?”
- “Because what I understand is that the cancer I have now is unrelated to the first one? Am I correct or?”
- “Ah, yes I want to ask some questions about the um, likelihood of our daughter getting cancer.”
- “Yeah, um, when you radiate, do the radiation, are you aiming right at the actual tumour itself or does the, is the whole of the prostate being radiated?”
- What is important to the patient in the face of his or her illness or condition:
  - “What’s *important* to me I love exercise – I was on the, a, Island Breaststokers Dragon Boat team for five years, world champions.”
  - “So, um, health, you know, being active and physically active and being able to be out there and exercising, is--and having a, you know, being strong as I can be, at my age, my tender age.” [this response was in answer to the clinician’s question of “what is *important* to you?.]”
  - “So, yeah, um, and a, I like to, ah I *don’t expect* to be a rocket scientist so I *want* a brain that will function for everyday activities. I *like* to do photography and, a, I *like* being involved, you know, in art things and whatnot.”

Notes:

(1) In order for biomedical information to be considered “patient-centred,” it must contain an explicit evaluation from the patient as to how or whether the treatment, illness, or symptoms are affecting the patient’s life. For example, whether and how the symptom is affecting or interfering with the patient’s life; how the patient feels about this particular symptom (is it tolerable or not?); do they have a question or concern about certain biomedical information?

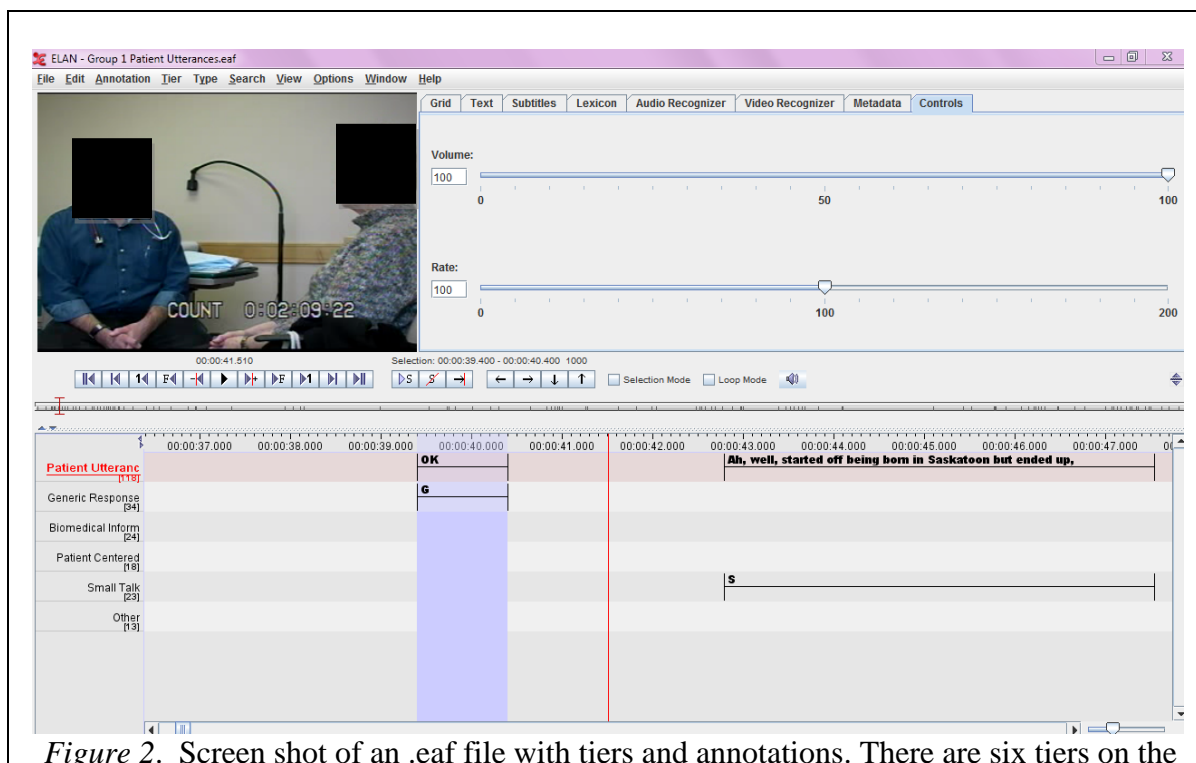
(2) In rare cases, a patient will accompany their utterance with a very expressive facial display to demonstrate how they feel about a particular treatment, symptom, or medical plan. If a patient **clearly** indicates in a facial display how they feel about a particular symptom or plan, then we will consider their display explicit and their biomedical statement would become patient centred.

(3) Sometimes when you read a biomedically centred utterance there will be an implicit suggestion of whether the patient finds the symptom, treatment, or side effect tolerable or an implicit suggestion that there might be an effect on the patient’s life. Do not classify these statements as patient centred. Unless the patient explicitly states whether the biomedical information is tolerable, how it is affecting his or her life, or how it is interfering with life activities, you should classify the utterance as Biomedically Centred Information. The reason for excluding implicit suggestions is that we want to teach physicians to recognize patient-centred information. For this purpose, clear and explicit examples are more useful than ones that are implicit or debatable.

**Other (O).** Classify an utterance as other if (1) you can’t hear or see all or part of the utterance or the context surrounding the utterance or (2) the utterance is very difficult to classify (i.e., you can make an equally good case for either classification).

### **Creating ELAN .eaf Tiers for the Five Kinds of Patient Information**

After finalizing the formal rules for the five kinds of patient information, it was important to set up an analysis system that would make the analysis as accurate as possible. Working in an ELAN .eaf file requires the analyst to see and hear the video at all times, which would not be true using a transcript. As described in the Method chapter, I had already set up an .eaf file for each consultation video, with the transcription of each patient utterance on the first tier. The analysis required five additional tiers for each .eaf file, one for each of the four kinds of patient information plus a tier for “Other.” Figure 2 below shows a screen shot of an Elan .eaf file with these tiers added. These tiers are where the analyst recorded his or her analysis decisions. For example, in Figure 2, the exact time segment in which the patient said “OK” is marked in an annotation on the top tier, along with the transcript of what the patient said. Later, the analyst can highlight this utterance (in blue) and click it to play just the segment of the video where that utterance occurred (and can do so repeatedly). The decision for this utterance was that “OK” is a generic listener response, so the analyst selected the same time segment on the second tier, which was for generic responses and annotated that with a “G.” The patient’s next utterance was “[ah well, started off being born in Saskatoon but ended up]”, which was small talk; this decision went in the appropriate time segment on the fifth tier, which was for small talk.



*Figure 2.* Screen shot of an .eaf file with tiers and annotations. There are six tiers on the bottom far left hand side of the image; one tier is for patient utterances, four tiers correspond to the four different kinds of patient information, and one tier for utterances that are classified as "Other". The text of two patient utterances are annotated on the patient utterance tier. The analyst's decisions about the types of information contributed are annotated on the "generic response" tier and the "small talk" tier.

## Decision Tree

The analyst who has read and understood these detailed and complex rules is still not ready to do the analysis efficiently. During the process of creating the operational definitions, it became clear that it was easier to decide about the different kinds of patient information one at a time rather than deciding among all of them at once. In order to capture a logical sequence for considering each possibility, I created a decision tree (Bavelas, Kenwood, & Phillips, 2002). A decision tree guides all analysts through the same systematic decision-making process. Specifically, it restricts the analysts to making one small, dichotomous decision at a time and guides their thinking in a logical, step-by-

step direction, moving from the easier decisions to the more complex ones. The following paragraphs take the reader through the sequential process in the decision tree created for this project (a copy of this Decision Tree is in Appendix E).

The first step on the decision tree is to locate and play the patient utterance in the ELAN .eaf file for that consultation (not on a transcript). The next step is to consider the first question posed by the decision tree:

Is the utterance small talk? Is this the type of information that you might give a person when you meet them for the first time? E.g., talking about the weather or talking about where you were born?

In order to answer this question, it is essential, first, to re-read the full operational definition of “*small talk*” then to play the patient utterance and the context preceding it several times (by selecting its annotation in ELAN), and only then to decide whether the utterance is small talk or not. If the decision is that the utterance is in fact small talk, then an “S” goes in a parallel annotation on the small-talk tier, directly below the annotation for this patient utterance in the same time interval (as shown in Figure 2). The analysis of this utterance would now be complete.

Otherwise, (if the utterance is *not* small talk), then the analysis continues and the next question is:

Is this utterance a generic response? Is the patient just showing that he or she understands or is following what the physician or family member has said? This will often be indicated by the patient saying things like, "yeah", "uh huh", "mm hmm."

In order to determine whether or not the utterance is a *generic listener response*, it is necessary to follow the same procedure as before: Re-read the full operational definition of “generic response,” watch the patient utterance and the context several times, and then determine whether the utterance is a generic response or not. If the utterance fits the operational definition, then a “G” goes in a new annotation in the generic response tier, directly below the patient utterance, which completes the decision for this utterance. Figure 2 shows a screen shot of an ELAN .eaf file with a generic utterance and a small talk utterance annotated on the appropriate tiers.

However, if the decision is that the utterance is not a generic response either, then the analysis moves to the third question in the decision tree:

Is the utterance a question? Or is the utterance an implicit request for confirmation from the physician that the patient is understanding correctly?

As before, it is necessary to re-read the full operational definition of *patient-centred information*, to watch the patient utterance and the context several times, and then to determine whether the utterance is one kind of patient-centred information or not. If it is, then “PC” goes in an annotation directly below the utterance, on the patient-centred tier, and the analysis is finished for this utterance.

If the utterance is neither a generic listener response or small talk, the analysis continues to the next question, which is quite detailed:

Is the utterance biomedically centred? Does it contain only biomedical information or medical procedural information (e.g., information about medical tests, appointments, or information from other physicians), without any explicit indication from the patient of whether the illness, treatment, side effects, or

symptoms are (1) affecting the patient's life, (2) interfering with patient's life activities, or (3) tolerable to the patient?

This question leads to the same steps as above, re-reading the full operational definition of *biomedical information*, watching the patient utterance and the context several times in ELAN, and then determining whether the utterance is biomedical or not. If the answer to any of the above questions is "yes," then the utterance is biomedically centred and a "BC" goes in a new annotation below the utterance on the biomedically centred information tier. If the answer to all of these questions is "no," then the analysis proceeds to the last question.

The final question is about patient-centred information and is one of the most complex:

Is the utterance this individual patient's perspective? Does the utterance contain biomedical information or procedural information with an explicit indication from the patient of whether or how the illness, treatment, side effects, or symptoms are either (1) affecting the patient's life, (2) interfering with the patient's life activities, or (3) tolerable to the patient? OR does the utterance include information about the patient's hopes, dreams, plans, goals, preferences, decision-making preferences, wishes, concerns, or fears?

After considering the multiple questions posed in this step of the decision tree, it is essential to re-read the full operational definition of *patient-centred information*, to watch the patient utterance in ELAN, and then to make a decision about whether or not this particular utterance was patient centred. If so, then "PC" goes on a new annotation on the patient-centred tier. If not, then the utterance does not fit any of the four possibilities,

and an “O” goes on the bottom tier, for Other. The analysis is complete for this utterance.

### **Steps of Analysis**

In addition to the Elan .eaf files, the full analysis rules, and the decision tree, the analysts had an overview of the steps of analysis. This document contained a list of everything the analyst would need to complete the analysis and a step-by-step account of the analysis procedures. Below is a copy of the Steps of Analysis document:

#### **Steps of Analysis**

What you will need:

- .eaf video file of the consultation interview for analysis, loaded onto your computer and opened in ELAN
- earphones
- transcript of this consultation interview for reference
- the decision tree
- the operational definitions document

#### **Step 1**

Open the .eaf file of the video you will be analyzing.

#### **Step 2**

Watch the video. The patient utterances for analysis are already identified in the eaf file. Each time you see an utterance for analysis, pause the video, play the utterance and the context several times, and then use your decision tree and the operational definitions to decide how to classify the utterance.

**Step 3**

When you have decided what type of information the utterance contributes, annotate the code/abbreviation (S, GR, BC, PC, or O) on the appropriate tier at the corresponding time. If you found the decision difficult to make, then type a note in the chosen annotation tier about what made the decision difficult and how you decided what you did.

Thus, in order to identify patient-centred information in each patient utterance, the analyst needs all of the information described above:

- The overview of the kinds of patient information
- The operational definitions
- Elan .eaf files for each video for analysis
- The decision tree
- The steps of analysis

These five items constitute the complete analysis system. Using it, an analyst should be able to make the distinctions such as those in Table 2. This table shows pairs of utterances from the same patient on approximately the same topic, one utterance that is biomedically centred and one that is patient centred.

**Psychometric Note**

Because this analysis system is not a “test” in the usual sense, many of the American Educational Research Association et al. (1999) *Standards for educational and psychological testing* do not apply. However, the development process described here meets the following standards that are relevant: 3.1, 3.2, 3.3, 3.5, 3.6, 3.7, and 3.22.

**Table 2**

Examples of Distinctions Between Patient Utterances that Contribute Biomedically Centred Information and Those that Contribute Patient-Centred Information

Group Number	Biomedically Centred Information	Patient Centred Information
Grp. 1	"Well, I've got a carcinosarcoma cancer, level 2, and there's concern (from the Doctors) about the sarcoma taking a walkabout."	" mm ah, <i>I'd like</i> to have some sort of um something that might take care of the little wandering cells and stuff you know.."
Grp. 2	" I've been told that I would need radiation following lumpectomy"	"but I don't know how many [sessions of radiation] so I am <i>hoping</i> to find out today"
Grp. 3	"Very frequent urination was the main reason [for the TURP]. Like less than, or more frequently than every half an hour or so"	"Like I drove down from Qualicum this morning and I had to stop (to urinate) on the way down."
Grp 3	" Really improved (the incontinence) for about 2 years, and then it started sliding back so I'm taking flowmax now"	" That's probably the thing that scares me the most, ah is incontinence, I like to do active things and don't want to be tied up like that"
Grp. 3	"Um, the only thing he [the other physician] seemed to be leaning towards, almost, was to wait to see what happens. Not do anything at this point."	" There's a possibility that I could be around for 15 years so that would give it lots of time to grow so I kinda think something has to be done"
Grp. 4	"The only one allergy I have is ah, Sulpha, that was 50 years ago"	"One other thing, they put me on a drug to help my valves. Can't remember the name of the drug now, to be honest with you but it was <i>not a good drug at all</i> , I got a serious rash on my legs and on my stomach"
Grp. 5	"I've got um originally I've had one source of pain that is in my right buttock. Somewhere down there is a gro-, there's a tumour and that is pressing on a nerve or something"	"Burning, sharp, twisting [referring to pain], and I just scream, I mean literally"

Table 2 Continued

Group Number	Biomedically Centred Information	Patient Centred Information
Grp. 5	"I've had bronchiectasis, COP D, the lot"	"but you know, as you say, for general purposes is my breathing a problem? No, because I don't do anything"
Grp. 6	"I don't feel that I have night vision problems"	"I haven't noticed any difference in in related to light level, it's only that, hey there's a street sign I want to read down there (pointing in the distance) and it isn't sharp enough for me to read yet until I get closer"
Grp. 7	"yeah, get control and then all of a sudden I've got this stomach thing and things got out of control or	"It kind of bothers me a little bit because you know, it's I sound funny to me SO I can only imagine what I sound like to anyone else"
Grp. 7	"Yeah, I haven't been taking it [the lactulose]"	" Yeah, there's no problem with it [the lactulose], I just haven't incorporated that yet"

## CHAPTER 4

### QUANTITATIVE AND IDIOGRAPHIC RESULTS

This chapter presents (a) the psychometric results for the analysis system (i.e., inter-analyst reliability and cross-validation) and (b) detailed qualitative descriptions of how being able to identify specific information about each patient's individual perspective contributes to the understanding of the consultation as a whole.

#### **Establishing Inter-Analyst Reliability**

A test of independent inter-analyst reliability addresses the first risk of an inductively developed system, namely, that the analyst would continue to make subsequent decisions inductively, based on implicit intuition rather than on the operational definitions. Such a system would not be replicable by other, independent analysts relying on the explicit rules. An analysis system is replicable when two people, working independently and guided solely by the explicit rules and procedures, make virtually the same decisions on a new sample of data. In this case, the two independent analysts should have a high degree of agreement when identifying the different kinds of patient information. This test required creating a sample of the data for the reliability test.

#### **Reliability Sample**

The reliability data was a stratified random sample of 12.5% of the data from the videotaped consultations. In order to ensure that the sample was representative of the full data set, the first criterion was that it should include data from each of the eight consultations. The second criterion was to ensure that the sample would include

segments from the beginning, the middle parts, and the end of consultations. The sampling procedure was as follows:

- Numbering the consultations from 1 to 8.
- Calculating the total time of each consultation and then subtracting the time of the physical exam (and the one occasion when only the nurse was present) to yield the total analyzable time of each consultation with the oncologist.
- Dividing every consultation into eight segments, each with one-eighth (12.5%) of the total minutes of the video in that consultation.
- Thus, every videotaped consultation had eight segments, where the first segment was the first 12.5% of its total minutes, the second segment was the next 12.5% of minutes, and so on until the eighth segment, which was the last 12.5% of minutes of that consultation.
- A random permutation table determined the selection of a different 12.5% segment from each consultation. For example, the 12.5% of consultation #2 was its 8<sup>th</sup> (last) segment.

As shown in Table 3, this sampling procedure created a reliability sample of a random 32.3 minutes of video, which included a different segment from each of the eight consultations.

Table 3

*Composition of the Reliability Sample*

	Group Number							
	1	2	3	4	5	6	7	8
Total minutes of consultation	44.0	61.3	34.2	37.9	32.0 <sup>a</sup>	17.3	20.1	28.3
Minutes of physical exam	2.4	0.2 <sup>b</sup>	9.7	6.0	0	0	0	0
Total minutes analyzable	41.6	61.1	24.5	31.9	32.0	17.3	20.1	28.3
Size of each 12.5% segment (minutes)	5.2	7.7	3.1	4.0	4.0	2.2	2.5	3.5
Which 12.5% segment to be analyzed	1	8	2	6	7	4	3	5
Minutes to be analyzed	1.4 — 6.6	54.5 — 2.2	8.4 — 11.5	19.9 — 23.9	24.0 — 28.0	6.5 — 8.7	5.0 — 7.5	14.1 — 17.7

<sup>a</sup> Note that this number only includes the time that the oncologist was present.

<sup>b</sup> The oncologist turned the camera off for all but 9 seconds of the physical exam, so only that amount had to be deducted.

### **Testing Inter-Analyst Reliability**

Another analyst (D.H.) learned the analysis procedures and the analysis software. His training period included supervised practice on data that was not in the reliability sample. After this training period, the formal reliability analysis began. It spanned several weeks during which the independent analyst and I proceeded to analyze the consultations one at a time. Prior to the reliability analysis of each consultation, we spent some time practicing doing analysis to re-familiarize ourselves with the analysis system and procedure, then we did our independent analyses of that consultation. When finished, we compared our results, calculated the percentage agreement, and then discussed and resolved any disagreements by consensus. The reliability assessment was the initial percentage agreement; the later consensus resolutions became the final analysis decisions for that segment of data.

### **Results for Inter-Analyst Reliability**

The independent analysts agreed on 90% (205) of the 228 decisions made for the reliability analysis. There was no apparent pattern to the disagreements, and this high level of agreement showed that the analysis system was independent of its developer and replicable by a new analyst. These results and the procedures described here meet the applicable American Educational Research Association et al. (1999) *Standards for educational and psychological testing*, namely, standards 2.1, 2.5, and 2.10.

### **Cross-Validation**

Another risk of developing an analysis system inductively is the possibility that this system would fit only the data used to develop it. *Cross-validation* is a procedure for

assessing this risk. The final test of the analysis system was to follow the cross-validation guidelines set out in Bavelas et al., (2002):

Having observed and made inductive propositions based on observed data, most inductive researchers go on to seek confirmation of their conclusions in new sets of data. One design for formalizing this process is analogous to the statistical procedure of cross-validation in multiple regression. When approaching a new set of data inductively, the researcher [initially] limits the analysis to a subsample of the whole (ideally, a randomly chosen subsample). Based on this initial inductive analysis, the researcher makes a commitment to what has been found and then is prepared to test it in the remainder of the sample. If the original pattern was random, it will disappear in the new data set. Depending on the outcome, a cross-validation strategy provides either a useful safeguard against the potential weakness of inductive research or a powerful demonstration of its validity. (p. 113)

If the initial inductive analysis was limited to the original data set and did not generalize to new data, then analysts working with new data would encounter utterances that did not fit into the rules. The result would be either low reliability, a large “Other” category, or both.

### **Results of Cross Validation**

Because the reliability sample was new data randomly sampled from all of the consultations, the results of the reliability analysis served a second purpose, providing an initial cross-validation of the analysis rules. The high inter-analyst agreement (90%) and

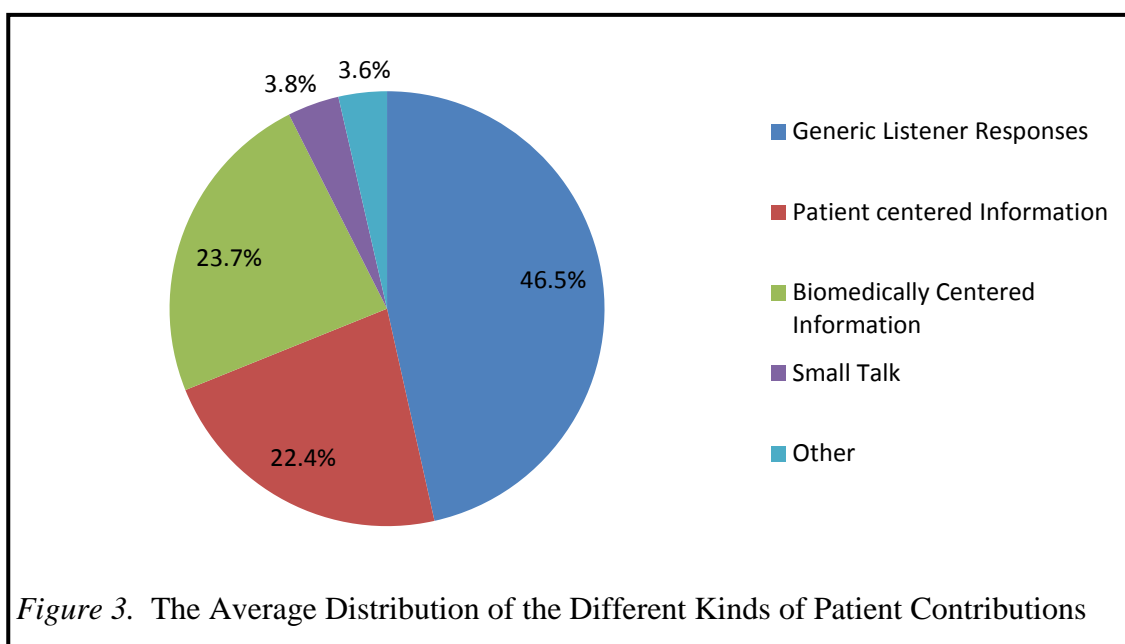
only 9 utterances (3.9%) in the “Other” category provided one form of cross-validation of the analysis system. A second test was the analysis of the remainder of the data. From the total of 1585 patient utterances in the full data set, 228 were in the reliability analysis and approximately 450 utterances were used to create the rules. This left approximately 907 utterances to be analyzed by the author alone. This analysis yielded only 32 utterances (3.5%) classified as "Other." Together, the results for inter-analyst reliability and cross-validation provide strong psychometric evidence for the analysis system.

**Summary of validity.** The American Educational Research Association et al. (1999) *Standards for educational and psychological testing* have explicitly eliminated older concepts of validity (e.g., construct, content, criterion, or predictive validity) and replaced them with a single principle that emphasizes the proposed use in a particular setting : *Validity* “is the degree to which all the accumulated evidence supports the intended interpretation of test scores for the proposed purpose” (p. 11). In addition to the accumulated evidence for development and reliability, this analysis system meets several of the relevant AERA et al. (1999) standards for validation: 1.1, 1.2, 1.3, 1.5, 1.6, 1.7, and 1.13.

### **Quantitative Results for the Whole Sample**

As shown in Figure 3, the greatest proportion of the 1585 utterances analyzed were simple generic listener responses: 46% of all patient utterances. The proportions of biomedically centred information (25%) and patient-centred information (22%) were similar to each other, as were small talk (4%) and Other (4%). However, this nomothetic information on the overall frequency of each kind of patient utterance is not informative for an idiographic analysis system because it does not provide insight into the nature of

the information contributed by each patient. That is, identifying the different kinds of information was a way to locate specific patient information; it was a means to an end and not the end itself. The case-by-case qualitative results in the following sections should give the reader a better picture of the ways each patient contributed information. Patients did not contribute categories of information they contributed information, specific to themselves.



### Idiographic Qualitative Results

The qualitative results for each patient include a short synopsis of the pre-consultation interview, a description of the role of patient-centred information during the consultation, and a synopsis of the post-consultation interview. (Recall that the guidelines for these interviews are in Appendix C.) These idiographic descriptions show a wide variety of ways in which patient-centred information came into the consultation and the effects it had on each consultation.

**Consultation #1: Female patient, 76 years old with ovarian cancer, meeting with a medical oncologist; her husband was present.**

**Pre-consultation interview.** During this interview, this patient told me that she had a carcinosarcoma, stage 2 ovarian cancer, so she would be needing to meet with both a radiation and a medical oncologist. She was there to meet with the medical oncologist in order to find out about the chemotherapy options. Her expectations were numerous, including several questions she wanted answers to: What was planned for her? How long would the treatment be? What would be the side effects of the treatment? She also indicated that she hoped that the doctor could provide "some definitive answers" for her "rather than giving [her] options." She clarified this by saying that she "[didn't] want options because [she] didn't know." I asked whether she was saying that she didn't know what to do. She said "Yes" and added that she "expected [him] to do the guidance." She also mentioned that she wanted answers because she and her husband had plans for a cruise this summer, and they wanted to know if they could go on the trip. At the end of the pre-consultation interview, she re-emphasized her hope that this doctor would provide direction and help guide her decision-making because she didn't like the pressure of having to make such important decisions when she didn't have medical expertise. She explained that she had had cancer in the past and had been asked to make decisions based on statistics. She didn't feel that she had enough expertise to interpret those statistics, and she thought the clinician was in a better position to make decisions about statistics.

**The consultation.** The consultation was 43 minutes long, including a brief medical exam. During the consultation, the patient made 199 utterances. Of these, 75 were generic listening responses ("mm hm", "um", and "yeah"), showing the oncologist

that she was following along. Small talk accounted for 38 of her utterances, covering topics such as where she was born and had lived and also people that she and the oncologist were mutually acquainted with. There were 25 utterances that provided biomedical information to the oncologist and 43 that contributed patient-centred information, that is, information about this patient's individual perspective; see examples in Table 4.

Recall that, due to her past experience with cancer, the patient went into the consultation wanting the clinician to tell her what to do. She made this expectation clear to the oncologist when she told him that she wanted to know “What you are going to do to me.” However, the oncologist first questioned her extensively about what was important to her, so she began to talk a lot more about what was important to her, what she liked to do, and what she wanted to be able to do in the future. Thus, the oncologist asked explicitly about her unique perspective, which only she could know. When she provided it, he then provided information about how the various treatment options would affect what was important to her, given the side effects and survival statistics. Near the end of the consultation, the oncologist made a recommendation for treatment, as she had asked for at the outset. However, his recommendation was based on the details he had elicited about her unique lifestyle, interests, plans, etc., and how they fit with the technical information that he had explained about the various treatment options.

Table 4

*Examples of Biomedical and Patient-Centred Information in Consultation #1*

Biomedical Information	
Topic	Patient Utterance
Administrative or procedural issues	"Yes, so I go back (to the specialist) in March to see if there's any."
Symptom information	"I haven't had pain since I've had the angiogram"
Medications	"Ah, no, a, occasionally I take a just a regular...Tylenol, ah that's it."
Nature and status of the disease or illness	"Well I've got a carcinosarcoma, cancer of level 2"
Patient-Centred Information	
Topic	Patient Utterance
The patient's expectations for the consultation	"Expectations, um, I want to know from you what you are going to do to me"
What is important to the patient in the face of the illness	"What's important to me, I love exercise - I was on the, a, Island Breaststokers Dragon Boat team for five years, world champions."  "I don't expect to be a rocket scientist so I want a brain that will function for everyday activities. I like to do photography and, ah, I like being involved in art things and what not"
Patient's wants	"I don't want to be an invalid"
Conceptualizing the choices and options available to patient	"If things are so bad - I'd just as soon take a potion and exit"

**Post-consultation interview.** When I asked the patient how the consultation went, she said "excellent." She said that it met all of the expectations she had set out in

the pre-consultation interview and that the answers she got were better than she had expected. The patient said that she had had a chance to talk about everything she wanted to talk about; there was nothing that she felt she did not get a chance to talk about. When I asked "Were there things that you discussed that you hadn't planned on talking about?", she answered,

When he asked about my goals and my expectations for-- That really surprised me because you know it's taking into consideration age, et cetera. That, that surprised me and it's focused you know on what's important to me and we got that clear and I think that helped him also clarify in his mind that we were on the right track.

The patient also said that "We [not "the oncologist alone"] made two decisions" in the consultation. The first decision was "which option [to choose] for the chemo," and the second decision was deciding "how soon to begin the chemotherapy." The patient said that the information that was relevant to those two decisions were the "pros and cons" of the different chemotherapy options and "how it fit into [her] life and values." The patient said she was "very satisfied" and on a scale of satisfaction from 1 to 10 she was "a 10."

**Summary.** The decision-making process changed over the course of the pre-consultation, consultation, and post-consultation. In the pre-consultation interview, the patient talked about *not* wanting to make a decision herself and wanting the oncologist to make the decision. In the consultation, however, the patient made the decision about which treatment she wanted, with guidance and a recommendation from the oncologist. In the post-consultation interview, the patient was able to articulate one of the ideals of patient-centred decision-making: She recognized the value of combining the biomedical

information provided to her (about the pros and cons of the different chemotherapy options) with the unique information about her life and how the treatment would affect her life.

**Consultation #2: Female patient, 72 years old with breast cancer, meeting with a radiation oncologist; her husband was present for the latter half of the consultation.**

**Pre-Consultation Interview.** In the pre-consultation interview, the first question was “What are you meeting with the Dr. [name of physician] about?” The patient answered that she was here for her “first appointment [at the BCCA] following surgery for breast cancer, of the left breast.” She added that she had had cancer of the right breast 19 years earlier. She thought that the reason for the appointment was “an assessment,” but she wasn’t totally sure. Her expectations for the outcome of the meeting were “to find out, um, whether or not I need radiation and if so how many treatments, the frequency of them, and if there is anything else I need to do.” She stated specifically that after her last cancer, 19 years ago, she had had to take tamoxifen for five years, and so she wondered if she would have to take it again since this cancer was much smaller than the last.

**Consultation.** This was the longest consultation, lasting 61.3 minutes. The consultation was also unique because the patient was deciding about whether to get chemotherapy, radiation, or both. Most of the other consultations were dealing with making a decision about either radiation or chemotherapy, not both. During the consultation, the patient made 499 utterances, only one of which was small talk. Most of her utterances (358) were generic responses. The clinician presented a great deal of information about the various treatment options (radiation, chemotherapy, and hormone

therapy), and the patient used generic listener responses such as “okay” and “yeah” to show that she was following this information. She contributed biomedical information in 72 of her utterances; see examples in Table 5. Finally, 65 of her utterances contributed patient-centred information, that is, the patient’s individual perspective; see examples in Table 5.

The consultation began with the patient indicating that she wanted to know what treatments were needed and then moved into a thorough history-taking. The patient contributed relevant medical information about her family history of cancer as well as medical information unique to her past experience with cancer treatment. She was able to contribute information about her different treatments including whether the side effects were tolerable or not. In the middle part of the consultation, the oncologist gave detailed information to the patient about the various treatments available to her, along with the likelihood and amount of benefit that she might expect from each treatment. During this period, the patient contributed mainly generic responses. By the end of the consultation, the patient had gathered a great deal of information and began to evaluate each treatment available to her and to reach a decision about whether or not she wanted each treatment. Throughout the decision-making portion of the interview the patient was able both to make decisions and to articulate her thinking regarding the decision-making and the complex medical information that had been provided to her. Her decision was to have no further treatment at all.

Table 5

*Examples of Biomedical and Patient-Centred Information in Consultation #2*

Biomedical Information	
Topic	Patient Utterance
Nature and status of disease	“he did a biopsy which came back positive”
Side effects	“There is still a little bit of pain where the incision was on the breast”
Other health issues	“ The only problem I have is a little bit of, um, high blood pressure, which is well controlled with medication”
Medical history	“I’ve got a brother who died about 3 or 4 years ago from bowel cancer”
Patient-Centred Information	
Topic	Patient Utterance
Explicit evaluation of past treatment	“I would say 4-6 months before I felt really strong like I used to be and so, no it was not a problem”
Patient’s questions about her condition	"Because what I understand is that the cancer I have now is unrelated to the first one? Am I correct?"
Patient’s goals for consultation	But I don’t know how many (sessions of radiation) so I am hoping to find out today
How the patient is making medical decisions	“Um I pretty much came here with an open mind and I even said to my husband, I will take anything they recommend”

Table 5 continued

Patient-Centred Information	
Topic	Patient Utterance
Explicit evaluation of side effect	"And I had, ah, an inflammation of the vagina which was at times very painful"
How the patient is conceptualizing the choices and possibilities available to her	"The way I look at it too is, my god I'm 72 years old, ah, how long am I expecting to live?"

**Post-consultation Interview.** The patient said that the consultation “went really well” and expanded on this by saying that “she really enjoyed all the explanations that he gave, the percentages of benefits and risks.” She said that “as far as I am concerned, it was a perfect explanation, you know, to make a decision right on the spot.” The patient said that the oncologist had presented her with information about all the different types of chemical therapies, including chemotherapy or pills like Tamoxifen. He showed her all the statistics about chemotherapy so that she quickly decided that she wasn’t going to have chemotherapy or any adjuvant therapy. Then the clinician talked about radiation, again covering the benefits and some of the risks of not having radiation. The patient said that the risks presented to her were so minimal that she decided that she doesn’t need to have any more treatment. She told me that she was leaving “very happy” that she doesn’t “have to take any more treatment.” When I asked about how she felt the oncologist understood her goals and values, she responded saying, “I think he understood quite well. too, what I wanted, what I wanted to know, and then at the end what I wanted or didn’t want and he was very open to that, there was no push to one way or the other as far as treatments are concerned.” The patient indicated that the statistics were very important to her in terms of making decisions: “for example, when I looked at the

statistics he was showing me, the chances of survival were 1% better having radiation as compared to not having radiation. So for me it was obvious that it wasn't worth getting, if it had been 20%, well I would have said, maybe I should consider that, but 1%--so the statistics were very relevant to me." The patient was a 10 on a satisfaction scale from 1 to 10.

**Summary.** Obviously, there was a marked change in the way the patient talked about her goals from the pre-consultation interview to the post consultation interview. This shift occurred during the consultation, as was evident in the way the patient talked about her goals at the beginning of the consultation to the way she was talking about her goals by the end of the consultation. In the pre-consultation interview and at the beginning of the consultation, the patient was clear about her need to know what treatment she would need and, if she needed radiation, how many sessions she would need. The statistical information she received shifted the patient's opinion about radiation. It was almost as if, at the beginning of the consultation, the patient didn't realize that she had a choice in the decision-making process. However, because the oncologist consistently implied that she had choices, she became very open about giving her own opinions on the various statistics. Ultimately, her decision was to have no radiation or other treatment—a decision that the oncologist reported later was reasonable but surprising to him because of her initial position.

**Consultation #3: Male patient, 69 years old with prostate cancer, meeting with radiation oncologist for first time.**

**Pre-consultation Interview.** In the pre-consultation interview, the first question was "What are you meeting with Dr. [name] about?" The patient answered that he "had a

biopsy and I have prostate cancer, so we are trying to determine what the course of action (is) today.” His expectations for the consultation were “that I have enough information that when I go to see [the urologist, next week], we can decide what is happening” ( e.g. what the course of treatment is). He also said that he had done quite a bit of reading before he came to this appointment and had a few questions that he wanted answers to; specifically, what treatment at the BCCA would entail if he had radiation and what are the arrangements for out-of-town patients?

**Consultation.** This consultation lasted 34 minutes including about a 9-minute medical exam, so there were 24.5 analyzable minutes. During the consultation, the patient made 99 utterances. Twenty-seven of the utterances were generic listener responses, most commonly “right” and “mm-hm.” The patient contributed small-talk information in 5 utterances and biomedical information in 27 utterances; see examples in Table 6. The largest proportion of his utterances were the 38 that contributed patient-centred information; see examples in Table 6.

The consultation started with the oncologist gathering information about the patient’s history (including past surgeries, procedures, appointments, and symptoms). In the middle of the consultation, they reviewed the patient’s current cancer diagnosis. It was during this part of the interview that it became clear that the patient and the oncologist had different information on the grade of his cancer. It took them quite a few exchanges to establish the fact that his cancer was a 7 grade and not a 6 grade, as the patient had understood after the biopsy. This new information changed the direction of the interview. At the beginning of the consultation, he had suggested that he and his urologist were thinking there was a possibility that he might not need treatment at this

Table 6

*Examples of Biomedical and Patient-Centred Information in Consultation #3*

Biomedical Information	
Topic	Patient Utterance
Nature and status of disease	“My PSA was going up, and sure enough there was something there.”
Symptoms of disease	“Very frequent urination was the main reason [for the TURP], like less than, or more frequently than every half an hour or so.”
Other health issues	“I’ve had different antibiotics, and some of them have made me sick and some have not.”
Medical history	“No. I am sexually active. and I don’t have trouble with erections.”  “Yeah, a couple [surgeries] on my nose, inside my nose and outside my nose.”
Patient-Centred Information	
Topic	Patient Utterance
Symptom with explicit indication of whether it is tolerable	“Um, ah I have a good stream coming out but it’s still more frequent than I would want.”
Symptom with an indication of how it is interfering with his life	“Like I drove down from Qualicum this morning, and I had to stop [to urinate] on the way down”
Patient’s personal judgment of the information	“I’m surprised to hear it’s a 7 [grade] , makes a bit of difference.”
Patient’s decision to rule out “doing nothing”	“I don’t think doing nothing is kind of an option myself, my dad only died five years older than what I am right now.”

Table 6 continued

Patient-Centred Information	
Topic	Patient Utterance
Patient seeking confirmation of understanding	“From my reading, oh I’m 69 this year, and they’re not all that keen on doing operations on 69-year-olds, am I right?”
Patient’s concern and fear	“That’s probably the thing that scares me the most, the incontinence. I like to do active things, and I don’t want to be tied up like that.”
Patient’s future plans and wants	“Also, the other thing is, um, I am lined up with a couple of holidays, and I really don’t want to do anything until October.”

time. After learning that his cancer was a 7 grade, the patient became certain that he definitely wanted some sort of treatment. At this point in the interview, they moved quickly onto other options available to him, clarifying some of the questions the patient had, based on his reading of literature about his cancer. In the later part of the consultation, the patient was leaning strongly toward having radiation treatment, so the rest of the conversation was spent figuring out how he could balance the need to start radiation as soon as possible with the holidays that he anticipated so much and had already booked.

**Post Consultation Interview.** The patient said that the meeting was “excellent.” He said that the oncologist was “extremely informative and [had] a nice manner.” When asked whether his goal of getting enough information to be able to decide on the next step was met, the patient said that he was “leaning a certain way, and [the oncologist] sort of confirmed that that might be the way to go, with the radiation rather than the surgery.”

He said that the oncologist confirmed that he was close to the age limit where they don't like to do surgery and also mentioned that he had had a similar surgery before and it "was not pleasant and I'd like to avoid it." The patient reported that the topics that he wanted to discuss were discussed; these were, (1) "side effects of the radiation," (2) confirmation that brachiotherapy was not an option, (3) timelines for treatment, e.g., how the radiation schedule and his holidays would work. The patient explained that his urologist had told him that there was no rush for treatment, so he had booked holidays. However, the oncologist had sent away his cancer diagnosis test results to Vancouver to be reviewed, and the review indicated that the cancer was more aggressive than they had originally thought. When I asked the patient about whether he felt that the oncologist understood his values and goals, he said, "Yes, I told him that incontinence is one thing that really bothers me, and he said, well actually, radiation is the better solution, there is less chance of that with radiation." The patient reported that he hadn't decided "100%" on radiation yet, as he still needs to talk to the urologist, but that he's "80% sure" that he will have radiation. On a scale of 1-10, where 10 is completely satisfied with the consultation, the patient said that he was a "10."

**Summary.** Almost 40% of what the patient said was patient-centred information about this patient's perspective. This high proportion suggested that, throughout the consultation, the patient was directing the conversation and the oncologist was following his lead. First, the patient asked many questions which the oncologist answered. Second, when the oncologist presented biomedical information, the patient explicitly stated his evaluation of this information, and the oncologist often followed up on the information that the patient had contributed. Third, this patient had done a lot of reading about cancer

and was very informed about the different treatment options and procedures. The oncologist would allow the patient to display his understanding regarding the treatment options first and would then fill in the gaps whenever the patient indicated there was a question.

**Consultation #4: Male patient in his eighties, Prostate cancer, meeting with radiation oncologist; his wife accompanied him**

**Pre-consultation interview.** The patient said that he was meeting with this oncologist about cancer of the prostate and that his expectation was that, by the end of the consultation, the oncologist "would outline a course of treatment." The patient indicated that his urologist had led him to believe that this treatment would likely involve hormones and then radiation. The patient's specific goals for the consultation were to (1) find out about the results of a recent bone scan and (2) to find out what the suggested course of treatment would be.

**Consultation.** The consultation was 32 minutes long. During the consultation with the physician and nurse, the patient made 145 utterances. Small talk accounted for one of his utterances, and 29 were generic listening responses ("mm hm, "um, "yeah"). There were also 72 utterances that provided biomedical information, and 37 of his utterances contributed patient-centred information, which provided information about this individual's perspective; see examples in Table 7.

This patient had an unusually lengthy and complicated medical history, including procedures and conditions such as atrial fibrillation, a triple bypass, kidney stones, macular degeneration, pulmonary fibrosis, multiple allergies to medications, aortic aneurysm repair, and a TIA. The oncologist and patient spent a large part of the first half

Table 7

*Examples of Biomedical and Patient-Centred Information in Consultation #4*

Biomedical Information	
Topic	Patient Utterance
Nature and status of disease	<p>“When I saw [another physician's name] in April, he told me that they'd found ah cancer cells.”</p> <p>"In October, it [the PSA] was still high, so he said let's do a biopsy and find out where we're at, and I had that in February."</p>
Administrative or procedural information	“No, I have not [had a CT scan], but I am going to have a CT scan done in April for Dr. [another physician's name].”
Other health issues	<p>"I have never been reported to have any sort of high blood pressure."</p> <p>"My eyesight is gone, I have macular degeneration, I'm now a client of the people across the street at the CNIB."</p>
Patient-Centred Information	
Topic	Patient Utterance
Side effect with explicit indication of whether it is tolerable	“Just to add to that, I seem to, ah, if, ah, drugs have a downside or a counter-effective thing, I seem to get them. The statin drugs are really a problem for me.”
Symptom with an indication of how it is interfering with his life	“Yeah, I don't bend over well and I don't do a lot of things.”
Patient's preference or want	"I would like to keep him [the urologist] involved."

Table 7 continued

Patient-Centred Information	
Topic	Patient Utterance
Patient's question about how long a specific treatment will be	"How long would that [the hormone treatment] perhaps be?"
Patient's opinion	"Um, well, you know, if that's your recommendation [to use the hormones to get the PSA to as low as possible before starting radiation]. I respect that."
Patient's resources or supports	"I kind of have my own [support group]. I have a dozen buddies at various stages of it [prostate cancer]."
Patient's opinion	"Um, well, you know, if that's your recommendation [to use the hormones to get the PSA to as low as possible before starting radiation]. I respect that."
Patient's resources or supports	"I kind of have my own [support group]. I have a dozen buddies at various stages of it [prostate cancer]."

of the consultation reviewing this medical history in order to ensure that the oncologist had a good grasp of the patient's current and past health conditions. This was evident in the high proportion of patient contributions of biomedical information. About half-way through the consultation, the topic shifted to the current cancer diagnosis, covering several areas: (1) a description of the details of the current cancer diagnosis, (2) the types of information to consider in terms of making a decision about whether to have treatment for this specific patient with his current health conditions, (3) the options available for treatment, and (4) the side effects of the various treatments. After they had reviewed all this information about the prostate cancer and relevant treatments, the oncologist recommended that the patient have hormone therapy and then radiation treatment. The patient said that he respected the oncologist's recommendation and agreed to start on

hormone therapy right away. The patient expressed his concern about keeping his urologist involved in his treatment, and the oncologist agreed to let the patient get the hormone injections done by his urologist.

**Post-consultation interview.** When asked how the consultation had gone, the patient said "really good." He said that "100%" of the goals he had set out in the pre-consultation interview were met; specifically, there was now a treatment plan in place, and although the official bone scan results weren't in yet, the oncologist thought they looked fine. The patient reported that the oncologist also gave him detailed information about the cancer and that some of this information was particularly helpful because it was new information that he'd never heard before. The patient appreciated the fact that he was given a course of action and information about the time frames associated with it. He also said that it was good that he could get the injections for the hormone treatment from his urologist. The patient explained that he didn't have many questions for the oncologist because the oncologist was "very informative." The patient indicated that he thought the oncologist had understood his values and goals and had addressed any concerns or questions he had. For example, during the consultation, the patient had asked about whether having so many x-rays and scans was a problem because of the exposure to radiation; the oncologist had explained why they weren't so worried about it with people his age. The decisions that were made were (1) to have a pelvic scan, (2) to have hormone treatment for as long as needed in order to get the PSA level to a negligible number, (3) to meet with the oncologist again, and then (4) to have radiation treatment. The patient said that he felt like there was only one course of treatment possible, so there wasn't really a decision to be made. The oncologist reminded him that there were a

whole host of medical problems that could kill him before the cancer would. The patient also indicated that he thought that the oncologist was very thorough in his consideration of the patients' complicated medical history when making a recommendation. When asked if there were any topics that they discussed that he hadn't planned on talking about, the patient answered that he hadn't planned on talking about his weight, but that the oncologist had brought up how he needed to lose some weight. He joked that he wasn't happy about this topic of conversation because his wife started ganging up on him with the oncologist and telling the oncologist about all of his bad eating habits. He said that on a scale of 1 to 10, this consultation was a "10", and he pointed out again that if he wasn't satisfied, it would be his own fault because the oncologist had allowed him to ask any questions he had.

**Summary.** This consultation was quite different than the first three above because the patient had a very complicated medical history, which required a lot of time ensuring that the oncologist understood the patient's history and current health. Going into the consultation, the patient already had a good idea of what the recommended treatment would be, so he wasn't surprised when the oncologist made his recommendation. It was interesting that, even though a lot of the consultation consisted of reviewing biomedical information, the patient was still able to find opportunities to bring in his own perspective. He did this by frequently giving his own personal evaluation on medications and side effects. He also had opportunities to explain the effects of his current health conditions within the context of his life; for example, his pulmonary fibrosis made it difficult to walk up hills. He also asked questions that allowed him to direct the conversation to topics that were important to him; for example,

he found a way to express the fact that he wanted to have his urologist continue to be part of his care team.

**Consultation #5: Male patient in his eighties, with lymphoma and metastasized lung cancer, meeting with a GP oncologist and nurse in the Pain and Symptom**

**Management clinic; his wife accompanied him.**

**Pre-consultation interview.** The patient said that he was meeting with the physician today because of "pain." He added that he had lymphoma and that "it has been treated for 3, 4, years." He had had "two lots of chemo and two lots of radiation" and he had "run out of options [for treatment]." He said that he had been told by numerous people that "there is no need for people to live with pain in this day and age," but in his case, pain had been a particular problem. Even his three doctors couldn't get his pain under control. He specified that he had pain in his buttocks as well as in the growths on his chest. He has had numerous problems with pain medications either not working or causing a reaction that included agonizing pain. He thinks that this bad reaction to the pain medications is because he has an allergy to medications with morphine in them. His goals for the consultation were to find a medication that will help with his pain that doesn't contain morphine or to find some other treatment that will help with pain relief.

**Consultation.** The consultation was 38 minutes long. The oncologist and the nurse were present for the first 32 minutes, then the oncologist left and the nurse continued talking to the patient for the last 6 minutes. During the consultation with the oncologist and nurse, the patient made 282 utterances. Small talk accounted for 13 of his utterances. Another 93 were generic listening responses ("mm-hm, "um, "yeah"). There were 96 utterances that provided biomedical information and 66 that were patient

centred, contributing information about this individual's perspective; see examples in Table 8.

The clinicians (physician and nurse) spent the majority of the first half of the consultation assessing the patient's current pain and reviewing with him the history of various pain medications and the reactions he had had to the different medications. The patient was explicit in emphasizing that his pain is extreme, that it is affecting the quality of his life, and that he has had extremely adverse reactions to most pain medications that are derivatives of morphine. The patient often used his gestures, prosody, and facial displays to demonstrate the severity of his reactions to the different pain medications. The patient acknowledged that his case was abnormal and that most people don't believe him when he tells of his reactions to these medications because it's so unusual. The clinicians and the patient came up with a "Plan A" for getting his pain under control and a "Plan B" if Plan A didn't work.

The patient agreed to Plan A and said that he was hopeful for some relief but wasn't expecting much. He definitely wanted to know what Plan B would consist of. Once they had figured out both a Plan A and B for the patient, the clinicians reviewed the procedure for getting the new medications and ensured that the patient was set up with other appropriate services (e.g., registered for hospice, has a home care nurse assigned). Before the physician left the consultation, he and the patient talked about the fact that the patient's family was coming home to see him, and they discussed estimates for how long the patient might have left to live. After the physician left, the nurse and patient continued talking for a short while longer. The nurse reviewed the complicated schedule for taking the various medications and ensured that the patient knew when and how much

Table 8

*Examples of Biomedical and Patient-Centred Information in Consultation #5*

Topic	Biomedical Information	Patient Utterance
Nature and status of disease	<p>“Originally I had one source of pain, that is in my right buttock. Somewhere down there, I don't know, there is a gro-, there's a tumour and that is pressing on a nerve or something”</p>	<p>"The last report I had on it [a growth at the bottom of his lungs], they didn't know whether it was lymphoma or lung cancer."</p>
Administrative or procedural information	<p>“Dr. [name] and Dr. [name], they just phone them [the prescriptions] into the Sidney Pharmacy.”</p>	
Other health issues		<p>"I've had bronchiesctasis, COPD, the lot"</p>
Medical history		<p>"The chemo and radiation held it [the tumour] at bay, but when these [chemotherapy and radiation] finished, it started to expand and other ones came up."</p>
		<p>"Now years ago, and this is quite some time, I had a morphine patch put on. Nothing to do with cancer, I don't know what it was for, and it put me on the floor: ambulance--hospital--rip it off--wait a while--and it went away "</p>

Table 8 continued

Patient-Centred Information	
Topic	Patient Utterance
Side effect with explicit indication of whether it is tolerable	<p>“But you know, as you say, for general purposes, is my breathing a problem? No, because I don’t do anything.”</p> <p>"Well I took one and I thought, well maybe, um, but it was every four hours. I took the second one, and within a quarter of an hour I was in agony, I was screaming, pounding the table, ‘Kill me!’ (puts hand over face and grimaces)."</p>
Symptom with an indication of how it is interfering with his life	<p>“Um, I’m never free from it [pain]. I, I, I, I, sit down and after, say an hour, I get up, ah, I, I’m, it limits everything I do.”</p> <p>"This has been going on for-- long time. And of course, when you stand it hurts, when you sit it hurts, when you lay down it hurts. Um, I can lay on my stomach sometimes, and it doesn't hurt as bad."</p>
Patient's hope	" I'm hoping for but not really expecting 100% relief from it [Tramadol and a higher dose of steroids]."
Patient's reasoning	"Well, if it gives me, if it doesn't bring this on [points at chest] again and reduces what's I've got down there-- Hoa! Anything is better than nothing in my state. "
Patient's preference or want	"Dr. [name] said that when, if we run out of relief with Endocet, she could try a patch, well I know we'd better not."
Patient’s question about his options	"And if I stop it [the current pain medication], um, what do I go on then?"

Table 8 continued

Topic	Patient-Centred Information	
	Patient Utterance	
The patient's perspective	"Well, it [Tramadol] didn't appear to help. but in hindsight, a little help is better than no help."	
Patient's past goals	"I was trying to make [stay alive until] Christmas at one time."	
Patient's support and future plans	"Well we got people coming home [to see me]."	

to take of each medication. She also answered any remaining questions the patient had.

**Post-Consultation interview.** The patient said that the meeting with the clinicians was "good." He reported that they had managed to come up with a "Plan A and Plan B" to address his pain. When asked whether his goals had been met, he said that he would call them "hopes" rather than goals. He explained this by saying that he doesn't really have any expectations, having had such a rough time with so many medications, but he has hope that this plan might work. He also made a point of saying that this physician accepted his explanation about how morphine derivatives have affected him so badly and that this was unusual: many physicians think he's "an old fool" who doesn't know what he's talking about. He explained to me that what was important in the consultation was that the he felt accepted by the physician. He also went on to say that he understood what the physician was telling him and that this physician thought the same way as he himself does. He said the conversation went "pretty well as expected" and that the "physician would have been willing" to talk to him about any questions or issues he had. He was comfortable with the physician and said that they were

"matching." He said that the physician understood and believed the information that he was providing and also provided good information to him as well. There were two key decisions made in the consultation, one was to increase the steroid, and the second was to start taking Tramadol. The patient added that he had no idea whether these decisions would be important or not; that would depend on whether the medications worked or not. Overall, he was very satisfied with the consultation, rating it a "10" on the satisfaction scale.

**Summary.** During the consultation, the patient provided a lot of patient-centred information to the clinicians about the amount of pain he was suffering, the effect the pain was having on his life, and the severity of the reactions he had had to different medications. The patient was very dramatic in his descriptions of the pain he was suffering, often demonstrating his physical reactions to the various pain medications. It became clear near the end of the consultation why he was providing such extensive descriptions and demonstrations of the negative effects of these medications. It was because he hadn't been believed when he described his adverse reaction to many physicians in the past. The patient confirmed that this was the case and said how much he appreciated that the physician and nurse had accepted that what he was saying was true. The patient's individual perspective was very important in this consultation because the clinicians built the pain management plan around two factors unique to this patient: (1) he was experiencing pain that was affecting all aspects of his life, and (2) that he did not want to try any medication that he had had an adverse reaction to in the past. All of the decisions made (and most of the discussions in the consultation) centred around these two individual perspectives of this patient.

**Consultation #6: Male patient, 74 years old with prostate cancer meeting with a radiation oncologist.**

**Pre-consultation interview.** The patient explained that his radiation oncologist had retired, so he was meeting with his new oncologist for the second time for ongoing treatment for prostate cancer. The patient's expectation was that things wouldn't change much with the new oncologist. He thought that it was likely that the oncologist would keep him on the same schedule he had been on with his previous oncologist and that this would include "a prescription for Zoladex for insertion, he [would] go to his GP to get it inserted and he'[d] continue to get PSA tests" until the levels were negligible. The patient recognized that this oncologist was new and might want to do something different, but he wasn't expecting that to be the case, and he wanted to stay on the current treatment. He said that he had a long-term goal to survive and had been very happy with the care that he had received throughout his treatment.

**Consultation.** This consultation was the shortest, 17.3 minutes. It was unique in the sample because the patient had been receiving treatment at the BCCA for several years, and this was his second meeting with his new oncologist (their first meeting was a year and a half ago). During this consultation, the patient made a total of 141 utterances. Small talk accounted for two of his utterances, and 71 were generic responses ("mm-hm" and "okay"). There were 34 utterances that contributed biomedical information to the oncologist and 30 that contributed information about this patient's individual perspective; see examples in Table 9.

At the beginning of the consultation, the oncologist asked questions and reviewed information about the patient's history of prostate cancer and also gathered information

Table 9

*Examples of Biomedical and Patient-Centred Information in Consultation #6*

Topic	Biomedical Information	Patient Utterance
Nature and status of disease	"So while I was there, they of course did a biopsy on it, and they said 'Oh, you are one of the small number of people for whom the PSA does not detect the, the cancer.'"	
Reviewing past treatment and physicians	"Yes, he [Urologist] was the one who-- he did the surgery and all that, of course. I didn't see him a lot after that but I did some."	
Procedural or administrative information	"Yes, I have, ah, my GP does those [administers the zoladex] ."	"The PSA, 'cause I've been doing the PSA test every four weeks."
Side effects of past treatment	"Oh, either way I don't remember any problems like that [diarrhea or constipation]. "	
Absence or presence of current side effects	"Hm, I don't feel that I have night vision problems."	
Assessment of current medication	"I can't tell whether it [the Flomax] makes any difference one way or another."	

Table 9 continued

Patient-Centred Information	
Topic	Patient Utterance
Symptom with an indication of how it is interfering with his life	"I don't think they're [his eyes] as good as they used to be and I, ah, the last time I was in to see my optometrist, I said 'I don't think, you know, when I drive down the street that I can read road signs as, as, easily as I used to.'"
Patient's preference or want	"That's [taking one pill a day] an advantage for me -- the reason for that is that I get up, I make coffee for us in the morning, and, and, and sometime after that I take pills, and I take pills for various and sundry things because I have an erratic heartbeat and of course I have all of this stuff and all these things--so once a day would be a convenience to me. all things being equal."
Patient's question about how to get the prescription	"So do you write the prescription or will it arrive at their office?"
Patient's perspective	"I really appreciate the medicine in this province, I'm an old American. and to my mind this is the best possible world, it has medicine as advanced as anybody. and I can afford it."
Patient's concerns	"It takes stress to get it [urination] started, and I find it interesting that the problem is much more common when I've been lying down asleep. I don't know if it's lying down, or if I'm inactive, or whatever it is. But I'm concerned about it."

about the side effects of the different medications that made up his treatment program.

The oncologist allowed the patient to talk uninterrupted for long periods of time and, in

this way gathered a lot of information from him, even in a short consultation. The patient reported that he had had a side effect (diminished lung function) caused by the medications that were part of his last treatment to reduce his PSA. The patient and oncologist agreed that it was best not to use that medication this time, to use a different medication instead. They spent the middle portion of the consultation deciding which medication to change to. The last portion of the consultation was spent discussing the time lines for the outlined treatment. They had agreed that the patient was going to begin to take a medication to reduce his PSA so they needed to schedule a PSA test prior to the patient's next appointment. Quite a lot of time was spent discussing this because the patient had been getting PSA tests done every four weeks and the oncologist wanted the patient to know that, from a medical standpoint, it wasn't necessary to check the PSA that frequently. The patient indicated that he liked getting the tests done fairly frequently because he enjoyed seeing the PSA numbers going down but that if it wasn't medically necessary he didn't want to add cost the medical system. In the end the patient decided not to have the tests done every month but to get a test done each month in the two months before his next appointment with the oncologist.

**Post-Consultation interview.** The patient said that his consultation "went well" and that the oncologist was a "neat person." He reiterated that he had been very fortunate with his various doctors. He felt that "they [were] frank with [him]" and answered any questions he wanted and that he liked them. The consultation went as he had expected, and the oncologist had suggested that they continue the same regime as in the past, with a minor change. This change was to discontinue one drug (because it had caused shortness of breath the last time the patient had taken it) and to prescribe a different drug. He

mentioned that some of the things he liked about the oncologist were that (1) he carefully questioned him about side effects he had had from medications in the past, (2) he warned him of one minor thing that might happen as a result of taking this new medication and told him what to do if this happened, (3) he agreed that following the same course of treatment as before was the right thing to do, (4) he was easy to get along with, (5) he was trustworthy, and (6) he was very open to questions. The patient felt that his goals were met "perfectly." When asked "How easy was it to understand the information provided by the oncologist?", the patient answered "very easy" and explained that the oncologist was very good at presenting information in a way that made sense to the patient. He gave this example: When the oncologist was outlining a choice that the patient needed to make between two different medications, he outlined the advantages and disadvantages of each medication for the patient. With this information, the patient was able to make a decision to change to a new medication that he only had to take once a day, which was a better fit for his lifestyle.

**Summary.** The patient's expectation for the consultation was to resume the same treatment program that had been successful in keeping his prostate cancer suppressed over several years. Although, the consultation was short, the patient was able to contribute his individual perspective to the physician, and his perspective affected the decisions made in the consultation. During the consultation the oncologist and patient decided that they would resume a very similar treatment program as in the past but that they would change one of the medications. They decided to switch to a new medication primarily because the patient told the oncologist about a negative side effect he had experienced when he was having his last treatment. The process of deciding on a new

medication also required input from the patient. First, the oncologist presented the pros and cons of each medication, then the patient was able to assess which advantages and disadvantages meant something to him within his particular life circumstances. For example, the patient emphasized that it was very beneficial to him to only have to take a medication once a day, so they chose the medication that made this possible. In the post-consultation interview, the patient indicated that the fact that the oncologist presented him with pros and cons for each medication made it easier for the patient to assess which medication would best fit his particular life circumstances.

**Consultation #7: Male patient; melanoma, meeting with a palliative-care physician and nurse in the Pain and Symptom Management clinic; his wife accompanied him**

**Pre-consultation interview.** The patient explained that he had a malignant melanoma and he was here to see the physician in the Pain and Symptom Management Clinic to get his pain under control. He had seen this physician previously, and at that time he was prescribed a course of medication that had succeeded in getting the pain in his jaw under control. Now, however, he was having side effects from the pain medications. The patient said that he was hoping to find out from the physician whether there was anything they could do about some of the side effects, which included twitching, sweating, voice changes, high blood pressure, and digestive problems.

**Consultation.** The consultation was 20 minutes long, during which time, the patient made 109 utterances. Small talk accounted for 1 of his utterances, and there were 30 generic listening responses ("mm-hm", "um", and "yeah"). There were 36 utterances that provided biomedical information and 36 that contributed information about this patient's individual perspective; see examples in Table 10.

Table 10

*Examples of Biomedical and Patient-Centred Information in Consultation #7*

Topic	Biomedical Information Patient Utterance
Nature and status of disease	<p>“They did some tests, and my white blood cell count was up, elevated quite a bit, and she [the family physician] said they also did, ah, X ray, and I guess there was quite a bit of stool in my system, it’s not coming out.”</p> <p>"Yeah, 'cause things were starting to get under control, and then all of a sudden I got this stomach thing, and things got out of control."</p>
Administrative or procedural information	<p>“Saw him [the patient’s oncologist] this morning.”</p>
Side effects without explicit indication of whether it is tolerable or not	<p>" Like last, last night was pretty---it [bowel movement] was fairly loose. There’s some of them. Though. have been pretty, pretty difficult."</p>
Answering nurse’s question about how much caffeine he ingests, providing biomedical information without an explicit indication of whether this is something that is important to him or not.	<p>“I don’t drink coffee in the afternoon.”</p>
Medications	<p>"Yeah, I haven’t been taking much [Lactulose]."</p>

Table 10 continued

Patient-Centred Information	
Topic	Patient Utterance
Side effect with explicit indication of whether it is tolerable and how it is interfering with his life	<p>“It hasn’t been all that great in the last little bit. But, ah, awful time with the twitching here, got a whole list of stuff. The twitching and the sweating has just been unbelievable. I’ve had to do laundry twice a day lots of times.”</p> <p>“Yeah, it, it’s like jumping into a shower to go to bed after I get up in the middle of the night. It’s awful.”</p>
Symptom with an indication of how it is interfering with his life	<p>“I wake up in the middle of the night and, ah, the, I’ve got one of these blankets from the hospital that they have and they just, the thing’s just soaking wet. And your pillow is wet, and everything just is soaked. You know, just this, and my head perspires so my, mainly from my, ah, my waist up.”</p>
A patient's explicit evaluation	<p>“Yeah, that [the odour from a bowel obstruction] was just hideous.”</p>
Patient’s question	<p>“What do you do [to stop the sweating]?”</p>
Patient's concern	<p>“It kind of bothers me a little bit because, you know, it’s, I sound funny to me. So I can only imagine what I sound like to anybody else. Maybe, I don’t know.”</p>

The physician began the consultation by asking the patient how he had been. The patient replied that he was “so so” and went on to explain the problems he had been experiencing lately. This list of problems (which were mainly side effects of the various medications the patient was on) became an agenda for the consultation; the patient presented a list of problems, and the physician dealt with each problem one at a time. Because the patient was on many medications that were successfully managing his pain,

the challenge for the patient and physician was to try to figure out how to eliminate the unwanted side effects while maintaining the pain relief. The patient described most of his side effects within the context of his life and rarely gave only a biomedical explanation of a side effect. This allowed the physician to see why and how the side effects were problematic for this individual patient. By the end of the consultation, the physician and patient had made decisions about trying a few new treatments that might help with a few of the side effects; they also decided when the patient would come to the clinic next.

**Post-Consultation interview.** The patient said that the meeting was “excellent and [he] thought the physician was wonderful.” He reported that all of the topics he wanted to discuss were discussed, and he felt that he could discuss anything with the physician. His expectations were met; while he wasn’t sure if they would be able to address all of his side effects, he thought they could get “most of them ironed out, or at least take a look at them and see if we can fix them.” When asked about whether he understood the information the physician provided, the patient indicated that the information was clear. He said that he felt that the physician seemed to understand his goals and concerns and that the physician was “very present,” not “off somewhere else.”

Many decisions were made during the consultation (e.g., to change a medication, to start taking a new medication, to come back in two weeks, to read an article, and to consider a new treatment). The patient emphasized that he felt the physician had considered his wants and needs when they were making those decisions. Finally, he said he was “very satisfied” with the consultation and added that, at the end of the

consultation, the physician “[had] a knack for making you feel better even if you [were] on your death bed.”

**Summary.** In the pre-consultation interview, the patient was very matter of fact about the side effects he was having problems with, which he described in highly technical, biomedical terms. However, in the consultation, once he had listed the problems, for the rest of the time, he tended to talk about the side effects within the context of his life. For example, when describing a side effect, the patient almost always included some indication of how it was interfering with life activities, whether it was tolerable or not, or his level of concern about that particular side effect. He talked this way more than other patients in the study. Perhaps this way of describing side effects through life activities occurred as a result of the patient and physician’s efforts to balance keeping him pain-free and still giving him a quality of life that was as good as possible. When the patient described how the side effects were affecting his life, it seemed that it became easier for the physician to understand which side effects were an issue for the patient. It may have encouraged the physician to help find a solution to the side effects that were most relevant to the patient.

**Consultation #8: Male patient; colon cancer, meeting with a palliative-care physician and nurse in the Pain and Symptom Management Clinic; his wife accompanied him**

**Pre-consultation interview.** The patient explained that he was meeting with the physician today to discuss the new medication he was prescribed last week, specifically, its impacts on his life. His expectations included hearing what the physician had to say; specifically, the patient wanted to hear the physician’s “comments regarding how I feel

I've been impacted.” The patient mentioned that, invariably, there would be some discussion of chemotherapy, but he didn't have any other specific goals for the consultation.

**Consultation.** The consultation was 28 minutes long, during which time the patient made 111 utterances. Small talk did not account for any of his utterances. There were 53 generic listening responses ("mm-hm", "um", and "yeah"). There were 13 utterances that provided biomedical information and 40 utterances contributed patient-centred information, about this patient's individual perspective; see examples in Table 11.

During the early part of the consultation, the physician gathered information from the patient about how he had been doing. The patient provided the physician with a few symptoms that “hadn't been great” over the past week, specifically, increased belching because gas couldn't make it through his system and blockages in his bowels. The patient reported that he was having a hard time with bowel movements, with very little being expelled. He reported the severity of the symptoms by describing how they were impacting his life; for example, he was having problems eating, sleeping, and walking due to the pain from the digestive track blockages. During the middle part of the consultation, after the patient had contributed information about the symptoms and the effect of the symptoms on his quality of life, the physician began to make some suggestions for medications that might help with the symptoms. The patient and physician discussed various options and decided on a course of action that included adding two new medications to the patient's regime. The patient was hopeful that these medications would help. Near the end of the consultation, the patient expressed his concerns about the way the BCCA deals with palliative patients. He said that he had

Table 11

*Examples of Biomedical and Patient-Centred Information in Consultation #8*

Topic	Biomedical Information	
	Patient Utterance	
Nature and status of disease	“Ah, no, the only thing I had drop into the toilet per se was just a couple of weeny stools like that.”	
	"The other stuff, this tar stuff, is just sort of oozing out of my anus and not gone any further except the toilet paper.”	
Administrative or procedural information	“Okay, and now we’ve got two patches left.”	
Symptom or side effect	"No, I do quite a bit of burping in spells which is almost”	
	"Sometimes like a hiccupping (characterizing the burping spells)”	
Medication information	“There’s five [patches] per package.”	
Topic	Patient-Centred Information	
	Patient Utterance	
Side effect with explicit indication of whether it is tolerable	“I- you know for my physique, size, I’ve normally been about 170 pounds all of my life, and I’m down around 155, which is not good. Too low, too low for me, and it’s because I’m not eating.”	
Symptom with an indication of how it affects life activities and how he copes	“So uh, no my pain isn’t bad, this [gesturing to belly] is more of a problem here because I know it’s abnormal and that sort of thing, but uh, uh, well, if I am in a chair that’s bothering me or pressing on this lump here [gestures to part of his back] in my back, well then I just [adjusts himself in his chair] relocate myself, but I am still not sleeping on my left side, which is my favourite side to sleep on, because that is just too much.”	

Table 11 continued

Topic	Patient-Centred Information	
		Patient Utterance
Patient's theory about his condition		<p>“So I don't know whether, uh, I know that some people's philosophy is that, uh, it is not good for your body to be undergoing sorta constant pain 'cause it sort of wears the body down, uhh, and so I am prepared to take some advice from you if you think it would be better for me to be more comfortable well, I guess I could give it a try.”</p>
Patient's question		<p>“Okay, uh, ah ,you gave me that form for this uh, palliative care drug program, and the pharmacy, uh, honoured that, ah, I just wondered now does, uh, what medication would come in under that? If Dr. [name] were to prescribe something for me, would that come under this thing?”</p>
“Patient's feelings		<p>“But, anyhow, I feel very good about the approach that you've suggested so far, and, ah, I am just naturally discouraged about this [cancer] right now.”</p>
The patient's concern about his overall care at the agency		<p>“[Wife's name] and I have discussed many times that when a patient gets involved in, um, in this situation here at the cancer agency, there doesn't seem to be anybody sort of looking at the overall situation, seeing what may be best for this patient. Now I think that you've given us some excellent guidelines here, ah, I feel you know I've I've gained far more from talking with you than talking to [other doctor]. And you know I am not disputing what his credentials are for oncology, but he hasn't been particularly forthcoming in offering a lot of good suggestions [for pain and symptom management].”</p>

Table 11 continued

Topic	Patient-Centred Information
	Patient Utterance
The patient's concern about his overall care at the agency	<p>“[The other doctor’s] been very good in. ah. talking about other options and stuff like that. But, ah, it just, it seems that from a patient’s perspective, it would be nice to have somebody that you could sort of go to, like we’ve found with you, [who] could say ‘Well , okay, you should be doing this or doing that.’ Whereas if we just stayed with an oncologist, he’s probably going to be looking at everything from the perspective of chemotherapy. And I would like a broader outlook, but maybe they look at my situation, ‘He’s terminal’ and say ‘Well, there’s nothing much we can do for him in the long run anyhow, so maybe that’s the only alternative.’ I don’t know but it’s just that, uh, I think that we have been a little bit disappointed in that aspect of the cancer agency, not having somebody objective, more objective, sort of looking at the situation.”</p>

found the care he had received through Pain and Symptom Management Clinic particularly helpful in terms of giving him care that took into account all aspects of the patient and disease. He added that he really appreciated the physician’s communication skills and thanked him for his care.

**Post-Consultation interview.** The patient indicated that the consultation went “very well” and that, even though they were being videotaped, “it felt very natural.” He said that his expectations were met, that the physician listened to his concerns about the symptoms and how they were affecting his life and then came up with a modified plan that involved two new medications. The patient reported that he was hopeful that these new medications would help. When asked if there were topics that they had discussed

during the consultation that turned out to be things he wanted to discuss, the patient said (1) that they had talked about the symptoms from the medications and (2) that the physician had brought up the topic of hospice. The patient noted that the physician “took the initiative” to bring hospice up and that he and his wife were pleased he had done that. The patient decided to go along with the physician’s recommendation and he was going to register for hospice, in case there was a down-turn in his health in the near future. The patient reported that he had no problem understanding the information the physician provided and that he felt that the physician understood his values and goals, specifically, that the patient was concerned about his quality of life. The purpose of the decisions they made to add medications was to increase the patient’s level of comfort and his ability to participate in the activities he enjoys. The patient also said that his decision to register for hospice was largely due to the information the physician provided. Specifically, he learned how registration for hospice would give him access to an emergency response team that would come to his home in the event of an emergency, which was very appealing to the patient; therefore, he thought it would be a great idea to register for hospice. The patient said that he was very satisfied with the physician and commented that “he was a great communicator.”

**Summary.** This patient had a terminal diagnosis and was struggling with trying to do everything he could to have a quality of life that was as good as he could have in the time he had left. This meant that it was important to manage any pain and other symptoms that were interfering with his quality of life. The consultation was not a first meeting between this physician and patient, which was evident from the content of the consultation; e.g., there was no history taking or talk about the cancer diagnosis. The

purpose of the consultation was to ascertain whether there was anything that could be done for this patient to make his life more comfortable in whatever way the patient thought was important. As in consultation #7, this patient described his symptoms within the context of his life. He described how bowel problems affected his appetite, sleeping patterns, and his ability to go on five-kilometer walks with his walking group. The physician recognized that these symptoms were particularly problematic for the patient and suggested medications that might help with very few side effects. The conversation about hospice was particularly noteworthy. The physician managed to find a way to bring up the possibility of hospice (which can be a touchy or painful subject) in a way that was positive for the patient and his wife. He presented a benefit of hospice (access to an emergency team that makes house calls) that was particularly relevant to this patient's concern about needing emergency treatment for a complete bowel obstruction. The patient indicated in the post-consultation interview that this information was especially appreciated because it relieved some of his worry about such an emergency.

## CHAPTER 5

### DISCUSSION

The goal of this thesis was to develop an analysis system that could identify the information that patients contributed about their own individual perspective during consultations with clinicians in a cancer care setting. The specific goal was to reveal, highlight, and explicate the details of the wide variety of information that patients can contribute when communicating with their clinicians. I was specifically interested in using an inductive approach to develop an analysis system, that is, one derived from what patients actually say in oncology consultations. An important criterion for the analysis system was that it should have clear operational definitions as well as psychometric evidence that it was replicable across analysts and data sets.

#### **Examining Individual Patient's Perspective**

Patient-centred communication has many benefits to patients (Canadian Medical Association, 2007). However, McCormack et al.'s (2011) review of the literature found that most of the studies and measures of patient-centred communication limited their assessments to the clinician's communication; these authors emphasized that, in order to have a comprehensive measure of patient-centred communication, researchers must also characterize and assess patients' communication.

Moreover, most of the studies that have assessed patient's communication have used nomothetic measures, which provide information about patients-in-general but do not provide relevant insights about an individual patient. The alternative methodology chosen here was an idiographic approach. When a clinician sits down with a patient to practice patient-centred communication, that clinician must treat, assess, and

communicate with this particular patient, not with patients-in-general. An idiographic measure is designed to capture this individualized information--not to be aggregated across patients.

The analysis system developed here for identifying individual patient's perspective allows analysts to make distinctions between four different kinds of information provided by each patient, namely, generic listener responses, small talk, biomedical information, and patient-centred information. The analysis system consists of an overview of the four different kinds of patient information, their formal operational definitions, Elan .eaf files for each video for analysis, a decision tree, and a document detailing the steps of analysis. The system has demonstrated high reliability with an independent analyst and cross-validation with the full data set. In short, it was replicable across analysts and consultation sessions.

An idiographic, qualitative analysis, which followed each consultation from the pre-consultation interview, through the video-recorded consultation, to the post-consultation interview, illustrated the wide variety of ways in which patient-centred information came into the consultations and the effects it had on each consultation.

### **Future Uses and Implications for the Analysis System**

#### **Training Medical Students**

In Canada, medical students are required to be familiar with the concept of patient-centred interviewing. Indeed, candidates' communication skills are evaluated in examinations of medical students and residents using the Objective Structured Clinical Examination (OSCE; Khalil & Bhopal, 2009). Therefore, the focus of communication training for medical students is usually on helping the students acquire patient-centred

communication behaviours, for example, open- and close-ended questioning, detection of verbal and nonverbal cues, elicitation of patients' concerns about their health, and elicitation of a patient's psychosocial history. These are all patient-centred communication behaviours from the clinician's point of view; they do not include what clinicians should listen for and notice from the patient.

Medical students learn to listen very carefully for biomedical information when talking to patients, but they learn far less about how to listen for information about a patient's individual perspective on his or her medical condition. Yet in order to have a patient-centred consultation, it is essential to be able to gather and respond to both kinds of information--surely a difficult task. It is possible that parts of this analysis system could be adapted to teaching students to distinguish among different kinds of patient information.

For example, a training seminar could include the following stages: First, the students would watch a 10-minute segment of one of the videos in this study. Second, they would be asked to identify and distinguish between patient utterances that contributed biomedical information and those that contributed the patient's perspective. Third, they would be introduced to the operational definitions of biomedical information and patient-centred information from this analysis system, with examples and discussion. Fourth, they would look at the same segment of video again, this time using the operational definitions to identify and distinguish between patient utterances. Finally, they would compare their initial identification of the kinds of the patient utterances with their second, systematic one and notice which utterances they identified differently. The goal of this seminar would be that the students would develop a more refined awareness

of the many ways in which a patient can contribute his or her perspective. They might be more likely to hear the individual patient's perspective the next time they were meeting with a patient.

One of the advantages of using video tapes of actual communication between patients and clinicians in the kind of seminar described above would be that the students could learn to listen for the individual patient's perspective by actually listening to specific patient utterances. The students could practice how to recognize information from a patient instead of just reading about it. This kind of learning prepares them for the kind of collaboration with patients that Bleakly and Bligh (2008) pointed out can be beneficial:

Collaboration between [medical] student and patient can offer a rich site for co-production of clinically relevant knowledge liberated from the conventions of medicalised learning. For example, the student, in turning to the patient's narrative, is faced with a complex account that aims to make sense of symptoms in quite a different way from conventional medical reasoning (which typically reduces the patient's complex account to a clinical formula for the sake of diagnostic focus). This is not to devalue the medical reasoning process, but to place it in a holistic context. Students need to know how to align generalised (nomothetic) evidence-based reasoning and specific (idiographic) narrative-based judgement. In a patient-centred approach . . . The patient now plays an active role as educator, rather than a passive role to the educational activities initiated by the doctor. The student is encouraged to take a more active role in

learning, in collaboration with patients, other students, and clinical teams.

(p.95)

In short, for a medical student in a consultation to be able to combine his or her generalized knowledge of biomedical information with the individual perspective of each patient, he or she will first need to be able to recognize that individual patient's perspective. My hope is that this analysis system could be used to teach medical students (a) to see patient-centred communication less as something they need to do and more as something collaborative and (b) to see that this collaboration requires gathering and recognizing each individual patient's perspective in whatever way the patient communicates it.

### **Evidence-based Decision-making.**

Recent definitions of evidence-based decision-making explicitly incorporate clinical expertise and patient values into the decision-making process (Lohr, Eleazer, & Mauskopf, 1998). An Institute of Medicine (2001) publication defined *clinical expertise* as “the ability to use clinical skills and past experience to rapidly identify each patient's unique health state and diagnosis, individual risks and benefits of potential interventions, and personal values and expectations. . . .” and went on to define *patient values* as “the unique preferences, concerns, and expectations that each patient brings to a clinical encounter and that must be integrated into clinical decisions if they are to serve the patient” (p.147).

Within both of these definitions is the requirement that, in order to have shared decision-making that is evidenced based, the patient's individual preferences, concerns, and expectations must be included in the decision-making process. Thus, in order to

evaluate a shared decision-making consultation as evidence based or not, it is necessary, first, to be able to identify patient utterances that contributed *patient values* and, second, to examine whether these patient values were incorporated into the decision. The analysis system developed here could play a role in this process.

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## Footnote

<sup>1</sup> *Prosody* is the linguistic term for the audible non verbal concomitants of speech, for example, intonation, word stress, rhythm etc.

**APPENDIX A1: Clinician Consent Form****\*Participant Information and Consent Form****Communication Processes in Medical Interviews****BCCA Principal Investigator: Dr. Grant MacLean**

Vancouver Island Centre: Telephone: 250-519-5572

**Co-Investigators:****Sara Healing**

Psychology Department, Uvic Telephone: 250-888-2216

**Dr. Janet Bavelas**

Psychology Department, Uvic Telephone: 250-727-6573

**Dr. Peter Kirk**

Clinical Professor, UBC Telephone: 604-992-0310

As a graduate student, Sara Healing is required to complete a research thesis as part of the requirements for her degree in Psychology. These videotaped consultations are the essential data for her thesis.

**Sponsor(s):** A Canadian Institute for Health research New Emerging Team (CIHR-NET) grant is funding this research.

**Purpose**

The purpose of this study is to develop a methodology for examining the processes by which physicians and patients make decisions. We are not judging whether a decision was “good” or not; instead we are developing a method for analyzing *how* decisions are actually made. You are being invited to participate in this study because you are an experienced specialist who routinely has consultations with patients that include many kinds of decision, large and small. Your participation in this study is entirely voluntary, and you are free to choose not to participate, to withdraw from this study, or to choose not to do any particular part of the study. In the event that you withdraw from this study, we will erase your data.

**Study Procedures**

If you agree to voluntarily participate in this research, we will videotape one of your medical consultations (e.g. a meeting with patient and family), using a video camera that is set up in the consultation room, the researcher will not be present during the consultation. We will only record the consultation if everyone (physician, patient, and family members) have agreed to participate in the study. Also, you will have a way to exclude parts of the interview e.g. the physical exam. At the end of the consultation we will give you the opportunity to watch the video and decide whether we can use the tape for our research. We estimate that your participation (including filling out the Permission to View form and watching the tape afterwards) would add about 5 minutes to an hour of your time, either after the consultation or by appointment at a later time.

**Potential Risks:** You might be concerned about a loss of confidentiality, however as you will see in the attached Permission to View form, you control access to the video data. We can assure you that we would never show a videotape in order to illustrate poor performance by a physician.

**Potential Benefits to You:** The potential benefits of your participation in this research include having the opportunity to learn about communication research (specifically, about decision making) and the opportunity to discuss your interview if you wish. Results of the study will be shared with you individually in an information session when the study is completed.

**Potential Benefits to State of Knowledge:**

This study will contribute to the current state of knowledge in that there are very few studies that look at actual communication within a medical consultation. A method for analyzing medical decision making would also be useful for training medical students.

**Confidentiality:** Your confidentiality will be respected. No information that discloses your identity will be released or published without your specific consent. Your identity will not be used in any reports about the study. In records that leave this centre you will be identified by a study code only. All information associated with this study will be kept behind locked doors or in secure computer files.

Research records and medical records identifying you may be inspected by representatives of Health Canada, and the UBC BCCA Research Ethics Board for the purpose of monitoring the research. However, no records that identify you will be allowed to leave the centre. These organizations have policies of strict confidentiality and the individuals inspecting your records must sign a BC Cancer Agency confidentiality form (the form is not applicable to Health Canada officials, who have the legal right to inspect health records and are bound to confidentiality by specific laws.)

We will protect your confidentiality by not using your name on any records; all records will be identified only by a unique number. However, anyone who knew you could recognize you on video, so you will control access to the tape (i.e. who, if anyone, can view it) by filling out the attached Permission-to-View Form after you have seen the tape.

If you choose, it is possible to obscure your face on the video for any use other than analysis (e.g., for scholarly presentations)

We will store the video in a locked filing cabinet in a secure office, along with a code that indicates the uses that you permit and the date on which the tape was made. In a separate secure office, we will store the documents that link your unique number with your name (i.e., this consent form and the Permission-to-View form). Because we need to move the data from the video to the hard drive of our computers, we will use password protected computers.

Dr. Grant MacLean, Dr. Peter Kirk, Sara Healing (Graduate student), Dr. Janet Bavelas and a research assistant will have access to the video data.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request to your study doctor or the UBC BCCA Research Ethics Board.

**Compensation:**

You will not be paid for participating in this study.

You do not waive any of your legal rights for compensation by signing this form.

**Contact for information about the study:**

If you have any questions or desire further information with respect to this study you may contact Dr. Grant MacLean at or [gmaclean@bccancer.bc.ca](mailto:gmaclean@bccancer.bc.ca) or Sara Healing at (250)-888-2216 or [shealing@uvic.ca](mailto:shealing@uvic.ca).

**Contact for concerns about the rights of research subjects:**

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC office of Research Services at 604-882-8598 or e-mail to RSIL @ors.ubc.ca.

**Consent:**

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to your employment.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

\_\_\_\_\_  
Subject's Signature

\_\_\_\_\_  
Printed name

\_\_\_\_\_  
Date

---

Signature of Person Obtaining Consent	Printed name	Study Role	Date
--	--------------	------------	------

Was the subject assisted during the consent process in one of ways listed below?

Yes  No

If yes, please check the relevant box and complete the signature space below:

- The consent form was read to the subject, and the person signing below attests that the study was accurately explained to, and apparently understood by, the subject (**please check if subject is unable to read**).
- The person signing below acted as an interpreter/translator for the subject, during the consent process (**please check if an interpreter/translator assisted during the consent process**).

---

Signature of Person Assisting  
in the Consent Discussion

---

Printed Name

---

Date

**APPENDIX A2: Patient Consent Form****\*Participant Information and Consent Form****Communication Processes in Medical Interviews****BCCA Principal Investigator: Dr. Grant MacLean**

Vancouver Island Centre: Telephone: 250-519-5572

**Co-Investigators:****Sara Healing**

Psychology Department, Uvic Telephone: 250-888-2216

**Dr. Janet Bavelas**

Psychology Department, Uvic Telephone: 250-727-6573

**Dr. Peter Kirk**

Clinical Professor, UBC Telephone: 604-992-0310

As a graduate student, Sara Healing is required to complete a research thesis as part of the requirements for her degree in Psychology. These videotaped consultations are the essential data for her thesis.

**Sponsor(s):** A Canadian Institute for Health research New Emerging Team (CIHR-NET) grant is funding this research.

**Purpose**

The purpose of this study is to develop a methodology for examining the processes by which physicians and patients make decisions. We are not judging whether a decision was “good” or not; instead we are developing a method for analyzing *how* decisions are actually made. You are being invited to participate in this study because this is the first time you are meeting with this physician. Your participation in this study is entirely voluntary, and you are free to choose not to participate, not to do any particular part of the study, or to withdraw from this study. In the event that you withdraw from this study, we will erase your data.

**Study Procedures**

If you agree to voluntarily participate in this research, we will ask you a few brief questions before the consultation with your physician. Then, we will videotape the

medical consultation between you and your physician, using a video camera that is set up in the consultation room (the researcher will not be present during the consultation). We will only record the consultation if everyone (physician, patient, and family members) have agreed to participate in the study. Certain parts of the consultation will not be videotaped, e.g., the physical exam. After the medical consultation you will be interviewed by the researcher, and this interview will be audio taped. After the interview, we will give you the opportunity to watch the video and to decide whether (and how) we can use the tape for our research. We estimate that your participation would add 10 minutes for the pre-consultation interview, 20 minutes for the post-consultation interview, and 5 minutes to fill out the Permission to View Form. You may if you wish review the video. The time taken to review the whole video will be the amount of time of the initial consultation.

**Potential Risks:** You might be concerned about a loss of confidentiality, however as you will see in the attached Permission to View form, you control access to the video data. If our interviews with you cause any stress (e.g. some perceived disappointment in the interview) then we will provide a referral to someone who can help you with this issue.

**Potential Benefits to You:** The potential benefits of your participation in this research include having the opportunity to learn about communication research (specifically, about decision making) and the opportunity to discuss your interview if you wish. Since you will have the opportunity to talk about your own goals and decision making you may become more aware of your role in the medical consultation. Results of this study will be shared with you individually in an information session when the study is completed if you wish.

**Potential Benefits to State of Knowledge:**

This study will contribute to the current state of knowledge because there are only a few studies that look at actual communication within a medical consultation. Developing a method for analyzing medical decision making would also be useful for training medical students.

**Confidentiality:** Your confidentiality will be respected. No information that discloses your identity will be released or published without your specific consent. Your identity will not be used in any reports about the study. In records that leave this centre you will be identified by a study code only. All information associated with this study will be kept behind locked doors or in secure computer files.

Research records and medical records identifying you may be inspected by representatives of Health Canada, and the UBC BCCA Research Ethics Board for the purpose of monitoring the research. However, no records that identify you will be allowed to leave the centre. These organizations have policies of strict confidentiality and the individuals inspecting your records must sign a BC Cancer Agency confidentiality form (the form is not applicable to Health Canada officials, who have the legal right to inspect health records and are bound to confidentiality by specific laws.)

We will protect your confidentiality by not using your name on any records; all records will be identified only by a unique number. However, anyone who knew you could recognize you on video, so you will control access to the tape (i.e. who, if anyone, can

view it) by filling out the attached Permission-to-View Form after you have seen the tape. If you choose, it is possible to obscure your face on the video for any use other than analysis (e.g., for scholarly presentations)

We will store the video in a locked filing cabinet in a secure office, along with a code that indicates the uses that you permit and the date on which the tape was made. In a separate secure office, we will store the documents that link your unique number with your name (i.e., this consent form and the Permission-to-View form). Because we need to move the data from the video to the hard drive of our computers, we will use password protected computers.

Dr. MacLean, Dr. Peter Kirk, Sara Healing (Graduate student), Dr. Janet Bavelas, PhD, and a research assistant will have access to the video data.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request to your study doctor or the UBC BCCA Research Ethics Board.

**Compensation:**

You will not be paid for participating in this study.

You do not waive any of your legal rights for compensation by signing this form.

**Contact for information about the study:**

If you have any questions or desire further information with respect to this study you may contact Dr. Grant MacLean at (250) 519-5572 or [gmaclean@bccancer.bc.ca](mailto:gmaclean@bccancer.bc.ca) or Sara Healing at (250)-888-2216 or [shealing@uvic.ca](mailto:shealing@uvic.ca).

**Contact for concerns about the rights or research subjects:**

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC office of Research Services at 604-882-8598 or e-mail to RSIL @ors.ubc.ca.

**Consent:**

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to your employment.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

---

Subject's Signature

---

Printed name

---

Date

\_\_\_\_\_  
Signature of                      Printed name                      Study Role                      Date  
Person Obtaining Consent

Was the subject assisted during the consent process in one of ways listed below?

Yes    No

If yes, please check the relevant box and complete the signature space below:

- The consent form was read to the subject, and the person signing below attests that the study was accurately explained to, and apparently understood by, the subject (**please check if subject is unable to read**).
- The person signing below acted as an interpreter/translator for the subject, during the consent process (**please check if an interpreter/translator assisted during the consent process**).

\_\_\_\_\_  
Signature of Person Assisting                      Printed Name                      Date  
in the Consent Discussion

**APPENDIX A3: Family Member Consent Form****\*Participant Information and Consent Form****Communication Processes in Medical Interviews****BCCA Principal Investigator: Dr. Grant MacLean**

Vancouver Island Centre: Telephone: 250-519-5572

**Co-Investigators:****Sara Healing**

Psychology Department, Uvic Telephone: 250-888-2216

**Dr. Janet Bavelas**

Psychology Department, Uvic Telephone: 250-727-6573

**Dr. Peter Kirk**

Clinical Professor, UBC Telephone: 604-992-0310

As a graduate student, Sara Healing is required to complete a research thesis as part of the requirements for her degree in Psychology. These videotaped consultations are the essential data for her thesis.

**Sponsor(s):** A Canadian Institute for Health research New Emerging Team (CIHR-NET) grant is funding this research.

**Purpose**

The purpose of this study is to develop a methodology for examining the processes by which physicians and patients make decisions. We are not judging whether a decision was “good” or not; instead we are developing a method for analyzing *how* decisions are actually made. You are being invited to participate in this study because you are accompanying a patient who is meeting with this physician for the first time. Your participation in this study is entirely voluntary, and you are free to choose not to participate, not to do any particular part of the study, or to withdraw from this study. In the event that you withdraw from this study, we will erase your data.

**Study Procedures**

If you agree to voluntarily participate in this research, we will videotape the medical consultation between the patient, yourself and the physician, using a camera that is set up

in the consultation room ( the researcher will not be present during the consultation) We will only record the consultation if everyone (physician, patient, and family members) have agreed to participate in the study. Certain parts of the consultation will not be videotaped, e.g., the physical exam. We will be interviewing the patient before and after the consultation. After the interview, we will give you the opportunity to watch the video of the consultation and to decide whether ( and how) we can use the tape for our research. We estimate that the patient's participation would add about 10 minutes for the pre-consultation consultation interview, 20 minutes for the post-consultation interview, and 5 minutes to fill out the Permission to View Form. You may if you wish review the video. The time taken to review the whole video will be the amount of time of the initial consultation.

**Potential Risks:** You might be concerned about a loss of confidentiality, however as you will see in the attached Permission to View form, you control access to the video data. If reviewing the video causes any stress (e.g. some perceived disappointment in the consultation) then we will provide a referral to someone who can help you with this issue.

**Potential Benefits to You:** The potential benefits of your participation in this research include having the opportunity to learn about communication research (specifically, about decision making) and the opportunity to discuss the consultation if you wish. Results of this study will be shared with you individually in an information session when the study is completed if you wish.

**Potential Benefits to State of Knowledge:**

This study will contribute to the current state of knowledge because there are only a few studies that look at actual communication within a medical consultation. Developing a method for analyzing medical decision making would also be useful for training medical students.

**Confidentiality:** Your confidentiality will be respected. No information that discloses your identity will be released or published without your specific consent. Your identity will not be used in any reports about the study. In records that leave this centre you will be identified by a study code only. All information associated with this study will be kept behind locked doors or in secure computer files.

Research records and medical records identifying you may be inspected by representatives of Health Canada, and the UBC BCCA Research Ethics Board for the purpose of monitoring the research. However, no records that identify you will be allowed to leave the centre. These organizations have policies of strict confidentiality and the individuals inspecting your records must sign a BC Cancer Agency confidentiality form (the form is not applicable to Health Canada officials, who have the legal right to inspect health records and are bound to confidentiality by specific laws.)

We will protect your confidentiality by not using your name on any records; all records will be identified only by a unique number. However, anyone who knew you could recognize you on video, so you will control access to the tape (i.e. who, if anyone, can view it) by filling out the attached Permission-to-View Form after you have seen the tape.

If you choose, it is possible to obscure your face on the video for any use other than analysis (e.g., for scholarly presentations)

We will store the video in a locked filing cabinet in a secure office, along with a code that indicates the uses that you permit and the date on which the tape was made. In a separate secure office, we will store the documents that link your unique number with your name (i.e., this consent form and the Permission-to-View form). Because we need to move the data from the video to the hard drive of our computers, we will use password protected computers.

Dr. Grant MacLean, Dr. Peter Kirk, Sara Healing (Graduate student), Dr. Janet Bavelas, PhD, and a research assistant will have access to the video data.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to insure that your privacy is respected and also give you the right of access to the information about you that has been provided to the sponsor and, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request to your study doctor or the UBC BCCA Research Ethics Board.

**Compensation:**

You will not be paid for participating in this study.

You do not waive any of your legal rights for compensation by signing this form.

**Contact for information about the study:**

If you have any questions or desire further information with respect to this study you may contact Dr. Grant MacLean at (250) 519-5572 or [gmaclean@bccancer.bc.ca](mailto:gmaclean@bccancer.bc.ca) or Sara Healing at (250)-888-2216 or [shealing@uvic.ca](mailto:shealing@uvic.ca).

**Contact for concerns about the rights or research subjects:**

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC office of Research Services at 604-882-8598 or e-mail to [RSIL @ors.ubc.ca](mailto:RSIL@ors.ubc.ca).

**Consent:**

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to your employment.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

\_\_\_\_\_  
Subject's Signature

\_\_\_\_\_  
Printed name

\_\_\_\_\_  
Date

_____ Signature of Person Obtaining Consent	_____ Printed name	_____ Study Role	_____ Date
---	-----------------------	---------------------	---------------

Was the subject assisted during the consent process in one of ways listed below?

Yes  No

If yes, please check the relevant box and complete the signature space below:

- The consent form was read to the subject, and the person signing below attests that the study was accurately explained to, and apparently understood by, the subject (**please check if subject is unable to read**).
- The person signing below acted as an interpreter/translator for the subject, during the consent process (**please check if an interpreter/translator assisted during the consent process**).

\_\_\_\_\_  
Signature of Person Assisting  
in the Consent Discussion

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Date

**APPENDIX B1: Nurse's Patient Recruitment Script****Nurse's Script (telephone):**

- Currently, there is a study at Vancouver Island Cancer Centre investigating communication between physicians and patients in medical consultations. I am wondering if you would be interested in having one of the researchers contact you to give you more information about the study?
- I want to let you know that your decision to participate or not participate won't affect your care in any way.
- If the patient says "yes, I am interested", the nurse says "Can I have your permission to give the researcher your phone number and name so that she can contact you and give you more information about the study?"
- If the patient says "yes," the nurse says, "She will contact you and give you more information."
- If the patient declines, the nurse will say nothing further about the study and will finish the conversation as usual.

**APPENDIX B2: Researcher's Patient Recruitment Script****Researcher Script (telephone):**

- Hi my name is Sara Healing and I am a UVic graduate student studying medical communication at the Vancouver Island Cancer Centre. I understand that you are interested in learning more about the study?

- We are studying communication processes between physicians, patients, and family members. Specifically, we are interested in the processes by which physicians and patients make decisions. The purpose of this study is to develop a method for analyzing how decisions are actually made by patients and physicians it is not to judge whether a decision is good or not. Few studies look at actual communication within a medical consultation and we believe that a lot can be learned from studies of this type.

- Do you have any questions so far?

- If you choose to participate in this study, this is what we will ask you to do:

- First, we will ask you a few brief questions prior to your consultation with the physician.
- Second, we will videotape the medical consultation between you, the physician, and any family member who might be accompanying you, using a video camera that is set up in the consultation room. We will not be videotaping certain parts of the consultation, for example the physical exam or any other parts that you choose. I will not be in the room during the consultation. I will set up the camera prior to the consultation and then leave the room with the camera running. At the end of the interview you will have a chance to watch the video tape of the consultation and decide whether we can use it for our research analysis.

- Third, after the consultation you will be interviewed by the researcher and this interview will be audiotaped. Your participation will take an additional 35 minutes above and beyond your appointment time.
- If you think you would be interested in participating in this study I will send you a consent form so that you can read it over, talk to any family members who might be accompanying you to your consultation, and take some time to decide whether or not you and your family want to be in this study. You don't need to decide now.
- I want to let you know that your decision to participate or not will not affect the level of care you receive.
- Do you have any questions?

**APPENDIX C: Examples of Questions from the Pre-consultation Interview and  
the Post-consultation Interview**

**Pre-consultation Interview**

- What are you meeting with Dr. X about today?
- What are your expectations about the outcome of this meeting?
- Do you have specific goals for this meeting?

**Post-Consultation Interview**

- To what extent do you feel like your goals were met in the consultation?
- Were there topics that you wanted to discuss that did get discussed? What were they?
- Were there topics that you would have liked to discuss and did not get to discuss? What were they?
- Were there topics that you discussed that yo
- Which goals that you identified prior to the consultation were met?
- Which goals weren't met? What's your opinion about why this did not happen?
- What's your understanding of the information provided by Dr. X?
- What's your impression of Dr. X's understanding of your values and goals?
- Were any decisions made during the consultation?
- If so, what were they?
- What information was relevant to each decision made?
- How satisfied were you with your consultation with Dr. X?

### Appendix D: Permission To View Form

“Communicative Processes in Medical Interview”: Permission To View Form

Your tape would be kept in a secure place and labelled with a code number and the date your tape was made. Your name will not be on the label of the tape. The sheet that connects your name with your code number would be kept in a separate place. Obviously, however, videotapes are not anonymous to anyone who knows you or would recognize you.

With that in mind, please indicate below the way(s) we can use the videotape made during this session. You can select some of these options, not others, or none at all. The researcher will answer any questions you might have about these options.

	YES	NO
1. <b>For research purposes:</b> Viewing and analysis by the Microanalysis Team in their research offices.	<input type="checkbox"/>	<input type="checkbox"/>
2. <b>For educational purposes:</b> Below are several educational uses of videotape from this study. <ul style="list-style-type: none"> <li>You can choose all, some, or none of these.</li> <li>If you choose any of them, you can also choose to have your face or voice made unrecognizable (e.g., digitally covered or scrambled) when used for educational purposes.</li> </ul>		
2a. Playing as an example for professional audiences (e.g., at a professional conference or a university).	<input type="checkbox"/>	<input type="checkbox"/>
2b. Playing as an example for classes at UVic: or UBC ( e.g. Island Medical program).	<input type="checkbox"/>	<input type="checkbox"/>
2c. Available on the Internet on sites restricted to professionals in the area of communication research.	<input type="checkbox"/>	<input type="checkbox"/>
2d. As a still photo in a journal article or book chapter.	<input type="checkbox"/>	<input type="checkbox"/>
2e. Available as a CD in conjunction with a journal article or book chapter.	<input type="checkbox"/>	<input type="checkbox"/>
2f. For any use other than research by the Microanalysis team, I want my face___ voice___ to be covered or scrambled digitally, so that it is not recognizable.	<input type="checkbox"/>	<input type="checkbox"/>
3. <b>Neither research or education uses; PLEASE ERASE THE TAPE</b>	<b>YES, ERASE THE TAPE</b> <input type="checkbox"/>	<b>NO, DO NOT ERASE THE TAPE</b> <input type="checkbox"/>

Name: \_\_\_\_\_ Group #: \_\_\_\_\_

Signature: \_\_\_\_\_ Study Name: \_\_\_\_\_

Date: \_\_\_\_\_

**APPENDIX E: Decision Tree**

Note that the reproduction on the following page is smaller than the original.

