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NARRATIVE MEDICINE AND TRADITIONAL MEDICAL INTERVIEWING APPROACHES IN WOMEN WITH BREAST CANCER

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NARRATIVE MEDICINE AND TRADITIONAL MEDICAL

INTERVIEWING APPROACHES IN WOMEN WITH BREAST CANCER

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DISSERTATION

Submitted in Partial Fulfillment of the
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Dedication

For Logan, you are the future.

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First, I want to thank the women who participated in this study and their willingness to let me walk with them in their breast cancer journeys. I am inspired by their stories. I also want to recognize the over 300 women with breast cancer who I have had the pleasure of knowing over the past 14 years whose experiences helped to shape this study.

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To my husband, Casey Eastman, who moved his office into our home so I could pursue my dream of obtaining a PhD. Finally, to my son, Logan Eastman, who at age seven announced he wanted to become a doctor, "so he could cure cancer, so people would not have to suffer". He inspires me every day.

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ABSTRACT

Interactions between early-stage breast cancer patients and their medical providers were analyzed, focusing on the content of the medical encounter and the patients' subsequent recall of that information. Traditional biomedical interviewing, narrative medicine approaches, and emerging types of dialogue were coded within these encounters. Observations of patient-provider interactions, structured and semi-structured patient interviews, and document analysis enriched this investigation. No "pure type" of patient-provider interaction was found. In order to relate the complex information about diagnoses and treatment options to women with breast cancer, narrative interactions included considerable biomedical information. Similarly, biomedical interactions often included narrative elements. A continuum was created and eight different types of dialogues were defined, as well as three other elements. A narrative approach was associated with improved patient recall when compared to more biomedical approach. This study suggests that narrative medicine may increase patient recall regarding diagnoses, treatment options, and actions.

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Chapter 1

Introduction and Literature Review

The quality of patient-provider interaction in the current healthcare environment is crucial for patient health. In the context of a cancer treatment facility, what information patients understand and act on can literally save their lives. Regarding interaction content, two trends have emerged, one supporting the traditional biomedical model that is more provider-focused and one employing storytelling that is more patient-centered. The first trend is evidence-based medicine in which medical decisions are based on what medical providers perceive as "hard facts." In this approach, providers acquire discrete information in interviews with patients and act on those medical contingencies. The second trend challenges the biomedical approach and advocates for narrative medicine, a more patient-centered model, inviting patient storytelling to a far greater degree than biomedical approaches (Bensing, Verhaak, van Dulmen & Visser, 2000).

This study analyzes patient-provider communication in a cancer treatment facility to determine the content of these interactions with both biomedical and narrative medicine trends in mind. More specifically, I observe patient-provider communication at the Hecurcan Center in the United States (a pseudonym). Physicians, residents, physician's assistants, and nurse practitioners are the providers in this study. Diagnosing and treating illness are listed as standard occupational duties in all of these professions (U.S. Bureau of Labor Statistics, 2012). I examine the interactions between ten women with early-stage (0-III) curable breast cancer and members of their surgery and oncology teams with a specific focus on both traditional biomedical interview and narrative approaches. I also explore what other types of patient-provider interactions arise in this setting. Data collection involves audio-recording

the women during actual medical encounters. The women are interviewed after these

interactions to gain further insight into their recall and feelings about what their medical

providers told them regarding their diagnoses, treatment options or other issues. I also

conduct follow-up interviews with the women one year after their diagnosis to examine the

women's level of recall of what they were told regarding diagnoses and treatment.

There is very little research on the use of narrative in the oncology setting, so this

study will add to our understanding of this approach and to the information already available

in primary care and family practice settings. Although a medical setting can place

restrictions on what providers and patients say, this study shows that the co-creation of more

stories helps to transform the traditional medical interview into a communication exchange

that is more interactive and patient-centered. Given these issue, the research questions

guiding this study are as follows:

> RQ1: Which form of interaction (traditional biomedical interviewing, narrative medicine approaches) do providers predominantly use?

> RQ2: What content is evident in patient-provider interactions in addition to traditional biomedical interviewing or narrative medicine content?

> RQ3: Does patient recall of patient-provider interview content differ between traditional biomedical interviewing and narrative medicine formats?

I situate this study within the field of health communication and the subfield of

patient-provider communication. I review the current state of research regarding patient-

provider communication generally by surveying three common themes that health

communication scholars frequently address. Then I specifically examine patient-provider

communication in an oncology setting. Next, I introduce the traditional and narrative

perspectives in patient-provider communication. I examine more traditional approaches to

patient-provider communication by reviewing literature on medical interviewing. Similarly,

I review the core ideas of narrative theory and the specific approach labeled narrative medicine. I close this section by introducing a health communication continua, which includes common factors used to evaluate patient-provider communication.

Health Communication

Health communication is a distinct area of study in the discipline of communication. In health communication, communication may be one dimension of an issue, may focus on the people who are doing the communicating, or may explore the devices that are being used (Parrott & Kreuter, 2011). This study utilizes all three definitions. Communicating to patients about breast cancer is a main goal at the Hecurcan Center. All staff members communicate with patients, but this study focuses on patients and providers and their roles as senders and receivers of information. Although multiple devices are used to communicate information, this study looks at the medical interview as a communication device or channel.

Geist-Martin, Ray, and Sharf (2003) define health communication as "the symbolic processes by which people, individually and collectively, understand, shape, and accommodate to health and illness" (p. 3). Health communication as a field covers a broad range of health issues in a variety of ways. Key areas of study in health communication include patient-provider interaction, social and community health issues, community organizing, health organizations, health campaigns, and media use for designing and delivering effective health messages (Thompson, Parrott, & Nussbaum, 2011). Other health communication scholars divide the field based on the type of interaction, such as interpersonal, social, community, team, or organizational (Wright, Sparks & O'Hair, 2008). Wright et al. also stress the importance of the cultural context, use of technology, and influence of media on communication.

Despite how health communication scholars divide the field, looking at the topics of the articles in the journal *Health Communication* from 1989 to 2003 indicates that provider-patient interaction is one of the most stressed areas, accounting for 20 percent of the total content (Thompson, Robinson, Anderson & Federowicz, 2007). Patient-provider communication is followed in frequency by health campaigns (13.4%), communication about health risks (11.8%), health and the aging population (8.4%), language and health (7%), and media use in health (5.9%). The least common topics are varied and account for four percent or less of the field's focus. *Health Communication* is a representative journal because the editor in chief, Teresa L. Thompson, is an expert in the field, well published in this area, and served as editor for both editions of *The Handbook of Health Communication*. In a field dominated by patient-provider studies, looking at the previous research situates and directs new research but also points to areas that push the boundaries of past research. To date, much of the health communication research is qualitative.

Although much of health communication research is quantitative, researchers advocate the use of narrative case studies that accommodate the complexity of the health-illness experience. Geist-Martin, Ray, and Sharf (2003) emphasize the context in which communication occurs not just at the level of interaction (e.g., interpersonal or community). Understanding an illness as complex as cancer and then acting upon that understanding takes collective effort. The effort should be centered on the patient's individual wants, needs, and beliefs.

Health Communication Applications to Patient-Provider Interaction

The study of patient-provider communication is one of the first topics health communication scholars explored. Korsch and Negrete's (1972) article, "Doctor-Patient

Communication," was foundational in this regard. The article explored communication between mothers and pediatricians at a University Hospital urgent care clinic regarding their child's illness. Despite the fact that decades have passed since this study's publication about effective communication skills, the findings still hold true for patient-provider communication. For example, Korsch and Negrete found that physicians used too much technical language and jargon, which hampered the mothers' understanding. This is true in contemporary studies, including my dissertation research reported herein. Mothers were also dissatisfied if the doctor failed to show enough interest in their child or acted in an impersonal way. The move to humanize health care encounters and act on patients' needs addresses this issue. About 26 percent of the mothers in Korsch and Negrete's study were not given the opportunity to express their greatest concern to the doctor. Providing an opportunity for storytelling may be able to resolve this issue. The doctors spoke more than the mothers in most cases did, but when the conversation was more balanced, the mother was more satisfied with information they received during the visit. This speaks to the importance of patient and provider co-creating the illness story.

Along a similar line, Street (2003) creates a useful model in which to frame health encounters, focusing on patient-provider visits. He stresses the importance of context in his ecological perspective. He defines ecology as "the study between an organisms and their environment" (p. 63). He further defines ecological perspective as one that "looks at the interaction between health care providers and patients as situated within and affected by a variety of social contexts" (p. 63). His model includes the interpersonal, organizational, media, political-legal, and cultural contexts. The interpersonal context in the model is the most complex, and he suggests that the interpersonal context has the most influence on the

encounter. The interpersonal context includes both provider and patient "goals, linguistic skills, perceptions, emotions, and knowledge as well as the constraints and opportunities created" in that context (p. 64). Street sees this interaction as socially constructed but is able to find reoccurring patterns in these encounters. By studying these patterns different themes arise that appear to be relatively stable in the field of health communication.

Three Themes in Contemporary Studies of Patient-Provider Communication

In health communication, the study of patient-provider communication is commonly divided into three themes: (a) the differing perceptions of patients and providers which affect healthcare communication, (b) the characteristics of the communication between patients and providers, and (c) the outcome of the communication (Wright, Sparks and O'Hair, 2008). Researchers have studied various patient and provider outcomes using these general divisions, which are described briefly in what follows.

Differing perceptions of patients and providers. Patients and providers are typically different from each other in many ways and have different perspectives of illness as a result. These differences lead to less effective communication, especially when using traditional medical interviews, with patients who have lower socioeconomic status determined by income, occupation, or education (Blanquicett, Amsbary, Mills & Powell, 2007). Therefore, patients with the fewest resources and least ability to obtain information outside a traditional medical encounter are the most disadvantaged. In Siminoff et al.'s (2006) study examining patient characteristics and communication patterns of newly diagnosed breast cancer patients and their oncologists, Caucasian patients spoke more with their doctors, and received more information in return than non-Caucasian patients. Despite this difference, in the context of a traditional medical interview 98 percent of the content,

across all groups was related to the patient's medical condition, and only 2 percent of the content addressed psycho-social issues such as coping with the disease or the disease's impact on the patient's life (Siminoff, Graham & Gordon, 2006).

One common theme is patient communication patterns; patients' needs for information are variable. Haidet, Kroll and Sharf (2006) studied this variability by conducting narrative interviews with primary care patients. They found that communication patterns and active participation in the medical encounter were linked to how the illness affected patients' life overall, whether patients believe their condition could be cured, the amount of illness-related activities they performed, and their levels of perceived partnership with their doctor. Arora (2003) similarly found that patient involvement in medical decision making varied among cancer patients, often connected to their stage in treatment but subject to change over time.

Thus research suggests that although providers may think they are giving the patient information patients need and want, patients may not understand the information due in part to the format in which providers present that information. Patient information is often provided in a written format; however, Lawrence (2007) reports that 47 percent of the adult population in the United States has difficulty locating and integrating information from written texts. Low literacy levels contribute to poor health outcomes because when adults with low literacy become patients, they typically do not understand the forms, consents, appointment slips, discharge instructions, and prescriptions that providers give them. Oncologists also give quite a bit of information about prognosis and possible side effects of treatment in the form of statistical percentages. Yet, many patients often do not understand

the statistical information providers give them in the course of a traditional medical interview (e.g., probability statements and percentages) (Rothman & Kiviniemi, 1999).

In fact, breast cancer patients have high unmet information needs in several areas due in part to the complex nature of having to choose among different surgical options, types of therapy, and whether or not to undergo reconstruction (Parker, Aaron and Baile, 2009). Oncologists need to be able to communicate these issues to patients while being empathic, reducing patient anxiety, and promoting trust. To successfully obtain these skills, providers likely require remedial communication training.

Characteristics of patient-provider communication. The characteristics of what is thought to be effective patient-provider communication are typically the focus of deficit communication skills and of provider training to reduce those deficits. Despite the need for physicians to communicate effectively with patients; Wright, Sparks, and O'Hair (2008) note that most physicians receive very little formal classroom training in on effective communication. What is more, providers may not apply or use the interviewing skills that they do learn in all settings. Ideally, communication skills providers learn these skills during clinical training with patients. In practice, as Hirschmann's (1999) ethnographic study of medical interns shows, these skills are almost impossible to learn in chaotic medical settings in which life and death decisions dominate the interns' experiences.

During a typical medical interview, the doctor enters the examination room, provides some type of introduction, inquires briefly about symptoms, interrupts the patient to ask additional questions, reaches a conclusion, and recommends a treatment. This interaction path has been criticized (Beisecker & Beisecker, 1993; Emanuel & Emanuel, 1992) and more participatory forms of communication between patients and providers have been

recommended. In response, an overview of collaborative models of interaction in healthcare is provided by Ho and Byland (2008). Ho, a communication scholar, and Bylund, a practitioner at Memorial Sloan-Kettering Cancer Center, argue that the Cartesian biomedical model, which stresses the division between the body and mind, is slowly being replaced by Engel's biopsychosocial model, which encompasses the physical, emotional, cognitive, and situational nature of an illness.

One type of biopsychosocial model is the patient-centered approach. A meta-analysis of 25 studies of health communication between cancer specialists and patients (including 4 studies of breast cancer patients) suggests that patient-centered communication can lead to greater patient satisfaction (Venetis, Robinson, Turkiewicz & Allen, 2009). Patient-centered is defined in the study as emotional displays from the provider, social and informal talk, providers soliciting patient opinions, and patients asking providers questions (Venetis et al. 2009). Health communication scholars are just beginning to evaluate these new models with the hope of improving various beneficial outcomes.

Communication outcomes. Increasing the level of patient input during the traditional medical interview is one way to achieve more favorable patient outcomes. In this regard, primary care physicians are more informative, supportive, and willing to build partnerships with patients. They typically use a more patient-centered approach in their communication (Street, Gordon & Haidet, 2007). One frequent solution providers use to increase patient input is having patients write down and rehearse questions to ask their doctors. This model, however, failed to result in the patient asking more questions in traditional medical interviews (Kidd, Marteau, Robinson, Ukoumunne & Tydeman, 2004).

When physicians and patients like each other, however, improved emotional states, greater satisfaction, and better health often follows (Hall, Horgan, Stein & Roter, 2002). In an observational study of the communication interactions of 72 patients with their family physician, for example, the relationship forged during less structured interactions often eased the way for communication of additional medical information and a more complete history and diagnostic process (Walker, Arnold, Miller-Day & Webb, 2002). These outcomes are beneficial for both the patient and provider. Much of the research on patient-provider interaction takes place in primary care clinics. In next section, I focus specifically on an oncology setting.

Unique Communication Needs of Women with Breast Cancer

Although much of the literature of patient-provider interaction applies to and has been studied with samples of women with breast cancer, these women also have unique communication needs. Hack, Degner, and Parker (2005) explored these needs in a literature review of 99 contemporary articles (1992-2004). They found two main goals of cancer patient-physician communication: the medical management of the cancer and attention to the patients' psychosocial responses to the cancer experience. Most importantly to early stage breast cancer patients was discovering the stage of the cancer and the likelihood that the cancer could be cured. In follow-up visits, the most important topics for breast cancer patients were about treatment side effects (short and long term) and outcome prognosis. Physician-directed or -dominated encounters tended to result in more unmet patient communication needs and higher rates of dissatisfaction. Alternately, when both parties could articulate their needs, this enhanced communication (Hack et al. 2005).

Physicians were more successful communicators when they tailored their presentation based on patient needs, values, beliefs, and emotional states (Hack et al. 2005). Many oncologists failed to use a patient-centered approach during their medical encounters. These providers neither gave patients time to ask questions nor addressed patients' psychosocial or quality-of-life concerns. Hack and colleagues (2005) found very few studies that addressed the external factors (e.g., medical system) shaping physicians interactions with patients. Using a narrative approach to acquire medical information may provide a solution to both of these shortcomings.

A second evaluation of contemporary (1984-2002) literature on physician communication with cancer patients, that includes two samples of breast cancer patients, addressed interpersonal communication, information exchange, and patient involvement in decision making during the medical encounter (Arora, 2003). A central finding in this review was that patients preferred physician communication interactions that provided them a caring atmosphere, where the patient was treated as a person as opposed to an object of study. In concrete terms, physicians are more successful working with breast cancer patients if they do the following: (a) listen to patient's stories; (b) minimize their use of medical jargon; (c) respond to patient concerns; and (d) refrain from underestimating patients' need for information or overestimating their own effectiveness at providing information. Despite a convincing body of research pointing to the importance of these communication skills, many providers consider interpersonal communication of any kind during the medical visit a luxury.

In sum, health communication scholars have identified a number of factors that contribute to successful communication during medical interviews. On one hand, the

provider's use of jargon (Arora, 2003; Korsch & Negrete, 1972), written reports (Lawrence, 2007), and statistical percentages (Rothman & Kiviniemi, 1999) can decrease patient understanding. On the other, discussing psychosocial issues, addressing patient emotions, and checking for patients' successful ability to cope with their illness (Ho & Bylund, 2008) as opposed to just discussing the facts of the disease (Siminoff, Graham & Gordon, 2006) can leads to greater contentment. Not surprisingly, breast cancer patients want a more balanced encounter in which both parties ask questions and co-create an illness experience (Street, Gordon & Haidet, 2007). Many believe that the narrative approach rather than the traditional medical interviewing approach holds great promise in terms of creating these co-constructed spaces between patient and provider. To better understand how these approaches differ, the next section introduces the concepts of traditional medical interviewing and narrative perspective.

Patient-Provider Communication, Traditional and Narrative Perspectives

Currently, providers expect patients to participate, at least to some degree, in medical decision making, which involves analyzing an immense amount of complex data that patients are often ill equipped to understand. Additionally, providers must communicate complex ideas and medical expectations to patients and do so in a way that patients will remember. The positivist scientific approach based on biology and chemistry dominates the medical realm of cancer patients. However, communication about diagnoses and treatment choices is as varied as each woman's experience. The reality of illness for each woman is "unique, plural, simultaneous, and local" (Lindlof & Taylor, 2011, p. 8). One example of medical communication occurs when a woman diagnosed with cancer discusses the meaning of cancer in her life and shares the story with her provider. She can frame the cancer as an

inconvenience (e.g., a woman needs to travel several hours to receive treatment each week) or as a life-changing enemy (e.g., when she is diagnosed a week before starting a job which she saw as a once in a lifetime opportunity). Each woman also ultimately decides which treatments she can accept and which she will decline.

Despite having the final say in which treatment(s) they will receive, the construction of a shared cancer experience by medical providers and patients is often constrained by the providers. From my fourteen years' professional experience working with cancer patients and observing provider-patient interaction, much of the providers' time and effort is spent conveying medical "facts" and keeping the medical interview on track in terms of those "facts." The patients and patients' family members may discuss what cancer means to them at home or in other private spaces, but they are unlikely to share all of this information with their medical team. How much or how little information patients and their families share appears to be effected by the conversation style, a style the provider typically sets. Generally speaking, at least two ways are available for providers when communicating with women who have cancer: a traditional biomedical approach and a narrative medicine approach. Conceptualizing the patient-provider interaction along a continuum is useful.

Biomedical-Approaches   **Narrative-Approaches**

More provider-centered   **More patient-centered**
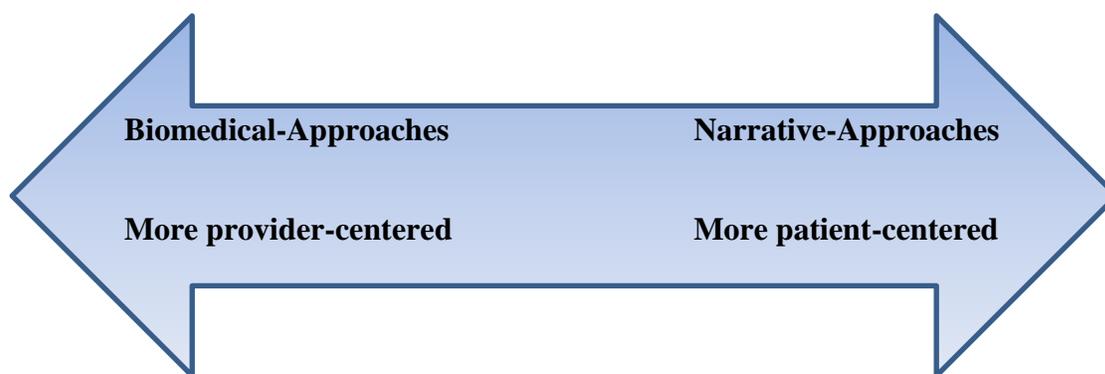
Figure 1. Continuum: Traditional Medical Interviewing to Narrative Medicine Approaches

On the far left-hand side of the continuum is the *traditional biomedical interview* that is strongly provider-led and provider-centered. Most often, patient-provider communication typically follows the traditional biomedical interview, which is "a purposeful conversation undertaken with a set of goals and priorities clearly maintained in the physician's [or provider's] mind" (Lichstein, 1990, p. 29). As implied by this definition, the provider drives the interview content and tone. The traditional biomedical interview is based on *biomedical thinking*. Engel (1996) argues that biomedical thinking is somewhat archaic, "a twentieth-century derivative of seventeenth-century natural science, [which] categorically excludes from science what patients have to tell us on the grounds of its being nonmaterial in form and not measurable" (Engel, 1996, p. x).

Slowly the medical field is moving to a more biopsychosocial model, which acknowledges that a provider is only part of the process. According to Engel (1996), "the answers [providers] get from a patient depend on the questions [they] pose and how [they] do so" (p. xi). From the biopsychosocial perspective, patients are collaborators in the process, even though the provider's goal is still to collect the patients' input. Providers then reframe this input into scientific language by including their observations and thoughts in the formal report. Further along the continuum of biomedical-to-biopsychosocial interviewing models is the use of storytelling and providers that encourage storytelling. As Engel (1996) argues,

> Readers need only review their own experiences with doctors taking their histories to appreciate the difference between encouraging narration and requiring reporting. The later approach is deliberately interrogative, the doctor assuming the initiative and agenda, the patient, an object of study rather than an active participant in his own study (p. xvii).

Traditional medical interviewing is dominated by the provider. In contrast, a more narrative method of interviewing turns the patient from an object of study into a fully integrated person engaged in telling the story of their illness. In the next sections, I explore current research about medical interviewing arranging my review of the literature in terms of the continuum—beginning with more traditional provider-led styles and transitioning to more patient-centered styles including the use of more narrative methods.

Medical Interviewing

Medical history, physical exam (H&P). Learning how to conduct a medical interview is a skill that providers first acquire while in training or school (medical, physician assistant, advanced-practice nursing, etc.). The medical history and physical examination, called the H-and-P (H&P), is an important first step in student learning. Hanson and Neuhauser, (2003) consulted with 49 practicing physicians to develop a guidebook for practitioners—a quick reference if you will. The guidebook outlines nine sections of the H&P: (1) chief complaint; (2) history of present illness; (3) past medical and surgical history; (4) medications, allergies, and adverse reactions; (5) health maintenance; (6) family history; (7) psychosocial history; (8) review of systems; and (9) physical examination. Hanson and Neuhauser explain the types of information providers should collect for each section. For example, in psychosocial history, the following information should be collected from the patient:

Personal History

1. Record the patient's place of birth (city and country).
2. Inquire about patient's religious preference and note possible medical implications.
3. Record patient's race, ethnicity, and cultural background, and possible health implications.
4. Record patient's marital status and number/gender of children.

    5. Ask patient to describe and record current residence and living conditions (e.g., three bedrooms, one bath, eight occupants).

A. Current Illness Effects on the Patient

    1. Ascertain and note patient's perception of the severity of the illness.
    2. Address death and dying issues, as applicable.
    3. Inquire about and note whether patient has established advanced directives (e.g. Living Will or Durable Power of Attorney for Health Care [DPAHC]).

B. Family Support

    1. List family members, significant others, and additional sources of support.
    2. Ascertain and note family's awareness of present illness.
    3. Determine and note physical proximity of family and other support persons.
    4. Record important contact phone numbers.

  (Hanson & Neuhauser, 2003, p. 6-7)

In the medical history, providers collect important information such as patients'

perception of their illness and possible religious or cultural implications for their treatment.

Discussing the patients' feelings about their illness or how they are coping with their illness

is commonly absent in the H&P. The guidebook's tone assumes the providers' position as

the leader—providers ask questions—and patients' position as the follower—patients

respond to provider questions. Whether a provider should verify possible health implications

in terms of the patients' religion, race, ethnic, or cultural background is unclear. Potentially

the provider simply presumes these effects, but the guidebook is vague in this regard. The

authors use strongly directive verbs such as "ascertain" and "determine," which implies that

the provider has the power to direct the interaction and should use that power to do so. The

guidebook also directs providers to "address" issues of death and dying without giving

providers any guidance as to how to approach such sensitive topics with the patient. To

address some of the H&P's shortcomings, certain providers have begun using the sensitive

medical interview.

Sensitive medical interview. Moving more toward the midpoint of the continuum, the sensitive medical interview encourages the patient to talk and the provider to show empathy toward the patient. This model emerges from Aldrich's (1999) perspective regarding the difference between an H&P (a form of history taking) and a more extensive medical interview. History taking, in Aldrich's view, is "an interchange focused more on *disease* and aimed at establishing and refining the doctor's diagnosis" (p. 10). He contrasts history taking with medical interviewing, which he argues is "a verbal interchange between doctor and patient that is focused on *illness* and is aimed at finding out the patient's point of view of what is wrong and its significance to the patient" (p. 10). Although the medical-interview-as-interchange implies a more equitable relationship between provider and patient, the provider nonetheless the model implies unequal power and status in the relationship—the provider is teacher or parent; the patient is a student or child.

From the contrast between traditional biomedical and Aldrich's view of the medical interview, he (1999) argues that the *sensitive interview* is a more effective model to follow, especially in outpatient settings such as the women's cancer center. In the *sensitive interview* the provider encourages the patient to talk, and the provider listens and displays empathy toward the patient. An excerpt from Aldrich's (1999) work is illustrative. This excerpt is from an interview with Mrs. Hardy, a 62-year-old woman, coming to the clinic for a check-up. After a brief introduction, Mr. Wilson, the student doctor, begins:

Mr. Wilson: Now, then, how can we help you?

Mrs. Hardy: I don't really have anything that serious; my husband and I recently retired and we've moved down here from New York, and our doctor there suggested that we might make contact with the university here, just in case something happens. I also haven't had a Pap test for a year or so, maybe longer.

Mr. Wilson: It's been some time since you had a check-up.

Mrs. Hardy: Yes, although I've had partial check-ups, I guess, from the gynecologist when I've had a Pap test. And I've seen an eye doctor when I needed some glasses.

Mr. Wilson: I see. Perhaps I should start by asking you if you take any medications regularly?

Mrs. Hardy: None, really, except aspirin for arthritis in my knees, but I've taken that for years.

Mr. Wilson: Arthritis can be frustrating.

Mrs. Hardy: Yes, it certainly can be. It's been in my right knee for a long time, maybe 10 years, but now it's beginning a bit in my left.

Mr. Wilson: Aspirin does the job?

Mrs. Hardy: Most of the time, although I have to take a lot of it, and it often causes ringing in my ears, which I don't like.

Mr. Wilson: You take a lot of it?

Mrs. Hardy: I usually take two tablets with each meal and another two at bedtime. I've tried some of the newer substitutes for aspirin, but the only one that's any improvement is Clinoril, and it gives me heartburn.

Mr. Wilson: It can be aggravating when the medicine that helps gives you more trouble.

Mrs. Hardy: That's true, and I'm particularly susceptible to stomach trouble. I had a duodenal ulcer many years ago, after a trip to South American, and now I take Maalox regularly. When I take Clinoril, I just have to take more Maalox.

(Aldrich, 1999, p. 70-72)

In this excerpt, the medical student asks open-ended questions and then moves to more specific questions to explore medical issues that emerge in the conversation. After reviewing Mrs. Hardy's arthritis, ulcer, and heartburn, the provider continues with questions that reveal stress, an occasional irregular heartbeat, cystitis (a type of bladder infection), a history of skin cancer, and beginning cataracts. After this discussion, Mrs. Hardy continues:

> *Mrs. Hardy*: Well, yes – for someone who thought she was perfectly healthy 20
> minutes ago, I seem to be falling apart! (p. 76)

Mr. Wilson's use of open-ended questions, empathy, and understanding evoked numerous medical issues for Mrs. Hardy. Thus, the *sensitive interview* appears to result in the patient revealing important information to the provider. Mrs. Hardy also seems satisfied with the encounter because she states:

> I'm glad I was assigned to you; I think you have a great future in medicine. You're
> the first doctor I've ever had who really listened to me (p.76).

> In this example the provider subtly directs the interview by asking clarifying

questions about topics the patient initially presented. The patient has time to talk about her concerns and feels that the provider listened to her, which in turn contributes to her satisfaction with the encounter. One caveat here, given the transcript, the provider overlooked the pap smear Mrs. Hardy mentioned. Although the reader does not know the length of time spent in the interview, Mrs. Hardy mentions that the interview was at least 20 minutes long.

> Unfortunately, using the sensitive medical interview may not be an option for all

providers and patients. As Aldrich (1999) argues in his closing statement of this section:

> The chances are that you will not see any private outpatients for some time; if,
> indeed, you see any outpatients during medical school, they may be on Medicare. If
> you do see patients in a low-cost clinic, remember that they probably have no other
> place to go for their medical care and may have become used to a more brusque
> approach than has been outlined above. It will be better for them and better for your

training, however, if you conduct the same kind of interview with them that you will later conduct with private patients (p. 77).

Aldrich's insight raises the issue of the time constraints and of the types and styles of communication that are feasible given time constraints in outpatient medical settings.

Medical training is sensitive to the differences in the use of communication style based on setting. Aldrich's (1999) arguments imply that after students enter actual medical settings, if those settings are public, low-cost clinics, sensitive interview processes may not be readily applicable (as opposed to patients in private clinics). Aldrich's discussion about the brusque approach suggests that patients in public, low-cost clinics may not have the expectation that they will be being treated sensitively. Time constraints and differential treatment among various patient groups (e.g., private verses public) is a common theme in medical interviewing, one I revisit in the following discussion of other approaches.

The three functions approach. Moving a bit further toward the patient-centered end of the continuum**,** Cole and Bird (2000) stress the importance of building a relationship with the patient. Their model of medical interviewing includes three core functions of the interview: (1) "to establish and maintain an effective doctor-patient relationship," (2) "to diagnose the patient's problems," and (3) "to educate and motivate the patient to cooperate with treatment recommendations" (p. 3). They explain the importance of effective communication for accomplishing the tasks inherent to the three functions, pointing out specific skills medical professionals must master to accomplish the function-related tasks. Each of the three functions can affect the quality of the medical encounter, as can the inter-relationships among the three functions. The following explains the skills and tasks of each function, according to Cole and Bird's model.

Relationship building. According to Cole and Bird (2000), relationship building

takes five central communication skills: nonverbal communication, expressing empathy,

providing personal support, working in a partnership with the patient, and showing respect.

Nonverbal communication includes the providers' non-linguistic behavior. The most

important aspect of nonverbal communication is consistency with verbal communication.

For example, a provider who appears bored or distracted will have a difficult time convincing

a patient that they care about that patient's welfare, even though they may say they care

about the patient's welfare. People tend to believe the meaning of nonverbal cues, especially

when the verbal message contradicts the nonverbal (Knapp, 1980). Effective ways for

providers to build relationships, as well as show empathy, support, and respect, include using

appropriate eye contact, leaning forward, using open body position, and sitting at an

appropriate angle and distance from the patient. Additionally, to successfully build

relationships, providers must *feel* the empathy and support they are trying to communicate.

Providers can also verbally express empathy through providing feedback, reflecting

on what the patient has said, or legitimizing their experience. Doing so includes statements

such as, "I can see this is upsetting to you"; or "Your reactions are perfectly normal" (Cole &

Bird, 2000, pp. 16, 19). Providers can give social and emotional support to patients by being

sincere in a desire to help patients. A sincere desire can be reinforced with statements such

as, "Let me know what I can do to help" (Cole & Bird, 2000, p. 19). Partnership statements

can be helpful for building relationships and often include the word "we" or suggest that

"working together" is the best way to reach a solution (p. 20). Finally providers can

explicitly communicate respect by validating patient experiences or praising patients on their

successes. Praise of this type could be using a statement such as, "You're doing a good job handling the uncertainty" (p. 20).

Diagnosis. According to Cole and Bird (2000), providers need several skills to assess and diagnose patient problems effectively and accurately. The first is the ability to ask open-ended questions and then pause afterward, remaining quiet until patients complete their opening remarks (Cole & Bird, 2000). If a patient stops speaking but does not appear to have completed their thoughts, providers might encourage them to continue by using a facilitating remark such as, "go on" (p. 27). Alternately, providers can encourage patients to continue by remaining silent or using a surveying remark such as, "What else is bothering you?" (p. 31). In some cases, providers may need to clarify information or check with the patient about the patient's understanding of a situation. Clarification communication can include the provider asking additional questions or restating or paraphrasing the patient comments. Cole and Bird (2000) also explain that for accurate and effective diagnosis, providers should avoid closed-ended or leading questions. Closed-ended questions like, "Do you feel better today?" can evoke one-word answers that provide very little information. Leading questions such as, "You don't feel worse now, do you?" may evoke affirmative or agreeing responses to please the provider.

Educate and motivate. Providers need to give patients medical information, so that patients can make informed decisions about treatment. Cole and Bird (2000) argue that the provider must assess the patients' understanding of their medical issues and whether they have any false information (by current medical standards). Providers then need to negotiate a treatment plan with the patient. Cole and Bird suggest that providers can motivate their patients in a non-judgmental way by making general statements such as, "Most patients have

trouble keeping up with their medications. What trouble have you been having taking your

medications regularly?" (p. 41). Depending on patient responses, ideally providers would

work with patients to develop a collaborative solution to the problem.

Although Cole and Bird's (2000) model appears to encourage patients to lead more of

the interview interaction (which might include patient narratives or storytelling), the

approach is still strongly provider-led. That is, providers are guiding the interviews. Cole

and Bird suggest that providers prevent patients from talking about issues outside of

question-response interactions. They argue, "When a patient rambles or discusses many

different themes together in a disjointed manner, the physician can help guide the interview

in a more efficient way by using facilitation to direct the patient" (p. 70). Efficient in this

regard means that providers should obtain the needed information in the shortest period of

time possible. The provider, not the patient, constructs an orderly, chronological story of the

patient's illness. To do this, providers might ask additional questions or "interrupt the

patient's narrative to ask some clarifying questions" (Cole & Bird, 2000, p. 78). Thus, the

provider constrains and shapes the patient's narrative into the type of narrative the provider

requires.

Ideal medical interviewing. Enelow, Forde, and Brummel-Smith (1996)

recommend using communication skills similar to Cole and Bird's (2000) model in what they

describe as an "*ideal interviewing technique*" (Enelow et al. 1996, p. 9, emphasis added).

Enelow et al. contrast the medical interview and history-taking, arguing that the former is

"more than just history-taking. It is the process whereby the interviewer seeks to understand

all the factors—biological, psychological, and social—that play a role in the patient's

becoming ill and that will affect his getting well" (p. 3). Their approach is similar to Street's

(2003) ecological model.

Enelow et al.'s ideal interviewing technique includes using the following: warm

greeting, appropriate eye contact, open-ended questions or silence, empathic statements, and

discussions of patient psychosocial needs. They suggest the use of facilitation; facilitation

involves using one-word comments such as, "yes," or nonverbal cues such as nodding or

remaining silent to signal to the patient that providers would like more details. Although

moving further toward the narrative end of the traditional-narrative continuum (see Figure 1),

the key difference between the ideal interviewing technique and a narrative approach is

power sharing. Enelow et al. state, "The interview's function is to elicit the story of the

patient's medical and psychological or social problems … [and] … "learning to interview is

actually learning to help the patient tell that story" (p. 13). Thus, the authors suggest that

providers need to help patients tell their stories, rather than believing patients already have

this ability. Using the ideal interviewing technique means that providers might use

facilitation, confrontation, direction, or suggestion to steer the interview so that patients can

tell their stories.

Enelow et al. (1996) argue that providers may more frequently use the skills

comprising the ideal interviewing technique when dealing with an *excessively talkative*

patient. As they explain, "such a patient slows down the clinician and imposes a burden of

self-restraint upon him. This is not, however, the only reason that such patients are irritating

to the interviewer. There is usually an aggressive quality to such a patient's communication,

which has a controlling or dominating effect" (1996, p. 102). This quotation paints talkative

patients as aggressive, irritating problems with which provider must deal—certainly not a

perspective found in the narrative approach. Despite claims about providers *helping patients learn to tell their stories*, Enelow et al.'s language implies that providers only allow a limited amount of patient talk. Although the provider is supposed to direct the interview, when a patient moves into a more directive role, the patient is "troublesome." In other words, the verbiage sets up the medical interview as an adversarial encounter, one that providers must control.

Enelow et al. (1996) also raise the issue of time as a reason for limiting patient input. As they assert, "time constraints may require that the doctor become very active in limiting the length of the patient's answers" (p. 103). They note the economic reasons for limiting patient input, arguing that doctor-patient relationships have changed because "managed care … has led to limitation of the amount of time the physician can spend with many, if not most, patients… the physician may be unable to devote more than 15 minutes to each patient" (p. 8). Despite their understanding of economic contingencies, they explain that the ideal interviewing technique is "best applied in an unhurried context" (p. 9). Because time is always a factor in a managed-care environment of public medical settings, potentially only private-clinic patients will have access to Enelow et al.'s ideal interviewing technique. This issue comes up repeatedly in the patient-provider literature, a point I revisit in the next section about doctor-centered versus patient-centered interviewing.

Doctor-centered and patient-centered medical interviewing. The continuum (see Figure 1) can also be conceptualized in term of being more (or less) doctor-centered or patient-centered. Smith (2002) defines these two distinct forms of patient-provider communication. In doctor-centered interviewing the provider "takes charge of the interaction to meet her or his own need to acquire the symptoms, their details, and other data that will

help her or him identify a disease" (Smith, 2002, p. 3). In contrast, patient-centered interviewing "encourages patients to express what is most important to them" (Smith, 2002, p. 4). Smith argues, however, that patient-centered interviewing should "complement doctor-centered interviewing" (p. 4)—not used in isolation.

Frankel (2002) sees the patient-centered medical interview as having both structure and dynamics. The usual structure of the doctor-centered interview has been the provider asking the questions and the patient responding. According to Frankel, whoever asks questions creates "an obligation on its recipient to provide an answer" (p. xiv). Despite Frankel's focus on patient-centered interviews, again the approach implies that patients who ask too many questions are *difficult*. Frankel's work on the dynamics of the patient-focused interview includes issues such as the process of constructing the patient-provider relationship, especially whether providers use empathetic statements. Another important part of this dynamic involves who is directing the interview or whether patient and provider share the interview-guiding function. Similar to other patient-provider interviewing models, Frankel (2002) echoes some of Aldrich's (1999) and Enelow et al.'s (1996) concerns about how the setting influences the medical interview (e.g., a clinic, a hospital). Specifically, Frankel is concerned about how the setting's internal structure (e.g., managed care or private practice) affects patient-provider relationships.

Both Smith's (2002) and Frankel's (2002) patient-centered interviewing models utilize many of the skills from previous approaches to medical interviewing. Smith argues that key skills include asking open-ended questions; using silence; building a patient-provider relationship by legitimizing patent feelings; and respecting, supporting and partnering with patients. Smith's book is organized around a series of steps that the

beginning providers must learn to perform until they become "reflexive" (2002, p. 35) or a

matter of habituated behavior. Smith (2002) recommends that providers study and learn the

steps in order, and uses explicit language clarifying what to do in each of the steps. One

example is to "obtain list of all issues patient wants to discuss (e.g. specific symptoms,

requests, expectations, understanding)" (p. 40). The following excerpt illustrates this step:

> DOC: Well, we've got about 40 minutes today, and I know I've got a lot of questions to ask and that we need to do a physical exam. Before we get started, though, it's most important to find out what you wanted to cover today. You know, so we're sure everything gets covered.
>
> PT: It's these headaches. They start behind my eye and then I get sick to my stomach so I can't even work. My boss is really getting upset with me. He thinks that I don't have anything wrong with me and says he's going to report me. Well he's not really my boss, but rather is … (student [DOC] interrupts)
>
> DOC: That sounds difficult and really important. Before we get into the details, though, I'd like to find out if there are any other problems you'd like to look at today, so we can be certain to cover everything you want. We'll get back to the headache and your boss after that. That's two things (holding up two fingers). Is there anything else?
>
> PT: Well, I wanted to find out about this cold that doesn't seem to go away. I've been coughing for three weeks.
>
> DOC: (holding up three fingers now) Anything else you want to look at today?
>
> PT: No. Well, I did want to find out if I need any medicine for my colitis. That's doing ok now but I've had real trouble in the past. My parents were very upset about that. It started bothering me way back in 1982 and I've had trouble off and on. I used to take cortisone and … (student [DOC]interrupts)
>
> The student has now interrupted her twice in order to complete the list of complaints. Done respectfully, this was necessary to complete the agenda in a timely way. (Smith, 2002 pp. 43-44)

Although Smith's illustration considers the time limitations of the appointment, the provider

interrupts the patient twice in the initial stages of the interview. These interruptions occur

after approximately 14 and 18 seconds (text was read at a moderate pace and timed with a

stop watch). These and interruptions like them can interfere with the patient storylines, and providers can miss important information as a result. I address interruptions and patient expectations and needs immediately following a brief look at the medical interview as therapeutic act.

      Medical interview as therapeutic act. Fitzgerald (2005) eloquently describes the therapeutic effects of patient-provider interviews. In the midst of various models providing functional advice to providers on medical interviewing and history-taking, Fitzgerald's comments point to the meta-communicative quality of patient-provider interactions as a whole. This work is one of the rare occurrences in the medical interviewing literature that frames the activity in such terms. Fitzgerald (2005) stresses that providers acquire more than simply a collection of medical facts through the skilled taking of a medical history; they can be a *potent therapeutic instrument* in patient lives:

> The history is more than the elucidation of the facts of the case, more than a construct of symptoms. It tells the tale of the reaction a unique human being has to those symptoms and their impact on the patient's mind and life, their family, and their hopes. Listening to them is more than an ingathering of indications for further studies. It is in and of itself a major therapeutic act, and the physician, himself or herself, is a potent therapeutic instrument. In conjunction with the laying of hands that follows in the physical examination, the meeting of doctor and patient fulfills some primal need of the vulnerable to be attended to, cared for, and cared about (p. 4).

Although the potential impact of a medical provider is important to note. Fitzgerald's arguments are a rare acknowledgement of this impact. Despite the caring tone, in terms of the patient-provider interview continuum, however, the burden of the therapeutic act rests

solely on the provider rather than being shared by the vulnerable patient. This is not to down play the importance of providers caring about and for their patients, but they need not face the burden of healing the patient alone. The patient, patients' family members, and in some cases even the patients' friends can help the provider understand and respond to the patients' situation.

Before closing the review of the left-to-midrange end of the continuum in Figure 1 (provider-directed to patient-directed but not yet incorporating the narrative approach), I briefly talk about provider interruptions and patient needs and concerns. Although traditional approaches mention these issues, the approaches rarely place stress on them. They do warrant more attention.

Patient interruption and medical interviewing. In Smith's (2002) example transcript, the student provider interrupts the patient on three occasions in a short period of time. Smith's documented interruption pattern is consistent with other research (e.g., Beckman & Frankel, 1984). In Beckman and Frankel's study of patient-provider communication, for example, providers interrupted patients' opening statements after a brief period of time (18 seconds on average) and took control of the interview. Although the internists and medical residents in the study began with an open-ended question such as, "What seems to be the problem?" (p. 692), they only allowed 23 percent of the patients to complete their comments without interruption. This study identified the following four types of interruptions: (1) moving to a closed-ended question about a specific symptom (e.g. "How long have you been coughing up blood?" p. 692), (2) asking for an elaboration of the problem presented (e.g. "Tell me more about this nervousness" p. 693), (3) restating what the patient has said (e.g. "You're out of breath all the time" p. 693), and (4) providing supportive

statement (e.g., "That sounds serious" p. 693). For all types of interruption in Beckman and Frankel's study, after the interruption, patients only complete 1 out of 52 of their opening statements during the rest of the medical encounter. The pattern of interruptions is common in traditional approaches that cast talkative patients as aggressive and troublesome and providers as *in charge* of the interaction.

Reasons for interrupting patient replies to open-ended questions are varied. Beckman and Frankel (1984) give four possible explanations. First, the provider might assume that the patient will give a direct answer such as "I found a breast lump." Second, the provider might assume that the patient's first answer is the most important. Third, the provider wants to be efficient so will cut off the patients who talk for too long. Finally, the structure of the medical interview, in which the provider's goal is to ascertain the "chief complaint" (p. 695), drives the providers' agenda. In terms of the last explanation, Beckman and Frankel (1984) recognize that patients likely have many concerns and may not rank or present them in a specific order. In summary, "over-directing the interview at the beginning of the visit may result in premature termination of opportunities for patients to present the very concerns that the initial segment of the visit is designed to capture" (p. 695). Although medical providers interrupt because they are trained to be "efficient", especially in managed care environments, most patients actually finish their opening statements of concerns in less than 60 seconds (Beckman & Frankel, 1984). This short time frame suggests that interruptions may be less important for efficiency and more a function of providers trained as *in charge* and drivers of the patient-provider interview. Sadly, Beckman and Frankel's study found that patient concerns were lost in 52 out of 53 cases in which interruptions occurred. As such, interruptions are neither efficient nor effective for patient care and treatment. Interruptions

and provider-driven medical interviews likely gloss over or ignore other patient concerns, concerns that effect medical diagnosis and treatment if providers are attending to patients as a whole—the ecological perspective (Street, 2003).

Patient needs and expectations and medical interviewing. Patients may be seeking out a provider for reasons in addition to diagnosis and treatment of a disease. Some of those reasons include obtaining information or reducing feelings of distress or isolation (Barsky, 1981). Understanding why patients believe that they are ill is crucial information for providers.

A patient's inordinate distress may stem more from his beliefs about what is wrong with him than from the pathologic process itself. Illness attributions are the causes that people imagine for their symptoms: what they believe is wrong with them and why. Illness attributions are helpful because they reveal some of a patient's personal and emotional experience of a disease. (Barsky, 1981, p. 494)

Providers that ask only about physical symptoms may have patients who are dissatisfied with their care. Barsky (1981) believes providers can address patient concerns by asking them about their specific requests and concerns. Although Barsky does not classify asking about concerns as listening to the patient's story, his examples illustrate patient stories. The first story is of a 54 year old man who returns for a follow-up visit after having a heart attack. The patient has already been diagnosed and placed on heart medications. When the provider asks the open-ended question, "How did you hope we could help you today?" the patient responds:

Well I was hoping you could tell me if being on all these pills means that I had a specially bad attack, or whether everyone gets treated like this. I never took so much

as an aspirin in my life, and now they've got me eating pills day and night. And I

worked carrying heavy boxes around and now they won't let me walk to the corner

for the paper…I want to know if I had a specially bad attack and if I had brain

damage while I was having that trouble breathing (p. 495).

In this case, if providers only ask questions important to the provider (e.g., questions about

the patient's blood pressure, when headaches occur) they may never hear or understand their

patients' true concerns or uncover the hidden reasons for patients' clinic visits. The sensitive

interview, patient-centered interview, ideal interviewing technique, and aspects of the other

patient-provider interviews I have reviewed explicitly or implicitly instruct providers to

attend to patient needs and concerns.

Traditional medical interviewing end of the continuum. Throughout these

examples, teaching medical interviewing follows a functional formula or step-by-step

approach to patient-provider interviews. Whether in handbooks (Hanson & Neuhauser,

2003), flowcharts (Tierney & Henderson, 2005), systems of steps based on functions (Cole &

Bird, 2000), listings of key points (Enelow, Forde & Brummel-Smith, 1996), or types of

patient-provider interviews (Aldrich, 1999; Smith, 2002), the traditional biomedical approach

and derivatives thereof are reductionist in character and fail to recognize the constitutive

power of communication. Communication does more than simply relay information, and

communication theorists consistently critique the simplistic transmission model of

communication, especially in organizational settings (e.g., Craig, 1999; McPhee & Zaug,

2000). Communication—what is said, by whom, and how, in conjunction with social norms,

settings, power relationships, expectations, communication history, and so forth—combine in

unique ways to create a particular reality for communicators (e.g., Lutgen-Sandvik & McDermott, 2008).

Most training models implicitly rely on the transmission idea about communication. Simplifying the steps might make patient-provider interviewing easier to teach, but this approach ignores the unpredictable and complex process of reality-creation that happens between and among communicators. Rarely do traditional models see the patient as a co-creator of the illness story, as this is a complex idea difficult to teach with 1-2-3 step approaches. Additionally, traditional biomedical patient-provider interviewing models rarely if ever overtly incorporate narrative as a means of building relationships, making diagnoses, and discovering patient fears and concerns. Because humans are story-telling animals, narrative is a powerful means of connecting and understanding (Fisher, 1987). I move now to explain narrative theory, which is the basis for a narrative approach. I follow the narrative theory explanation by fleshing out the narrative medicine approach in more detail.

Narrative Theory

Fisher's Narrative Paradigm (1985, 1987) argues that people experience and understand life as a succession of ongoing stories with struggles; protagonists and antagonists; and openings, centers, and closings. Because narrative is retrospective and people's lived experiences do not actually unfold as neatly as people recount their stories, using narratives makes sense of and derives meaning from what occurred and how it affects communicators' lives in the present. In the Narrative Paradigm, Fisher contrasts the rational world paradigm with a narrative paradigm and outlines the elements of what he calls narrative rationality. Many of these ideas are applicable to patient-provider communication.

Rational World Paradigm versus Narrative Paradigm

The rational world paradigm is a perspective on human communication that suggests people are logical beings who make decisions by weighing out the evidence and arguments of various positions. Although not explicitly stated, much of the training literature on patient-provider interviewing is rooted in this paradigm. Fisher counters the rational world paradigm with the narrative paradigm (1984). He argues that humans tell stories in order to communicate important symbols and meanings to each other. These stories are based on good reasons, whose details vary based upon the culture, historical references, life history, and individual characteristics of the storyteller. However, the themes of human narratives are meaningful across civilizations, place and time. The rational world paradigm must be learned, due to its dependence on factual knowledge, rules and tests. In contrast, narrative rationality is a natural capacity, present throughout human history and across cultures.

Narrative Rationality

Fisher argues that narratives have their own forms of rationality or ways to evaluate the worth or character of a narrative. Narrative rationality includes narrative coherence and narrative fidelity. Narrative coherence is a measure of how well the story "hangs together" (1987, p. 47). First, the story is compared to other stories to see if any major points are left out. For example if a provider did not include both positive and negative consequences of a chemotherapy treatment in their story, it would be less coherent. Second, the characters in the story must act in a consistent way. For example, if providers state that they care about patients as people, but speak to them in a technical or generic way about their medical condition the providers would lack coherence. Their motivation for assisting the patients may also come into question.

Narrative fidelity is a measure of how well a story appears to be true based upon the listener's experience. Although technical data can be considered when evaluating truthfulness, technical information is not the most important factor in terms of narrative fidelity. The emotions and values embedded in the story, which lead to humane actions, are more important in determining fidelity. For example, the story of choosing a breast surgery (lumpectomy verses mastectomy) includes the emotions and values associated with a loss of attractiveness and womanhood.

Application to Patient-Provider Communication

Many of the main assumptions of Narrative Paradigm theory are applicable in a medical setting. First, Fisher (1987) argues that human beings are storytellers by nature. Because humans are natural story tellers, the Rational World Paradigm seems unnatural to many patients. Asking patients to tell their story is much easier because the format is already known. Models of patient-provider communication rooted in the Rational World Paradigm are likely to fail, partially or fully, because patients may not understand what the provider is asking them (due to part to use of jargon) or how they are supposed to respond.

Second, after patients lay out the plot of their stories, the patients and providers can find knowledge, truth, and reality in the stories. Judging the narrative rationality of a story in this way is a more natural process than evaluating medical "facts." Gathering a list of facts about when a patient found a breast mass, what date she had her mammogram, and so forth fails to address how she felt at that time and how her feelings influence her treatment decisions.

Third, patients are creating a story of illness, which becomes their reality no matter which method a provider uses to discuss their disease. Providers that fail to listen to the story

may not address or understand the patient's underlying values, which are embedded in the story. For example, a woman who believes that her cancer is a punishment from God for some previous immoral behavior may not accept any treatment. However if a provider addresses this issue and discusses the nature of forgiveness in her religion and the provider's gift of healing as coming from God, then they may be able to make a treatment plan.

Narrative Medicine

Narrative theory informs a promising approach to patient-provider interaction and communication, known as *narrative medicine*, in which the provider is able to recognize, comprehend, and decipher patient stories, and then take action (Charon, 2001; Harter & Bochner, 2009). Narrative medicine is championed by applied health communication scholars (Harter & Bochner, 2009, Rawlins, 2009, Harter, Japp & Beck, 2005), as well as by physicians (McLeod, 1998, Young & Flower, 2002). Despite the promise of this approach, the study of applied narrative medicine is partial, taking place mostly in primary care settings. To date, the medical community has limited empirical evidence of the effectiveness of narrative medicine dialogues compared to traditional biomedical interviewing for engaging cancer patients in their own care. This study extends the research on narrative medicine, specifically comparing this approach to the traditional biomedical (i.e., Rational World Paradigm) approach.

Narrative medicine skills, including utilizing *narrative competence*, defined as "the ability to acknowledge, absorb, interpret and act on the stories and plights of others" (Charon, 2001, p. 1897), may improve provider communication effectiveness. Charon believes that barriers to effective communication can be broken down using story telling in doctor patient communication. Her goal is to make the medical experience not only a "high-

stakes technical enterprise, but as one among many human efforts toward communication"

(Charon, 2009, p.121). She begins her appointments not with a fixed script, but allows the

patient to tell their own story. When she sees a new patient her opening statement is "I will

be your doctor, and so I must learn a great deal about your body and your health and your

life. Please tell me what you think I should know about your situation" (Charon, 2009, p.

122), then she sits and listens.

The essence of narrative medicine is storytelling, story evoking, and narrative

competence. Story telling is relating medical information through the tools of plot,

characters, episodes, and so forth. Story evoking involves asking patient to tell stories

related to their illness or wellness, or having patients ask questions without prompts or

interruptions from the doctor. Narrative competence encompasses using "words and [other

representations] to produce a creative interpretation and representation of an encounter with a

patient" (Younie, 2009, p. 54). Charon (2006) explains that the impetus for this approach was

partly the influence of the women's movement and a trend toward consumerism in health

care. Women and men were beginning to question the overstated power and tone of the

medical provider during the traditional medical interview.

> Studies of medical conversations amplified the until-then silenced conversations
>
> between doctors and patients, those conversations that often dismissed, derided, and
>
> disrespected patients who were trying, simply, to tell what was the matter. Such
>
> dismissal, we found, was not only the product of the individual doctors' intentions or
>
> goals but also the result of the structural practices that had grown up in American
>
> medicine (p. 193).

Structural features of the traditional medical interview include the need for both parties to take turns, the acceptance of interruptions by the providers, the use of technical jargon by the providers to show expertise, and the consensus that patients should provide the "right" answers to the providers' questions. This leads providers in to a pattern of "withholding critical information and thereby deceiving patients about their medical conditions, ignoring what patients brought to the conversations, and controlling what would be talked about and how" (p. 193).

In narrative medicine, patients share not only symptoms and thoughts about their illness, but how they feel about the situation, and how the illness is interconnected with their daily life (Charon, 2009). One critique of this approach is that it is too time consuming, given the current time-limits placed on doctors. However, narrative approaches which stress patient participation, resulted in increased consultation time in only two of seven studies (Harrington, Noble & Newman, 2004), and by only 1.2 minutes, or 6 minutes respectively. Indeed, a physician who responds empathetically to a patient's story expends very little time, 25.8 seconds for the entire communication event (Bylund & Makoul, 2005). As such, the time-limit critique has found little empirical support.

Backing from the medical community for narrative medicine has grown with the concern for quality provider-patient interactions. For example, the Journal of the American Medical Association has published Charon's (2001) and others' work championing the approach. Doctors from respected medical schools such as Duke University, and Carnegie Mellon University have praised narrative methods (McLeod, 1998, Young & Flower, 2002). Columbia University's College of Physicians and Surgeons now has one of the first programs in narrative medicine (http://www.narrativemedicine.org/about/about.html).

Finding meaning, dignity, and humanity through narrative. Speaking from his personal experience as a cancer patient, Frank (1991) offers an example of an illness narrative, as opposed to talking about a disease. He defines *disease talk* as a discussion of the progress of treatment, in which his body is seen as "it." He compares the conversation with his doctor to a conversation with his auto mechanic, although the conversation about his body is done with more class, it includes less detail. In contrast, the narrative Frank proposes is one of *illness talk* in which the patient talks about "my" body, how it has changed, and how "I" am affected. Illness talk has become part of the mainstream, in the form of personal stories about illness, including breast cancer narratives.

Having a serious illness is a novel situation for most people, and they often use metaphors to change unfamiliar terms into familiar ones (Petraglia, 2007). In breast cancer, lymph systems are seen as rivers with rocks that stop debris, and support groups of other women with breast cancer are seen as a sisterhood. Petraglia calls narratives "extended metaphors" which "make novelty comfortable by linking the unknown and the known" (p.496). In the very important narrative known as the life story "seeing our lives unfold in a comprehensible way keeps chaos at bay and, literally keeps us sane" (Petraglia, 2007, p.496). Narrative helps women to understand the complex decisions they will be asked to make during treatment and beyond.

Women often use stories to express how improving relationships with others, becoming mentally and physically stronger, and ignoring minor problems to focus on more important life issues became part the their breast cancer experience (Thomsen & Jensen, 2007). A story can function as a conduit, leading to greater understanding of how a person's notion of self is changed by illness. Narratives that re-frame life stories have been called *re-*

alignments, and appear to be a common occurrence (Watson, 2007). As a doctor working with women with breast cancer, Watson draws an analogy to the medical world, "as I care for cancer patients and struggle to realign the numbers on laboratory reports, I wonder whether they are struggling to re-align their stories" (p.1284).

Narratives can also help patients retain their dignity in the medical encounter. Parsons and Hooker (2010) find that dignity is enacted through narratives. Patients' narratives "reflected back to them by doctors and nurses, constitute the opportunity for the demonstration of the sometimes fleeting and subtle forms of attending, validating, caring, and responding" all of which are dignity enhancing. Dignity is promoted by health care providers' supportive actions or violated when providers appear to be apathetic or indifferent to patients' illness stories.

The biomedical model of healthcare addresses disease but not always illness. Charon (2001) makes this point quite eloquently when she states "a scientifically competent medicine alone cannot help a patient grapple with the loss of health or find meaning in suffering" (p.1897). Over 13 years ago Sharf (1999) said that health care communication "needs to be expanded to account for personal, social and societal well-being, in addition to biological survival, the human quest for meaningful existence and spiritual concerns" (p.196). In Newman's (2000) theory of health as an expanded consciousness, a health crisis is not seen as a negative event, but one in which a person can transcend previous limitations in their environment.

In summary, the use of illness language (Frank, 1991), metaphors (Petraglia, 2007), and stories (Arora, 2003; Hartner & Bochner, 2009; Harter, Japp & Beck, 2005; Rawlins, 2009) may increase patients' understanding and satisfaction with medical encounters.

Showing interest and concern for patients' needs (Arora, 2003; Parker, Aaron & Baile, 2009) and engaging in conversation (Korsch & Negrete, 1972; Venetis et al., 2009) also seem to increase patients' satisfaction. In contrast, when providers dominate the conversation patients' are less satisfied with the communication (Hack, Degner & Parker, 2005). Table 1 synthesizes the literature reviewed in this chapter. Specifically, Table 1 compares and contrasts the communicative features of traditional interviewing and narrative medicine approaches, extending the continuum in Figure 1.

The various continua in the model include aspects that are often studied in patient-provider communication—the features of patient-provider medical interviews. Viewing the usual criteria for evaluating a medical interview in terms of a continuum, instead of elements which are present or absent, is helpful in deciding whether an interview is more traditional, narrative, or hybrid. A continuum also allows providers to shift from one style to another during the same encounter. Although the continuum is one way to view and define a medical encounter, health communication scholars continue to expand research on patient-provider interaction. Therefore, other factors will likely be discovered that affect patient-provider communication. For this study the various aspect continua (i.e., "continuum") will be used as a guide to categorize sections of medical encounters with early stage breast cancer patients. I explain my methodology fully in the next chapter.

Table 1. *Traditional and Narrative Patient-Provider Communication Continua*

Traditional Medical Approach ➡	Narrative Medicine Approach
More closed-ended questions	More open-ended questions; use of silence
Patient interrupted	Patient finishes statements
Provider initiates conversation	Patient/provider initiation is about equal
Patient has unmet needs, concerns	Patient's needs, concerns are addressed
Provider dominates conversation	Patient/provider contributions are equivalent

Provider asserts power
  * Makes definitive statements (e.g. I recommend)
  * Treatment plan determined by provider
	Patient and provider share power
	  * Make cooperative statements (we, let's both)
	  * Treatment plan is negotiated
	  * Provider asks for patient's opinion

Provider uses medical jargon, technical terms, Statistics	Provider uses common terms, explains in plain language, uses metaphor
Focus on medical facts	Focus on psychosocial issues, emotions, coping—encourages storytelling, life narratives
Provider redirects patient often	Limited redirection of patient
Impersonal, little/no conversation	Use of conversation, show interest in patient's concerns
Limited use of empathetic, supportive, respectful statements	Conspicuous use of empathetic, supportive, respectful statements

Provider's nonverbal behavior undermines relationship, empathy, support and respect for the patient
  (limited eye contact (e.g., on computer), leaning back, closed body position, sitting above or standing while patient is sitting, sitting too close or too far from patient)
	Provider's nonverbal behavior enhances relationship, empathy, support and respect for the patient
	  (appropriate eye contact, leaning forward, open body position, sitting at an appropriate angle and distance from the patient)

Chapter 2

Methodology

The use of narrative medicine in an oncology center was the focus of this study. The goals of this study were: to examine the types of interviews used at the Hecurcan Center; to compare patient perceptions of traditional medical interviewing and narrative medicine approaches, to determine if either approach was more likely to result in richer patient recall; and to evaluate which approach lead to greater patient satisfaction. Specifically, the current study explored the following research questions:

RQ1: Which form of interaction (traditional biomedical interviewing, narrative medicine approaches) do providers predominantly use?

RQ2: What content is evident in patient-provider interactions in addition to traditional biomedical interviewing or narrative medicine content?

RQ3: Does patient recall of patient-provider interview content differ between traditional biomedical interviewing and narrative medicine formats?

In what follows, I describe my subject position as a researcher and explain why an interpretive perspective is the best approach for this study. I develop a theoretical model that informs the study. I describe the setting, sample and data collection tools. Finally, I illustrate how the data is analyzed in terms of each RQ.

Researcher Subject Position

As a starting point for my thinking about my commitments, I reflected upon the questions posed by Littlejohn and Foss (2008). First, I consider my epistemological commitments, questions of knowledge. Second, I explain my ontological commitments or questions of existence. Finally, I present my axiological commitments, questions of values.

Epistemological Commitments

I believe that most knowledge is acquired through experience. I would have said all knowledge is obtained this way before I had my child. I now believe that there is some knowledge that humans are born with, including the drive to interact and communicate with others. Years before he ever said a word, actually minutes after his birth, my son was able to express to my husband his needs as he carefully gave him his first bath and wrapped him in blankets. His gentle, easy going nature made everyone want to be around him including the nurses, who would keep him for hours in the nursery at the hospital. I was grateful for their assistance because I needed the rest, but I noticed most of the other babies were brought back to their mothers very quickly. These traits continue to make up a large part of who my son is today.

As applied to my research setting, some women are liked more by their providers than other women. This creates greater opportunities for relationships, and enhanced communication with their providers (Hall, Horgan, Stein & Roter, 2002). From my observations in the physician workroom at the Hecurcan Center, patients who are liked are spoken about in positive terms. The providers talk about their strength, courage and how unfair it is that such a "nice people" have cancer. They go out of their way to provide information on the latest clinical trials and support services. Patients who are difficult or too pushy with providers may not be offered clinical trials because they are too difficult to work with. Providers talk about how they dread entering the exam rooms of these types of patients. The providers often pass them off to an intern (a first year student) so they can take their history. Thus the patients are deprived of their time with the attending doctors.

I also used to believe that knowledge was absolute, but as I have gotten older, and hopefully wiser, I no longer believe that this is true. I worked and collected my data in a medical world that reveres the scientific method. Facts make up the medical world, but those facts are subject to change. At one point mastectomy was the only surgical treatment for breast cancer, and now lumpectomy and radiation are seen as equally as good. This occurred in part due to the pressure that women with breast cancer and their advocates placed on the medical community. It was also a reaction to an authoritarian medical system (Segal, 2007).

I believe knowledge is socially constructed, both at the personal and societal level. Medical providers can sometimes only see the diseased part of a person. However I believe, as do others (Frank, 1991) that knowledge about that person, is best seen in a holistic way, as an illness story. Often it takes time to uncover this picture of the person, because although some things about them are easy to see, other things remain hidden, maybe even to them. For example a woman with breast cancer who is also a mother may openly discuss the logistics of balancing treatment and child care with her provider. But, she will not openly discuss her fears about dying and leaving her children. She may not even be aware of more subtle changes taking place during treatment that make it more difficult for her to nurture her children. I now turn from questions of knowledge to questions of existence.

Ontological Commitments

I accept as true, that the choices that humans make are constrained by their environment. Women with breast cancer have to make complex choices about the types of treatment they will receive and their oncologist's may not have the communication skills to help them to fully explore all their options (Parker, Aaron & Baile, 2009). Even if their oncologist is a highly skilled communicator, the choices that are available are restricted by

the medical setting and culture. An oncologist would never recommend a religious ritual as a primary treatment for a woman with breast cancer, although they might be open to the inclusion of rituals as a complementary part of a woman's care.

I have already outlined my belief that all human beings have traits which define them which are difficult to change. However, throughout their lives humans are able to move through various states of being which are not fixed. An oncologist might be directive with a woman that they see as passive or indecisive, but I believe that women can change during the course of their treatment. I have seen women who began their treatment in shock, following doctor's orders without question, who later began to question their treatments and advocate for themselves. Some of these women have become outspoken public advocates for women with breast cancer.

I also believe that all human beings experience the world at an individual and group level. A woman's experience of having breast cancer, like all other experiences in her life is both individual and social. The woman's experience is unique, however other women that have had breast cancer, the woman's support system, and the medical team, all share and co-create her experience. There may be some general principles about what it is like to have breast cancer, cancer, or even a very serious illness. But, it is also important to look at each woman's individual situation and how that affects her experience with breast cancer. I now move from questions of existence to questions of values.

Axiological Commitments

As a researcher who has spent fourteen years in the field working with breast cancer patients, I have a deep understanding of the issues the women in this study encountered. As an affiliated member of the breast team, I was a full participant as well as a key researcher in

the study. My extensive knowledge and experience in the setting enhanced both access to the site and comprehension of the dense medical jargon used in patient-provider interviews (Tracy, 2011).

My first experience in the setting was as a social worker, which led to some inherent assumptions. The first was that human beings operate within systems. In this case, there were layers of systems, the larger medical community, the medical center, the clinic, and the patient's family and friends. These systems can be studied and navigated by human beings. The second assumption was that systems can be changed. However, change is a long and difficult task because human beings do not like change. Advances in the treatment of breast cancer occurred in my relatively short time in the field, however very little has changed in how this information is disseminated. As previously presented, the medical interview, and the history and physical have changed very little over fifty years. Finally, my ultimate goal is changing the system to make it more equitable.

From communication I added the concept of agency. Human beings should be treated with dignity and respect because they are the force which both creates and changes a system. The goal is not for me, as the researcher, to empower people, but to seek out conditions in which people can empower themselves. Like Fisher (1987), I believe that one of the most effective ways to communicate is through stories. By looking at stories, the main values of a culture can be revealed, questioned and changed. My ultimate goal is to change the medical setting, creating better communication for patients and providers. If this study fails to provide practical applications, I would not consider the study "successful."

Interpretative Perspective

An interpretative perspective makes most sense in terms of this exploratory study of - provider interaction in terms of narrative medicine, which is a relatively new approach to patient-provider communication. Patient-provider communication, even when about medical issues, creates a unique, collaborative reality, meeting one of the distinct commitments of interpretivism (Lindlof & Taylor, 2011). This study also sought out a deeper understanding of the women, honoring their experiences, yet understanding that knowledge gained through any research is only partial and can always be expanded upon.

As a member of the breast team I was an insider. My adviser served as editor and sounding board. As such, she reread and reviewed transcripts, reviewed analysis categories and findings, provided manuscript editing and feedback, and served as an academic supervisor for the project's data collection. By working collaboratively on the project, the insider- and outsider-perspectives served as a triangulation regarding the trustworthiness of the study's findings (Tracy, 2011). As a researcher I know that my knowledge and understanding of the women, and of the setting, influenced what I saw and what I reported. The exact text of the communication and multiple interviews with the women provided both verbal and narrative data. By presenting unedited selections the women can speak more directly to the reader.

An interpretative methodology also responds to Charon's (2001) call "for qualitative clinical research to complement quantitative clinical research [because]…both the singular and the statistically significant must be comprehended in the study of disease or its treatment" (p.83). As such, this study explored the characteristics of micro-level interactions

and exchanges between providers and patients and the patients' subsequent recall of those

interactions.

Influence of Narrative

Although Charon is not a health communication scholar, her work is often cited by

those in the field, and can be seen as an extension of Walter Fisher's (1987) narrative

paradigm theory, applied to medicine. Charon's ideas are also about a process of

communication and an attempt to make the medical encounter a more natural exchange. She

explains her technique of sitting quietly while a patient tells their own story of health and

illness (Charon, 2009). This is in stark contrast to traditional medical interviewing, where

the physician usually leads the interview, thus retaining all the power in the relationship.

Charon (2001) provides examples of how her method gets to the heart of a patient's

concerns, and can be faster than the traditional medical interview process. She states, "If the

physician cannot perform these narrative tasks, the patient might not tell the whole story,

might not ask the most frightening questions, and might not feel heard" (p.1899).

Charon's methods have not yet been widely accepted in medicine, which should not

be a surprise to anyone who has worked in the field. She is a physician coming out against

traditional medical interview training techniques. This is despite the fact she is a faculty

member at Columbia College of Physicians and Surgeons, and that her article was published

in the Journal of the American Medical Association (Charon, 2001), one of the most

respected and read journals in the country. Charon draws her examples from personal

experience. Qualitative work is unusual in the field of medicine and may not be convincing

to providers who are used to relying primarily on quantitative data (e.g. clinical trials) which

adhere to the standards of evidence based medicine. In order for traditionally trained

providers to consider her method, she encourages the collection of data in all programs currently using narrative medicine techniques. Health communication scholars have adapted her theories to study stories of illness.

Influence of Humanism

A focus of contemporary scholarship in health communication is on humanizing health care, currently achieved by listening to patients' stories. Sharf, Harter, Yamasaki and Haidet (2011), state that "until recently, the explicit acknowledgment of narrative activity in clinical work was whispered on the fringes of mainstream medicine" (p.40). Now research and practice are coming together. Both positive and negative stories create narrative meanings, or intertextuality (Harter, Japp & Beck, 2005). The growth of internet support groups for different illnesses, which provide forums for patients to tell their stories, is one example of how meaning can be created. The co-construction of these illness stories can also create collaboration and support (Beck, 2005). Sharf et al. (2011) question the western understanding of medicine as a science and take a constructionist – relational view. "Medicine is far from an unmediated representation of reality. Health care participants construct understandings of experience and use those interpretive frames to guide future actions" (p. 43). They compare clinical encounters to stories and performances, but state this is being expanded to include other types of expression, including using pictures, poetry, movement, quilting, and movie making to represent the lived experiences of people with illnesses. Often the stories are influenced by their setting, which illustrates the importance of their structure.

Influence of Structuration Theory

Structuration theory (Giddens, 1979) takes into account how people communicate and the setting in which they are in. An important concept in the theory is duality of structure. This duality allows for social constructs to be created and modified during communication acts. For example, when women and their providers are talking using a traditional medical interview approach they are reproducing this structure, but the insertion of stories within that structure transforms the structure into something new. Over time, traditional medical interviews can be reshaped by the women, based in part on their varying degrees of agency. This is why a woman who is familiar with medical terminology may be able to challenge the provider lead medical interview, creating a patient lead interview. This both reinforces the structure of the interview, and creates a role reversal. Using the concepts of social constructionism and duality of structure together a more complex picture of patient-provider communication emerges.

The duality of structure (Giddens, 1979) also includes the concept of transformation. By taking part in a conversation with her provider a woman can transform the structure of the medical interview, thus affecting that provider's performance with future patients. For example, a provider who successfully uses a metaphor of rocks clogging a stream to explain the human lymphatic system might use the same technique to explain the system to another patient. These transformations help to bridge the post-positivist world of the provider and the interpretivist world of the patient.

Resulting Model

A patient-provider communication model consisting of three nested circles was created utilizing these influences. The setting, as viewed by structuration theory (Giddens,

1979) is the outermost circle. Narrative dialogues are represented by the middle circle. I

defined narrative dialogues as segments where the providers listened to the illness stories of

patients. Listening included at minimum not interrupting the patients (Charon, 2009), or co-

creating the illness stories (Beck, 2005). I drew from Frank's (1991) characterization of

illness stories, which include how patients cope or respond to their illnesses. Because a

medical setting can also constrain narrative dialogues, traditional medical interviewing, and

all combinations of these techniques, is also included in the middle circle. Narrative creates,

recreates and expands a more humanistic version of a medical encounter (Sharf, Harter,

Yamasaki & Haidet, 2011), which is represented by the upward arrow. Traditional medical

interviewing can sometimes create a less humanistic version of the medical encounter,

represented by the downward arrow. The circles are represented by dashed lines because

each circle affects, and is affected by the other circles. The visual model is shown in Figure

2.
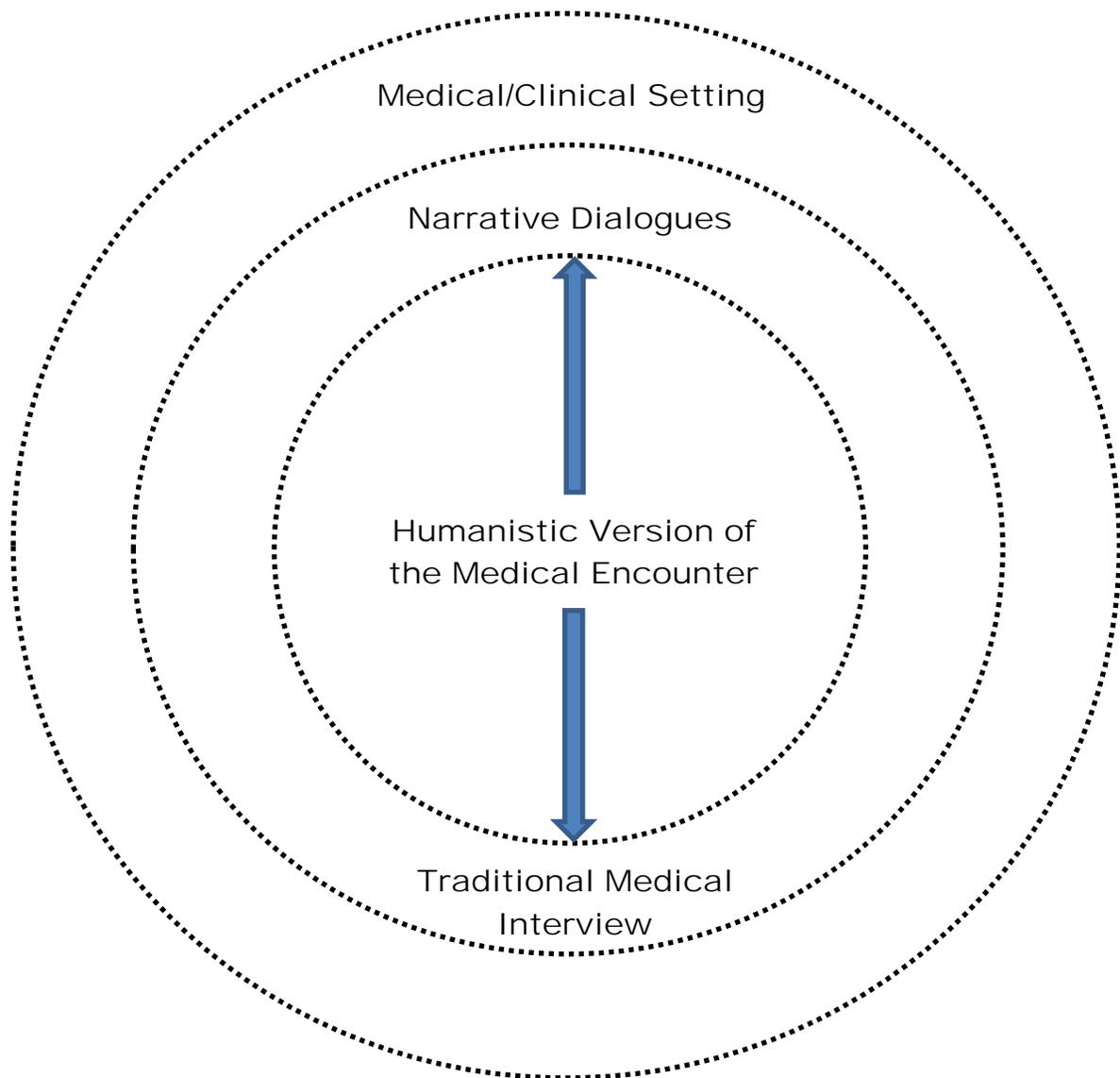
Figure 2. Patient-Provider Communication Model

Setting, Sample and Data Collection Tools

The next section addresses the setting of the Hecurcan Center, how participants were

selected for the study, and why some potential participants were excluded. Next I explain the

tools used for data collection, followed by the process for data analysis in terms of each RQ.

Importance of Setting

In order to transport the reader more effectively into the examination room several methods attempt to re-create patient-provider interactions. Field notes, from field observations of patient-provider interactions were used to capture nonverbal behavior. The setting was described in detail to preserve the appearances and activities which took place, which were not captured on the audio tape.

Sampling and Participants

Sampling. Inclusionary and exclusionary sampling criteria were used in the study (Lindlof & Taylor, 2011). Participants were women, over the age of 18, with early stage breast cancer, who spoke English. Non-English speaking women were excluded from the study because of the inherent communication difficulties which can arise when medical information is interpreted (in the case of spoken language), or translated (in the case of written language). Women with metastatic (stage IV) breast cancer were excluded because their communication with providers is often different due to the serious and chronic nature of their condition (Step & Ray, 2009). There is also the added dimension of discussing negative prognosis and end of life issues, which can increase communication difficulties (Ozanne, Partridge, Moy, Ellis & Sepucha, 2009). Finally, women who were determined as not legally competent (e.g., suffering from dementia or in need of guardianship) were excluded, as the study focused on women's recall regarding patient-provider communication.

Some atypical cases were included in the study (e.g., a premenopausal woman with breast cancer, and a physician with breast cancer). There was also some degree of convenience sampling. Women, who were willing to participate in the study, were recruited and selected solely from the Hecurcan Center during a specific time frame. The doctors,

nurses, social workers, and other practitioners on the breast team, agreed to inform their patients about the opportunity to participate in the study. Flyers posted at the Hecurcan Center also advertised the study.

Participants. Ten women who met all selection criteria were enrolled in the study, ranging in age from 35 to 66 years (mean 51, median 53). All were diagnosed with early-stage breast cancer: two with Stage-0, three with Stage-1, four with Stage-2, one with Stage-3. Five identified as Hispanic and five as White. Education ranged from 11th grade to Ph.D. Median household income was $25,000. Participants selected pseudonyms, which are used in this paper.

Data Collection Tools

Three basic tools or approaches were used for data collection. These included observations of patient-provider interactions, interviews with patients, and document analysis. In this case, documents were patient medical records.

Observations. All observations of provider visits with diagnosed early stage breast cancer patients were conducted at the Hecurcan Center. Care was taken to record the patient's stage in their diagnostic process from the medical record. Each visit was labeled with the type of provider(s) seen (surgeon, oncologist etc.); the number of the visit with that provider (first, second, etc.); and a list of other providers the woman had already seen. Because of the large amount of information given to patients shortly after diagnosis, and the importance of patient recall of this information for positive treatment outcomes, these visits were the focus of the study. The main medical providers were two female oncologists, one male and one female surgeon, and residents, physician's assistance and nurse practitioners

who were team members. Visits were audio recorded and field notes were added to capture

nonverbal behavior and researcher reactions to each encounter.

Interviews. A structured interview guide was used to collect general demographic

information from the women including age, race, nationality, socio-economic status, and

level of education. Individual semi-structured interviews were conducted with the women in

the study, both after their recorded visits and one year after the completion of their treatment.

The interviews had three goals, gathering information, understanding the women's

experiences, and gaining their perspective (Lindlof & Taylor, 2011). The semi-structured

questions were used to try to more fully understand what the women experienced in their

encounter with the providers. Open-ended questions were used to encourage storytelling.

These interviews utilized Charon's (2009) technique of sitting quietly and not interrupting

the patient as they tell their story. Both types of interviews were audio recorded and took

place in various private locations. (See Appendices A and B interview guides).

In response to concerns raised by Human Subjects protection, specific questions that

the women asked during the interview (if any) were carefully written down and directed to

appropriate staff members. For example, if a woman asked a question about her next

appointment the scheduling staff was consulted, or if a woman had additional medical

concerns the provider and members of the breast team were consulted. As the safety and

wellbeing of the patients was of upmost importance, interviews were discontinued if

participants became distressed.

Document review. To augment the structured demographic interview, information

on disease stage was documented by patient medical record review. The record was also

used to double check the patient's progression in treatment. This review provided

background information that informed observations and sensitized interactions in interviews.

Data Analysis

       Capturing the medical interview in text. The interpretation of audio-taped medical

interviews is affected by transferring them to the written page. Mishler (1984) recognizes

that there is a fundamental problem in representing speech as text. Many elements may be

lost, including pauses, interruptions, overlaps, and false starts. Only by going back and forth

between text and tape can the context and meaning of the medical encounter begin to be

understood. A second issue raised by Mishler (1984) is the inherent difficulty in breaking

down medical interviews using a standardized coding system. When using a quantitative

coding system each phrase must be in one group or another. Calculating the frequencies of

statements and creating a list does not capture the full meaning of those statements because

the context is lost. Switching to themes instead of a strict system of coding can help to

mitigate some of these limitations. Finally, what is most important is to "make explicit the

'intuitive steps' involved in coding" (Mishler, 1984, p. 47). In the next section I explain the

manner in which I answered each research question.

       General considerations. Patients were asked to select pseudonyms to be used in this

report, so the patients would be able to recognize and comment on their contributions, but

they would remain anonymous to readers of the report and to each other. All audio files were

transcribed by a professional medical transcriptionist and cross checked for accuracy. In all

cases, selections of text were carefully chosen or cleaned so that identifying information

(e.g., family history, dates of illness, etc.) was omitted. Data were analyzed manually, that is,

I did not use qualitative data analysis software.

Research Question 1. To answer RQ1, Which form of interaction (traditional biomedical interviewing, narrative medicine approaches) do providers predominantly use? I compared and contrasted the audio recordings and my field notes in order to code the interviews or elements thereof accordingly to the continua in Table 1. As such, I designed an a priori coding schema to answer this question, rooted in my review of the literature. The following reveals my considerations during this coding process. The first step of data analysis involved categorizing the overall patient-provider interaction as tending more toward a traditional medical interviewing or a more toward a narrative medicine approach based on the health communication continuum. However, it soon became apparent that very few encounters contained only one approach. Therefore my unit of analysis became sections of text within each encounter.

To answer RQ1, I read the transcribed and annotated text of each medical encounter a number of times. The annotations included my field notes—observations of physical gestures and the positions and movements of the patients and providers during the encounters. I also listened to the audio tape many times in order to detect non-verbal cues such as interruptions and changes in tone (said softly, in a joking manner, etc.) and tempo (said rapidly, repeated slowly, etc.) that might influence the meaning of what was said. I used an iterative approach, going back and forth from the tape to the transcript and transcript to tape to capture the essence of the encounter. In order to capture this on paper, selected transcription symbols described below were used (Silverman, 1993, p. 118).

[	Speech is overlapped
=	Speaker continues with no gap, despite interruption
(1)	Silence, time in seconds, this example is one second

WORD	This word or words is louder than others
( )	Unable to hear text
(( ))	Text added by this author
. , ?	Traditional use

Traditional biomedical medical interviewing. Traditional medical interviewing was indicated for sections of text that tended towards the left side of the Table 1 continuum. This included when providers used more closed-ended questions then open-ended questions or silence; and when the patients were interrupted, or redirected by providers. Additionally, providers initiated most of the questions and dominated the conversation. The patients in these situations often responded with very short responses, including "yes," "no," "okay," "uh huh," or with very specific answers to the providers' questions. Providers also focused on the medical facts, used more medical jargon and technical terms, and/or made definitive "I" statements which determined the treatment planning process. There was very little personal conversation, or use of empathetic or supportive statements. Nonverbal behavior included limited eye contact, closed body position, and/or sitting at an inappropriate angle or distance from the patient. Finally, the patient may have expressed unmet needs (e.g., trying to interrupt the provider to get a word in).

Narrative medicine approach. In contrast narrative medicine was coded if the sections of text tended to fall towards the right side of the continuum. This included providers using open-ended questions and/or silence and allowing patients to expand upon their answers without interruption. Patients were able to tell their stories, how illness affected their decisions, and their lives. Providers and patients initiated about the same amount of topics for discussion and each spoke for about the same amount of time. Patients

and providers made shared treatment decisions and the word "we" was often used. Providers avoided using jargon, and explained complex terms, or used metaphors. Both the patients and providers engaged in more informal, personal conversation. The providers showed more interest in patients, specifically regarding how they were coping with their illness, and/or their emotional and psychosocial concerns. The providers made empathetic, supportive or respectful statements to the patient and their nonverbal behavior supported their words. This included appropriate eye contact, leaning forward, sitting at the correct distance with an open body position, or gently touching the patients' hand.

Research Question 2. To answer RQ2, "What content is evident in patient-provider interactions in addition to traditional biomedical interviewing or narrative medicine content?" I explored patterns that emerged in the text and in the annotations. I looked for patterns that re-occurred among the ten women but were not specifically coded with the continua in Table 1, my a priori schema for answering RQ1. These were coded using a grounded approach including open-coding, constant comparison method, and memoing (i.e., creating short descriptions for each code) to describe and label all units.

I compared the patterns from the first woman's interview with the second, third, and so forth until each pattern was distinguished. This step involved maintaining a running directory of explanations by examining each element outside of traditional biomedical/narrative content, creating a code name and abbreviation, and creating a short description of the code. Each new element was compared to previous codes to determine if it was similar to or different from established codes. If the new element appeared similar to an established code, it was labeled accordingly. If not, a new code, abbreviation, and description were created.

Research Question 3. To answer RQ3, "Does patient recall of patient-provider interview content differ between traditional biomedical interviewing and narrative medicine formats? I examined the interview data for each woman to see which parts of the communication with their providers they recalled. In this third step, I analyzed patient interview data for the richness of patients' accounts (the depth and breadth of recall regarding providers' communication) as compared to the recorded patient-provider observations. In order to assess richness, interview data was coded in terms of what parts of the interaction the women remembered, how many of the details they recalled, and how closely they understood the providers' recommendations and reports. Similarity was coded in terms of how similar the patients' accounts were to the providers', with a focus on the providers' instructions. The number of items patients recalled was compared to number of directive or informational points made in patient-provider interactions. Simple percentages were calculated to determine, based on provider-patient interview type, if recall by type varied. I choose to focus on patient recall instead of patient satisfaction because it allowed for this type of comparison. Patient satisfaction tends to be more subjective, especially for patients with early stage breast cancer who usually have excellent medical outcomes with treatment.

Chapter 3

Results

Patient-Provider Interview Types

RQ1 asked, "Which form of interaction (traditional biomedical interviewing, narrative medicine approaches) do providers predominantly use?" I found that patient-provider interviews tended more toward one or the other pure types (and were categorized accordingly), but nearly all included elements, to a greater or lesser degree of traditional biomedical interviewing and narrative interviewing. That is, traditional biomedical interviews at times included stories, and narrative interviews included biomedical information. What is more, some of the traditional biomedical interviews focused almost entirely on providing medical or logistical information. These were coded as sub-types of the biomedical approach. Data coding and analysis found evidence of both traditional medical and narrative medicine interview styles, both of which typically included five general characteristics.

Traditional Biomedical Interview Style

Traditional biomedical interviews, interviews in which the majority of the content included cognitive medically based information about diagnoses and procedures, were the norm in this study. There were different types of traditional biomedical interviews; these sub-types were provider-led, medical information provision, logistical, and patient-led.

Provider-led. The traditional biomedical interview approach is primarily one of question-answer and cognitive medical-information reporting (from doctor to patient) with reduced input from the patient. The first example is of a patient, Flossy, speaking with her oncologist about some pain she is having. This is her first appointment after beginning

chemotherapy. Flossy is with her significant other. She is sitting in a chair and he is sitting

next to her. When the oncologist enters the room she sits on a stool in front of both of them.

She asks how Flossy is doing and Floosy says she is concerned about some sharp pains she

was having in her chest.

Dr.:	How long did that last?
Flossy:	Um, maybe like (3)[
Dr.:	[A couple of seconds?
Flossy:	Yeah.
Dr.:	Were you short of breath?
Flossy:	No.
Dr.:	Okay, any cough?
Flossy:	No.
Dr.:	Was it just in one particular area?
Flossy:	Yeah, I actually grabbed on because it hurt so bad.[
Dr.:	[Like a spasm?
Flossy:	Yeah.
Dr.:	Where was this located?
Flossy:	Right here. ((patient is pointing to the middle of her chest and laughing nervously))
Dr.:	So it doesn't sound like it's a heart issue or anything.
Flossy:	Uh huh
Dr.:	Usually there are two kinds of pain we worry about. One is a heart pain and usually it's a heaviness that
Flossy:	Uh huh
Dr.:	=you can't really describe well. Just

Flossy:	Um hum
Dr.	=like somebody is sitting on your chest okay. Those we worry about. Those don't last for just a few of seconds
Flossy:	Yeah
Doctor:	=and those typically come with exertion. The other pain, um, that we worry about is the pain coming from a blood clot in the lung
Flossy:	Um hum
Dr.	=and usually it will present as a shortness of breath,
Flossy:	Uh hum
Dr.	= like a chest pain or pain taking a deep breath. Shortness of breath, some cough, and just generally feeling very tired after that. Now those kinds of like short stabbing pains and kind of like in the breast area, they are probably just muscle spasms. So we will just keep an eye on that. Okay?
Flossy:	Okay.

Notice in this exchange that Flossy says very little in comparison to the doctor, and the doctor asks all the questions (some of which appear leading) during this interview. The questions are all closed ended and redirect the patient to discuss her symptoms. The doctor interrupts the patient on two occasions, once after a silence of only three seconds. Flossy laughs nervously during the conversation. She seems to want to say more during each "Uh huh" (which were fairly loud) and then she starts to say "Um hum" softer and softer as the doctor continues to speak. Although this section was coded as traditional medical interview, the doctor does use appropriate eye contact, a friendly tone of voice, and common terms instead of medical jargon, which fall on the narrative side of the health communication continuum.

A second example is from Cecilia who was recently diagnosed with breast cancer and meeting with her oncologist for the first time. Cecilia has her sister with her at the

appointment and they are sitting in two chairs next to each other. The oncologist enters the room. She sets a laptop computer on the back table and walks up to the patient and introduces herself. She then sits near the back of the room, near the computer, perpendicular to Cecilia and her sister. At first it seems that the patient is being asked to tell her story, but it becomes clear that the doctor is directing the interview.

Dr.:	So let's focus now on your diagnosis of breast cancer.
Cecilia:	Ok.
Dr.:	Tell me, how this got to be discovered?
Cecilia:	Well, I found a lump (3)
Dr.:	[Um, hum
Cecilia:	=and when I had my mammogram, or I had my annual visit with my primary care
Dr.:	[Uh, huh
Cecilia:	=you know, she ordered a diagnostic mammogram.
Dr.:	Um hum (2) ((doctor is shuffling through papers and has lost eye contact with Cecilia)) Did you actually go to your, um, primary care as soon as you felt the lump? Or you waited?
Cecilia:	No, I waited, well, because I had an appointment coming up.
Dr.:	Okay.
Cecilia:	I actually had an appointment scheduled.
Dr.:	Okay, so when did you feel the lump?
Cecilia:	Probably it was in, probably the end of February, no maybe
Dr.:	[February?
Cecilia:	=January, February, I think it was the end of January, beginning of February

Dr.:   [And the, and the, mammogram that was done on March ((date deleted for privacy)) was an annual screening, annual study, because your last one was March ((date deleted for privacy)). Did you have mammograms prior to 2010?

Cecilia: Yeah.

Dr.:   Okay.

Cecilia: I brought copies of the last 4 years, and the results of the last 4 years, of the mammograms.

Dr.:   Okay.

Cecilia: So they should be on file.

Dr.:   ((Said very softly, almost to herself as she reads the report)) So there is an irregular mass with small calcs ((an abbreviation for calcifications, which can be a marker for breast cancer, but this is not explained to Cecilia))

    ((back to a normal volume)) And they ultra-sounded the mass in, uh, which breast?

Cecilia: Right.

Dr.:   And the left one was negative?

Cecilia: Yes.

Dr.:   Okay. 8:30 position, 3 cm from the nipple, they didn't size it, otherwise negative. Okay, and so they said this was worrisome requiring a biopsy, correct?

Cecilia: Yes.

Dr.:   And that biopsy was performed on ((date deleted for privacy)), is that right?

Cecilia: Um hum.

Dr.:   Ultrasound guided biopsy (8), and did you tolerate the biopsy quite well?

Cecilia: Um hum, Yep.

The doctor in this case allows the patient to speak at first, but soon jumps in with

many specific questions of her own, many that seem leading. She begins with an open ended

question, but interrupts Cecilia after only six seconds, three seconds of which were silence.

She continues to interrupt, or redirect Cecilia each time she seems unsure of an answer, such

as when she is trying to remember when she first discovered her breast mass. In contrast,

Cecilia allows the doctor to be silent for eight seconds near the end of this example without

saying anything in return. It is clear that the doctor is dominating the interview which begins

with Cecilia providing more detailed responses and ends with her simply giving one word

answers to the doctors' questions. The doctor never has direct eye contact with Cecilia, and

loses eye contact completely with Cecilia during the interview. At one point she has her

head down and is reading a report so softly that it was difficult to hear in the audiotape. Even

if Cecilia heard what she was saying the doctor used medical jargon, and this piece of

information was never explained to her.

Not all examples of traditional medical interviewing were as easily categorized as

Cecilia's. Sometimes traditional biomedical interviews included narrative elements, despite

the majority of interactions taking a strictly technical, cognitive approach. The following

exchange occurred in Tess's interview when discussing the risk of lymphedema (arm

swelling) after a lymph node biopsy.

PA: ((biomedical content)) One of the general rules is at least for 5 years, and
some surgeons say for the rest of your life, that arm is forbidden: no blood
pressures, no needle sticks, no vaccinations, no finger pokes, nothing sharp or
pokey; if you're going to work in the garden, wear gloves. ((narrative
content)) I use myself as the bad patient because I'm not very delicate and I
always have scrapes and scratches and things ((showing her arms to Tess))

> Every time you injure yourself and your immune system activates, your lymph system has to work to clean out…

Tess: Okay

PA: =what it cleaned up. Every time you make it work, it's like adding a little stick to your camel ((metaphor, common to narrative structures)).

Tess: I see what you're saying.

PA: ((metaphor continued)) I don't know how strong your camel is and I don't know when it's going to collapse.

Tess: Okay.

PA: ((return to biomedical content)) So, we train you to help take extra of that arm and be careful, and then we do our part by doing a careful surgery.

Tess's interview was almost wholly biomedical in character, as the patient was deciding about single- versus double-mastectomies and preparing for the upcoming surgery. Additionally, she was having an ovary removed by another doctor, and the interview included how the medical providers would collaborate in that effort. Within this traditional provider-patient exchange, however, the PA told a story to illustrate how easily Tess might hurt her arm. The PA punctuated this story with a metaphorical idiom ("the straw that broke the camel's back").

Medical-information provision. Another type of traditional biomedical interview was one in which only medical information was provided by the practitioner. As such, this interview could be considered a sub-type of provider-led traditional biomedical interview. The content focused not on give and take but on didactic practitioner-presented medical evidence. In this interview type, providers spoke at length about medical diagnoses, procedures, or treatments with very little interruption by the patient. The patient, if they responded at all, merely said, "ok," "uh huh," "yeah," "um hum," "yes," and so forth. In the

excerpt, Lovie is coming to her second appointment with her oncologist after having some

additional testing on her breast. The doctor has a great deal of information to give to her.

Lovie, her daughter and granddaughter are all in the room. Lovie is sitting in a chair and her

daughter is sitting next to her. Her granddaughter is leaning on the chair at the beginning,

but as the visit continues she slumps down onto the floor and remains there. The visit last 52

minutes comprised almost entirely of medical information giving.

> Dr.: So, the other category is chemotherapy and, based on what we know, that you have almost, um, maybe the 29-30% is the benefit of all those people in this group. And so it is around that range, anywhere from 24 to 37%, so it's probably, I have to look because this is not colored ((doctor staring closely at the chart, which is in black and white)), but it should probably be in the ballpark of like 25 to 30% benefit, okay? ….

> ((Doctor moves over to the next section on the back side of the report and starts to draw))

> Okay, so the last category, okay, is an anti-body. If you lose me, just let me know. So, this antibody is called Herceptin– the antibody is called Herceptin …Let me just check something…

> ((Doctor is looking closely at the patient records))

> So, basically, if you look at the breast cancer cells, so 25% of them, you might remember this discussion; have a protein on their surface. It's called HER/2neu – that's the name of the protein HER/2neu. So, this is a marker of aggressive disease, and there is an antibody that we give to target that protein, and so it kills cells very specifically. Now, based on your report, by textbook, by the standard guideline, you are not a candidate for this, you are not a candidate for this because this is technically HER/2neu negative. Now, this is where, this next thing that I am going to talk to you about, this is where it gets a little complex…. ((doctor continues in a similar manner vein talking about HER/2neu negative proteins and then asks,))… So, the question now is, are the people who are 3 the only ones who have a response? How about those people who are 1 or 2? Maybe there is also a response to the antibody that we are just not aware of because we're not giving them these antibodies? Does that make sense?

> Lovie: Yes

Although the doctor used visual aids and Lovie had heard about antibodies in a previous appointment, the volume of information provided here appeared overwhelming. Lovie, however, answered affirmatively that she understood. In the medical-information provision interview type, patient input is so minimal that the term "interview" almost does not apply as a descriptor. Breast cancer information and the various contingencies with which providers must deal are exceedingly complex, and chemo regimens create another level of complexity. As such, some patient-provider interviews were more didactic in character: providers related and patients responded in monosyllables indicating that they heard, understood, or both.

Logistical. In the logistical traditional biomedical interview, interactions focused on basic logistics regarding treatment. These were back-and-forth interactions between the providers, patient and involved others (e.g., residents, nurses, social workers, navigators, family members, etc.). The end of Cecilia's visit with her oncologist is a good example of logistics. The patient's sister, an assistant and this researcher get the patient moving to her next destination after a fair amount of discussion.

Sister:	Okay, so let's see here. So the surgery could happen in…anytime within the next couple of weeks, hopefully.
Dr.:	Yeah, I mean it could, yes it could.
Sister:	We hope it's not longer.
Cecilia:	Generally speaking though]
Dr.:	It's a matter of Dr. ((name deleted)) schedule and unfortunately I don't have Dr. ((name deleted)) schedule.
Cecilia:	Well, I understand that, yeah
Dr.:	Cause I don't have OR schedules.

Cecilia:	Uh huh, Yup.
Sister:	Okay well alright well at least you.. she's got the appointment now for her right?
Dr.:	Yeah, I've already requested it, so it's just them a matter of looking at her schedule and saying, " Oh yeah Dr. ((name deleted)) can see you tomorrow." Or whatever. Okay?
Sister:	Okay, so they'll do that over there.
Dr.:	Exactly.
Sister:	Okay?
Cecilia:	So…ooo how late today can I get to radiology and]
Asst:	Downstairs and lab is downstairs.
Dr.:	Yeah, so go before they close at 5 and they can put you in.
Researcher:	What time is it Dr.?
Dr..:	It's 4:36
Cecilia:	So I should do that before I go to the … scheduling first?
Dr.:	No you have to go to scheduling first and I'm putting in the request, they have to put it in the ((name of computer program deleted)) before people can see it in the lab or x-ray. Okay?

The content of the logistics included the physical location of services, operating hours of services, insurance coverage issues, dates and times of pending appointments, and so forth. Discussions of chemotherapy regimens, which often included time frames, were excluded from this category and categorized as medical-information provision.

Patient-led. Another type of the traditional interview was the patient-led traditional biomedical interview. This was a bit of a shift, and although did not fit the provider-led model of a traditional medical interview, focused on biomedical information. In this interview, the patient mirrored a traditional doctor's style by asking a series of questions to

the doctor (often using medical terms) for which they expected answers. A representative

example comes from Betty who is at her third appointment with her oncologist. She is sitting

in a chair in the exam room and I am sitting next to her. Betty has waited over an hour for

the oncologist. When the oncologist finally enters the room everyone looks exhausted. The

oncologist and I have both been in the clinic for ten hours at the beginning of Betty's

appointment. The oncologist rests her arms on the back counter of the room, not out of

disinterest, but because the stool that is provided for the doctors has no back or arms. Betty

had her surgery first and is returning to discuss additional treatment possibilities, including

chemotherapy and radiation. After the oncologist gave her some information about several

options the Betty then began to ask questions.

Betty:	Right, and what does it do to your immune system overall?
Dr.:	The immune system, your white count can drop 7 to 10 days, usually that's the, the maximum, nadir after chemotherapy. Okay? After chemotherapy. Um.
Betty:	How about radiation?
Dr.:	The radiation therapy is local. Okay? It won't, it won't affect anything outside typically, it won't affect anything outside the breast. But some people do feel tired. But in general if there is any side effect it will be (2) to the breast.
Betty:	Okay, not to the immune system at all?
Dr.:	No, no, no ((softly)) It's not a substitute for these ((Dr. is pointing to a graphic of the types of therapy, she has this paper propped up on the back wall of the room and Betty has turned her chair to face them)) because again this is the s the other side of that graph. That's to complete your local therapy to give]
Betty:	[Cause I haven't had a cold, I don't get colds even.
Dr.:	So that's why, that's why, these numbers are high ((her present health indicators, as shown on another graph))

Betty: Yeah, cause I don't get colds. I don't have...I've never had flu shot.

Dr.:   [I rated you as excellent health ((showing her the graph))

Betty: I've always done it through actually basically food, yeah, and herbs.

In this interview, Betty asked the questions that were important to her using the correct medical terms, "immune system" and "radiation." She also told the doctor that food and herbs were important to her. At this point the doctor provided her information about possible side effects of the treatment options. Betty then returned to the subject of herbs.

Betty: Yeah but, can I still take some of the herbs that I take?

Dr.:   If you decide to do this ((chemotherapy)), then I will have a dietitian check and make sure that they are not, they won't make the side effects more, because it depreciates…a lot of these herbs are metabolized in you know the liver, and these drugs too are metabolized there.

Betty: I was going to say, they probably are metabolizing there too, aren't they?

Dr.:   The majority of medications are metabolized there. So, there's an enzyme and the drug is metabolized, so if you have a competing, same spot, then it may either potentiate or lessen the side effect.

Betty: Okay.

Dr.:   Okay, you don't have to make the decision today.

Betty: Okay, yeah, I'd like to read that.

((Dr. gives patient the paperwork for the study she is considering))

There is a bit of a role reversal in the patient-led interview. The patient asserts queries and preferences, pushing the provider to reply and comply (hopefully). In the previous excerpt, Betty continued to express what is important to her and uses medical language to do so. That is, she talked to the doctor in the doctor's language. She also

requested more information to take home to read, including the technical protocol for the study she was considering.

Narrative Medicine Approaches

In contrast to a traditional interview, a narrative medicine dialogue approach is marked by storytelling, story evoking (asking patient to tell stories related to illness/wellness or having patients ask questions without prompts or interruptions from the doctor), and narrative competence (e.g., using "words and [other representations] to produce a creative interpretation and representation of an encounter with a patient" (Younie, 2009, p. 54). In my patient-provider communication model, I defined narrative dialogues as segments where the providers listened to the illness stories of patients. I identified four different types of narrative dialogue approaches; these sub-types included narrative evoking, narrative co-creation, patient initiated narrative moments, and supportive narratives.

Narrative evoking. The first representative example is one in which the provider evokes stories from the patient by asking open ended questions, allowing time for the patient to speak, and eliminating interruptions. Tess is at her second appointment with her surgery team. This interaction is with the midlevel provider. Tess is sitting on a chair and the provider is sitting directly across from her.

Midlevel:	Have you thought about what breast surgery you were interested in? (2)
Tess:	I have, um (2) probably a mastectomy.
Midlevel:	Now, on one side or both sides?
Tess:	I would, I would do both since they found something on this side.
Midlevel:	Do you understand what they found?

Tess: Yeah, they said it was a papilloma and they described, um, that there are some that are nothing to do with cancer, and this one could be, could cause cancer, or there could be cancer cells in there, I guess there are cancer cells everywhere, but.

Midlevel: Typically, papillomas are thought of like skin tags

Tess: Uh huh, uh huh

Midlevel: Like those things on your neck.

Tess: Uh huh

Midlevel: Three percent of them can be malignant. These things are in the sarcoma family. They become malignant when they border on 5 centimeters.

Tess: Okay?

Midlevel: That's the size of my fist. ((She makes a large fist and shows the patient))

Tess: Uh huh.

Midlevel: I don't think that this thing is that big.

Tess: Okay.

Midlevel: When they're small, almost 100% of the time they are completely benign.

Tess: Okay.

Midlevel: We take them out, the bloody nipple discharge stops, life is good, and there is no further care needed, not even radiation therapy.

Tess: Okay.

Midlevel: So, I don't want you to rush into a bilateral mastectomy because you heard the word cancer.

After this the midlevel provider spends some time giving the patient detailed information about mastectomy on one side, and a biopsy on the other side (option 1); or mastectomies on both sides (option 2), as well as reconstruction options for one or both sides. She returns to a more narrative approach, requesting the patient's opinion after she provides the information.

Midlevel:	Those are kind of the two options that you have available to you.
Tess:	Okay
Midlevel:	Does one seem to be more likely to you than the other?
Tess:	The first one makes more sense to me.
Midlevel:	Okay.
Tess:	So that I … if I'm going to have reconstruction, reconstructive surgery, and I can do the second breast at the same time, then it's pretty much the same. So I'm just afraid, I mean, you know, I wanted to do both of them probably just to be done with it, that's how I felt. So, I mean, like you said, later on I can always choose that later on anyway.
Midlevel:	Or, later on, once this temporary situation is a little bit removed
Tess:	Uh huh
Midlevel:	You could choose to keep it and just have that side lifted to match the other side. And that gives you some time and distance
Tess:	Um huh
Midlevel:	To think about it maybe in a different way, okay
Tess:	Uh huh

This encounter includes open ended questions which evoke a story from Tess. She is given the freedom to explain exactly what she understands about her medical situation in her own words, without interruption; as well as to express her fears about not having more aggressive surgery. Tess is articulating her understanding of the situation, when she states that a plan for a less aggressive surgery "makes sense", but also that she is "afraid" and that is why she "felt" (note past tense) she originally wanted both breasts removed. The provider clarifies Tess's medical situation in a narrative way. The provider pauses when she talks about a mass being 5 cm, noticing that Tess is confused. She then physically shows the patient (by making a fist) how large this is. The provider offers two similes to explain the

word papilloma (like skin tags, like those things on your neck) and an optimistic and supportive statement about treatment stating once a papilloma is removed "life is good" and no further action is needed.

The provider expresses concern by emphasizing that she does not want Tess to feel rushed into making a decision about surgery. In fact she is speaking slowly throughout this encounter, and mentions that she wants to give Tess the "time and distance" to think about what to do. The provider reinforces her concern for Tess with supportive non-verbal behavior. She makes eye contact with Tess, has an open body position, and sits at an appropriate angle and comfortable distance from her.

Narrative co-creation. A second representative example of narrative style can be seen in an encounter with Cars. Typically during the physical exam, providers used a more narrative approach, which encourages mutual discovery between patient and provider. This diverges from the more medically fact-based cognitive interactions. Cars came in for her third appointment with her oncologist, her first appointment after beginning chemotherapy. This example is in contrast to the traditional biomedical interviewing style used to discuss chest symptoms with Flossy. In this case the patient, provider and her friend, attempt together to discover if the therapy has been effective. This exchange takes place during the physical exam.

Dr.	This actually feels (2)
Cars:	Mobile.
Dr.	Softer, a little bit more mobile.
Cars:	Yeh, yeh, that's what I thought too, yeh.
Dr.	Ok (2) because before it was like

Cars:	It was hard
Friend:	Solid, um huh
Dr.	(12) ((doctor does the breast exam during this silence)) And sometimes when it becomes flatter, when you make the measurements it's not, you know
Cars:	Right
Dr.	It kind of spreads out
Cars:	uh huh
Dr.	But this one area is 5.4
Cars:	Uh huh
Dr.	Have to look what it was before (5) ((during the silence the doctor is measuring the mass with calipers)) 5.4 x 5.3 (6) ((during the silence the doctor is examining in Cars armpit)) and there are some lymph nodes
Cars:	Uh huh ((Cars closes and ties her gown))
Dr.	Did you make notes? ((to patient's friend who has Cars large notebook and reports on her lap))
Friend:	It's right here
Dr.	That's from the mammogram
Friend:	Screening mammogram, the mass itself 5 cm ((looking through the report, but seeming a bit unsure as her voice gets softer))
Cars:	Uh huh ((her friend walks toward her, holding the report))
Dr.	So the mass itself was about 5.7 by 5.5 before ((Cars, her friend and the doctor are all reading the report, which her friend provided, Cars puts the report back in her folder))
Cars:	Okay, so it's shrinking
Dr.	It looks, like, uh, it's a little bit smaller, definitely not bigger.
Cars:	Yeah!

Dr.	The lymph nodes, I think the lymph nodes are a little bit more, um, less, um, less prominent.
Cars:	I thought so too. I can say, it felt like a huge almond before, you know.
Dr.	It did.

In this exchange there are very few direct questions asked. Cars, her friend and the provider each contribute to the conversation. Cars' and her friend's thoughts are taken into consideration by the doctor. All three come to a somewhat cautious, but hopeful conclusion that the chemotherapy is already working. Cars is able to express her concerns about the mass and lymph nodes getting smaller using her own words. The doctor supports her statements, and even uses the report from Cars own folder to explain what is happening.

Patient-initiated narrative moment. A representative example of third type of narrative style, which I have termed a patient initiated narrative moment, comes from Cecelia. This occurs during her first, very lengthy (1 hour, 21 minutes) appointment with her oncologist. This moment occurs 39 minutes into a more traditional medical interview where the oncologist asked closed ended questions and drive most of the interview. Cecilia is sitting in a chair, her sister is sitting next to her and the doctor is sitting on a stool. The doctor was occasionally typing on her computer, but during this story she is looking at Cecilia, as Cecilia tells a story about leg cysts in her family.

Cecelia:	I mean I've had this. My mother's had one, one of my sisters has one, same place.
Dr.:	Hum. Okay.
Cecilia:	My mother's was drained.
Dr.:	Uh huh.

Cecilia: They took the fluid, you know the fluid out of it. I think she had to have it done twice. When I suggested that to ((doctor's name deleted)), then I thought it could come back

Dr.:   Well if it's not bothering you.

Cecilia: Well, it doesn't affect range of motion, and it's not painful. I didn't see any reason. They wanted, you know, to do surgery. I didn't see any reason to, you know, to do that.

Dr.:   Okay.

Cecilia: Cause, I just figured they'd make my knee worse.

Dr.:   Alright, so now we go back to your breast cancer.

Cecelia, up to this point, has been answering question after question from the oncologist, with short statements of medical facts (e.g. Doctor: What kind of reaction do you have to these medications? Penicillin?, Cecelia: "I threw up"), or one word questions such as "Yes" , "Yeah", "Right", and "No".   This is a story that Cecilia wanted to tell, and importantly, it is a story about weighing her options and deciding not to have surgery on one part of her body (her knee). The oncologist brings her back to discussing her breast cancer fairly quickly (44 seconds), which is why, in comparison to the other two examples, this is a narrative moment.

Supportive narratives. Providers created extended supportive narratives for patients. This also included offering social support non-verbally through touch and tone of voice, and orally with particular phrases and terms. A representative example was a midlevel provider's interaction with Tess regarding her mastectomy.

Midlevel: I always offer that if my ladies don't want to unwrap themselves, come here and I will do it. You don't have to look that first time unless you want to, and you're ready to do that. And we gently help you through this process of being able to look at it, having that first cry

Tess: Uh huh

Midlevel:	=being able to touch that area, being able to do wound care in that area
Tess:	Uh huh
Midlevel:	=because it's still going to be part of you.
Tess:	Right.
Midlevel:	And we get you through that.
Tess:	Uh huh
Midlevel:	And I say that because I have women in the long-term follow up clinic that still will not touch their surgery site, even after a lumpectomy.
Tess:	Umm, uh huh.
Midlevel:	So, part of our job is to make sure that all of you – mind, body, spirit, emotion – all make it down this process, okay? So, yes, I'm sure there are going to be times we sit and cry together.

This type of narrative falls under the category of conspicuous use of supportive statements.

The provider's focus is clearly on the woman as a whole "mind, body, spirit, [and] emotion".

The provider also shares her power and shows empathy by using the word "we" in her final

statement. The provider offers to cry with Tess, as a supportive, empathic act. In addition to

the biomedical and narrative styles already presented, other interview elements were

discovered which were present throughout the styles, often reflecting unique patient-provider

situations (patient needs, provider demands etc.). They are presented next.

Other Interview Elements

RQ2 asked, "What content is evident in patient-provider interactions in addition to

traditional biomedical interviewing or narrative medicine content? I found three additional

elements that were present in patient-provider interactions: visual cues, humor, and

understanding checks. Visual cues used during interactions included medical reports, and

graphs or picture drawn by the providers to describe treatments or procedures (e. g.

flowcharts of surgery). These visual cues provided another channel through which complex medical information was conveyed to the women in the study. Both the providers and the patients referred to parts of the medical chart during their interactions.

New patients were routinely given a canvas bag with materials about the Hecurcan Center, including important phone numbers and support group listings, as well as brochures about their specific type of cancer. During their first or second visit breast patients received a copy of their biopsy report. Providers went over the report in detail and patients were advised to keep this report. Providers sometimes gave patients other types of reports or graphs to look at, such as their oncotype scores. This graph depicts the benefits of several types of treatments based on tissue from patients' tumors. Providers often discussed the test with patients and provided literature. The following encounter is with Tess and the midlevel provider:

Midlevel:	Do you have more questions for me?
Tess:	Only that I know that, um, Dr. ((the oncologist, name deleted)) said something about sending, um, I guess, the tumor to California?
Midlevel:	to Oncotype ((said softly, almost to herself as if making a mental note))
Tess:	to see if….okay… "I just wanted to make sure"… she said that
Midlevel:	Right
Tess:	= to make sure that you guys were aware of that.
Midlevel:	OncoType Diagnostics. Have you gotten the brochure on that?
Tess:	No.
Midlevel:	Are you interested in getting a brochure that explains what they do?
Tess:	Certainly.
Midlevel:	Did she explain it to you?

Tess:	Briefly. I mean, she explained that they send it off to California and test it to make sure that the chemotherapy would be beneficial to me for that specific type of cancer that I have.
Midlevel:	Exactly. So, let's hope that you end up in the low-risk group and just need endocrine therapy, okay?
Tess:	Yes, that would be nice.

The midlevel provider discussed the information with Tess and at the end of the visit

provided her with a brochure about the testing, thus using both verbal and visual channels.

Visual cues appeared to be important anchors assisting in the recall of information.

Cars, in her follow up interview, one year after her treatment discussed the

importance of the visual cues provided by her oncologist.

She got out a piece of paper and her pen and she drew out for me my situation, (2) my

cancer, the cancer that was yeh ((pensively)), and my situation, my circumstances,

and where I stood and the (2) the different avenues, the different possibilities that I

could go to, and was so patient with me, showed me exactly what I needed to do.

Cars remembered this visual cue and how she chose to take some of the avenues of treatment

(chemotherapy), but not others (radiation).

The providers and patients also physically showed areas of concern using their own

bodies. This occurred during conversations and during physical examinations. For example,

Mimi assisted the provider to understand which areas she was concerned about during a

physical examination of her breast.

Dr.:	But you found, you felt something on the left you said?
Mimi:	It wasn't on this side; it was on this side ((she has her hand on her right breast))
Dr.:	Okay, Okay. So uh, this was a left breast discomfort or something or did you actually feel something.

Mimi: No, there's little, there's little lumps right there ((has her hand on her left breast))

This interaction helped to clarify the area that the patient was concerned about, which was in addition to the area on her left breast which was found to be breast cancer. After some additional discussion the patient and provider decided that a biopsy of the right breast was also needed for everyone's piece of mind. Fortunately no breast cancer was discovered in the right breast.

In spite of the often serious nature of medical encounters, light moments were fairly common. Both providers and patients used humor to break the tension of the medical encounter. For example, a midlevel provider said to Tess "Your heart rate is a little fast, or is it just cause I have a white coat on today?" This caused all of us to laugh, and actually helped lower Tess's heart rate. Humorous moments were often spontaneous. Near the end of Lovie's encounter with her oncologist the research nurse walked in to assist with the scheduling of some additional tests.

Nurse: ((to the doctor)) I'm not sure if she's had imaging?

Dr.:   ((to the nurse)) She probably had a chest x-ray but I have to check if it's within 90 days.

Nurse: ((to the doctor)) We need an EKG, and then are you, is she postmenopausal?

Dr.:   ((to the nurse)) She's 55; she doesn't have uh, she had a hysterectomy, partial, so she will not get pregnant, for sure]

Patient: I hope not !

Lovie's comment caused spontaneous laughter in the room disrupting what had been a very serious discussion about the need for her to have chemotherapy.

In addition to humorous breaks, different parts of the medical encounter were often broken up by the provider asking a direct question to the patient. Often these questions included language in which the provider questioned the patient to see if they understood the information provided in the encounter. These phrases were labeled checks for understanding and included statements at the beginning, middle and end of encounters, or between major discussions (such as discussing surgical options, then moving to chemotherapy). They included the following: "First of all, what questions do you have for me, let's start with that?"; "Do you have any questions for me?"; "Any questions so far?"; "Do you have any other questions?"; Do you have any questions before I examine you?; "Any questions or concerns?"; "What questions do you have?"; "Did I answer all your questions?" ; and "Do you have any burning questions before I leave?" Also included were more specific checks on the content of the medical encounter including: "Does that make sense?"; "Does that sound reasonable to you?"; "Um, questions, worries, or other things that I can order to help?" and "Okay? Was there anything I left out, anything you needed to mention to me?"

Visual cues, humor and understanding checks all served to move the patient-provider interaction forward. They helped to clarify information, created a much needed break from the serious nature of the interaction, or produced an opportunity pause briefly before moving on to another topic. They were found throughout the different types of communication approaches, from interviewing to more narrative sections of the medical encounter. While it appeared that visual cues might have assisted women to recall information, the topic of recall is discussed more fully in the next section.

Patient Recall Regarding Provider Communication

RQ3 asked, "Does patient recall of patient-provider interview content differ between traditional biomedical interviewing and narrative medicine formats? I found generally, that women recalled more of the patient-provider interaction content when providers used a narrative approach. Overall, women recalled general ideas from their medical encounters without many specific details. However, those general ideas were quite similar to the ideas discussed by the providers during these complex interactions.

Looking at the transcribed medical visits, the range of separate discussion topics was 5-13, with a median of 12.5 topics. These were overarching topics such as chemotherapy, radiation therapy, mastectomy, and reconstruction. I did not include topics for which the providers asked one or two questions as part of a medical history (e.g. How many pregnancies did you have?). I did include topics which were discussed at length and might impact breast cancer treatment (e.g. several pages of discussion regarding a patient's arthritis that impacted the types of anti-hormonal breast cancer treatments she could receive because these treatments can cause bone loss and bone pain).

Taking these overarching topics and comparing them to how many topics patient's recalled in their post-appointment interviews, the range was from 15-42% of the topics. The 42% was an outlier; this patient was a medical provider who was very familiar with the setting and terminology. The median amount of topics recalled was 20.5%. Of the topics recalled 60% of them were presented in a narrative format. Removing the data from the medical provider increased the number of topics remembered which were presented in a narrative format to 67%.

For example, Tess was able to state that the provider discussed with her what was "going to happen with the left breast with a mastectomy and the right breast having a biopsy." Both of those sections of text were coded as utilizing a narrative medicine approach. She reported that the doctor addressed her specific concerns, saying, "I was a little uncomfortable with what was going to happen with the right breast, with the biopsy, um, because I had one before and then I was concerned with them having to put the rod in my breast, and that procedure, but I understood what they were going to do." Tess stated that she "felt comfortable" with her interaction with both medical providers.

In a second example, Cars recalled that her breast mass was getting smaller. She stated "we see some shrinking in the tumor, so that's good." This section of the encounter was coded as narrative medicine; specifically it was an example of narrative co-creation. Importantly, the patient uses the word "we" when describing this fact, as opposed to saying "the doctor" said my tumor is shrinking. Cars did not recall any additional specific medical topics, which were discussed during her visit. She was able to state that "everything's looking good. Uh, tests are clear." Significantly, the topics she was unable to recall were presented in a traditional medical interviewing format.

Franny, in contrast, was able to recall more specific details discussed during the interaction with the provider. She recalled issues related to "chemo" (chemotherapy), which was presented in a biomedical interviewing format. She also recalled a discussion about "bone density", including that she should "reinforce bones with calcium and Vitamin D and weight bearing exercise", which was presented in a narrative medicine format. She remembered that "I need a mammogram, and if that one is okay, then we'll probably just do it once a year", this was coded as a patient initiated story (i. e. narrative moment) about how

often she had mammograms in the past. She also recollected that she required some other type of testing, but was less clear of what it was "a screening, I assume she meant a blood test." In addition she focused on the question she asked the doctor, coded as patient led medical interview. She stated "I was very interested in what she was saying about the memory thing [memory loss]…the breast cancer chemo and, um, and the treatment, the Femara …[and] learning to focus better."

Recall during Follow Up Interviews

Follow up interviews were conducted about a year after the initial interviews. There was some variance based on the length of each woman's treatment. All interviews took place after their treatment had ended; and all women (based upon chart review) were found to have no current evidence of cancer. In general the women spoke more about their overall experiences, but when encouraged to think of specific encounters they did remember some specific topics. Because these interviews took place after many encounters, percentages of topics recalled were not computed. What does appear to be important was the overall tone of the communication by the providers.

The best example of this is Franny, whose first response was very general. **"**What I remember, that's not about the content, but just that I felt like I could ask her [the oncologist] questions and she took the time to answer them." When prompted for a specific example she said "a lot of the discussion was about, as I remember, was about whether I should keep taking the Femara, which is an aromatase inhibitor, about the new research that is being done on that." She also offered a specific suggestion:

I do like to have the reports or whatever information is gathered…to me that is an important piece, is to have all the information about my health so I can, you know,

make decisions based on the information and I know what's happening. I appreciate

when the information is given right way, and in writing because it's hard to remember

sometimes all that stuff when you are going through cancer and cancer treatment.

Franny was specific not only about the content, but the channel (in writing) through which

she would prefer to obtain medical information. This highlights the importance of visual

cues in patient recall.

A second example is Flossy, who at first said she remembered "not very much, it's

such a blur." With some prompting for a specific example she remembered an encounter

after her lumpectomy "then I come back a week later and it [the cancer] was in the margins,

so I had to go back for another surgery and that's the one that tops them" and "I remember

my reconstruction." About losing her entire breast (the second surgery was a mastectomy)

she said:

It taunts me. I mean having a boob removed I mean it's going to taunt you for the

rest of your life anyway, so I mean that, just the two surgeries was just a little bit

much, but they [the medical team] can't help it, how can they see everything, you

know it just happened and that's part of life.

Flossy embraced a survivor identity. She was wearing a pink shirt from a breast cancer

survivor's race during her visit. She told me her employer had sponsored a team and she

walked with her co-workers. Then she said, "You can conquer anything in the whole, after

you do breast cancer you can do a whole lot more."

In contrast, when asked about what she remembered from her conversations with the

providers, Lovie said, "actually, you know what, I don't remember nothing."   Even with

prompting her example was very general. She stated "If I had a concern, they, I would tell

[oncologist's name] and all the rest of the team, they were really good, they would help me solve it, or, just remember things, but I can't remember it now", and "overall everything was great."

Betty gave a similar general example stating, **"**I can't remember exactly every question I would ask them [her doctors], but I do know they were very responsive and all the doctors were willing to go out on a limb for me and try to help me." When prompted for a specific example she said, "one of the things that sticks out is [doctor's name]… he really tried to reach out, and I do remember that, I remember his kindness."

Cars had a similar memory about the general tone of the communication with her medical team. She said:

> I do remember every time I met with my surgeon, and my oncologist, and basically anyone that had any interaction with me, they were all so positive, I mean they were (2) I wasn't afraid to come here for my appointments, because I always got this positive feedback, this positive energy, and any question I had was always answered with (2), with not only knowledge, but love and caring.

In her example it is clear that the provider's more narrative approach made a difference in the way she was able to cope with her decision.

> When it was time to do the surgery, the mastectomy, and um (6) she [her surgeon] just reassured that, she really felt like, if there was any other to do this, she would do it, but there, this was what **had** to be done. So taking to her about that was very comforting knowing that she was very (3) experienced , and uh (3), and again she another one that I just totally trusted, that when I went in for that surgery she was going to be there and she was going to do the best that she could.

When asked about her interactions with her doctors and herself she stated, "They [the providers and team] became like a trusted friend" and "I wasn't a number, I was a person to them."

Clearly Cars had an emotional response to her providers and how they communicated with her. In the final chapter the implications of these results are discussed further.

Chapter 4

Discussion

Summary of Key Findings

By looking in depth at the experiences of women with early stage breast cancer, patterns of interactions and common characteristics of encounters were discovered. Both traditional biomedical interviewing and narrative medicine approaches were used by providers, often within the same medical encounter. The setting, the Hecurcan Center, was an important factor influencing the context of the medical encounters. My patient-provider communication model integrated structuration theory, narrative, and humanism (refer to Figure 2) and guided my analysis of the interactions between patients and providers.

Patient-Provider Communication Model

Structuration theory (Giddens, 1979) considers how people communicate in a specific setting. One important concept in the theory is duality of structure. This means that interactions, for example medical interviews, can be created and modified by patients and providers. A provider may follow a format for their interview, asking first about family history, second about past medical history, third about past surgical history and fourth about social history. However, the patient may tell a story related to their family history of cancer which addresses many of these issues at once and gets to the heart of their concerns – my mother died of cancer, am I going to die too? This creates a new, more narrative form of interview. The provider may then add to their format – if patients have a family history of cancer which includes a death, ask about their concerns. Therefore the structure of their interview format is changed and continues to change.

The influence of narrative (storytelling, story evoking) is also evident in this example. The medical encounter, instead of being an interview, can include the shared stories of patients and providers (Charon, 2001, 2009). As in the example above, stories may reveal the underlying fears and concerns of patients. They can also help to clarify complex medical issues. The use of stories can also lead to a more humanistic medical encounter (Sharf, Harter, Yamasaki & Haidet, 2011), in which patients' understandings and experiences of illness are the main consideration.

Encounter Types

In order to evaluate the types of medical encounters, I conducted an extensive literature review of both medical interviewing and narrative approaches to health communication. I created my continua by synthesizing the results of this review into a table (refer to Table 1). A continuum model allows for hybrid styles of medical interaction to be recognized and coded. Instead of looking at traditional medical interviewing and narrative methods as mutually exclusive, medical interviewing elements can be combined with narrative elements to form new subtypes. I discovered four types of traditional biomedical interviewing and four types of narrative medicine approaches throughout the medical encounters.

Traditional biomedical interviewing. Four types of encounters were coded as traditional biomedical interviewing, provider led, medical information provision, logistical and patient led. Provider led biomedical interviews fell to the left side of the continuum (refer to Figure 1 and Table 1). A common characteristic of these encounters was that they were provider driven. Providers initiated and dominated the conversations, asked more closed ended questions, and often interrupted or redirected the patients. They focused on

medical facts using technical terms and jargon, and provided little emphatic or supportive statements. In addition the providers' non-verbal behavior included limited eye contact, closed body position, or sitting or standing at an inappropriate height, angle or direction from the patients. A presence of a majority of these factors lead to coding a section of text as provider led.

Medical information provision and logistics, also on the left of the continuum, shared many of the characteristics of provider led interviews. However in medical information giving the patient had even less input, often being reduced to saying "uh huh" or "ok", while being presented with volumes of medical information. In logistics, the patient was given a set of directions to follow (e.g. go to the lab, then to the x-ray department etc.) over which they had little input. In the patient led medical interview, further to the middle of the continuum, patients asked the majority of questions, however they copied the providers' interviewing style. For example, they asked the doctors closed ended questions and used medical terminology (e.g. Will they be putting in a port? [a devise used to give chemotherapy]). The patient has reclaimed their power in the relationship by leading the medical interview however they are also perpetuating a more traditional interviewing style.

Narrative medicine approaches. Four types of narrative medicine approaches were coded, narrative evoking, narrative co-creation, patient-initiated narrative moments and supportive narratives. On the right side of the continuum, narrative evoking occurred when providers promoted storytelling. This was done by asking open ended questions and then allowing patients to answer without interruption or redirection. The encounters focused less on medical facts and technical jargon, and more about how patients were feeling and coping with their illnesses. The language used was often conversational, empathetic and supportive.

The patients' needs and concerns were addressed and the treatment plans were negotiated between providers and patients. In narrative co-creation this negotiation became collaboration. Narrative co-creation is also on the right hand side of the continuum. Providers and patients discovered together what the next treatments should be; consequently power was shared between them. They each contributed about the same amount of text to the story. In both of these subtypes the providers' non-verbal behavior supported their speech. They had appropriate eye contact, were leaning forward with open body position and were at an appropriate angle and distance from the patient.

A patient initiated narrative moment was somewhat different than the first two subtypes because the patient introduced the story. The patient's story often began in the middle of a traditional provider led biomedical interview, or in between medical topics, often focused on a specific concern. The provider may have joined into the story (narrative co-creation), or the provider may have redirected the patient back to more "pertinent" medical concerns (provider led interview). By redirecting the patient the provider lost the opportunity to explore the patient's story, which often revealed underlying fears.

Supportive narratives were placed more towards the middle of the continuum because they were initiated by the providers. Providers used these narratives to fully address patients' concerns by outlining how they (and their team) could assist patients to cope with their illnesses. This was typically in direct response to patients' questions, or non-verbal cues expressing discomfort with a topic or procedure (e.g. patients had wide open eyes, or had their arms wrapped tightly around their body).

Other Common Elements

Three common elements, in addition to the eight approaches were also observed. In addition to traditional biomedical interviewing or narrative medicine content, nearly all patient-provider interviews contained visual cues, use of humor and understanding checks. A visual cue was a pictorial representation (e.g. drawing, graph, brochure etc.) of the information which was presented verbally by the provider. Humor was used by providers and patients, often after very serious discussions, to lighten the tone of the encounter. Understanding checks were used by the provider to break up sections of the encounter into pieces. The patient was asked a question about their understanding of the previously presented medical data (e.g. "Does that make sense"). This could have presented an opening for a patient initiated narrative moment, however in most cases the patient answered affirmatively and the provider moved to the next topic using an interviewing style.

Patient Recall

Patient recall was affected by type of encounter and became more general over time. Providers discussed 12.5 topics (median) per encounter, so breaks were needed. Despite these breaks the patients only recalled 20.5% of the topics which were presented. They could not recall about 80% of the information. A majority (60-67%) of the topics they remembered were presented in a narrative way, as opposed to in a traditional medical interview format. As time passed the patients remembered less details about specific encounters. The patients then expressed the importance of being able to talk to and ask questions of their providers. They also stressed the importance of the overall tone of the communication. The providers were remembered if they incorporated a more patient-oriented approach into their communication.

Key Implications, Limitations and Future Directions

There are three target audiences for this study, health communication scholars, medical providers and patients. I will address the implications, limitations and future directions focusing on how they apply to each group. As this was an exploratory study, no claim to generalization is made from the data set; however, two finding are clear. Women appeared to remember more medical details when providers utilized a narrative medicine approach. They also had rich recall regarding the parts of the interactions in which they asked a question, which implies that increased patient agency aided in the recall of information. Although patient interviews did not provide detailed richness in terms medical information, the patients in the narrative interactions were able to recall many of the major points of discussion (high similarity with the providers) when interviewed after the encounter. Over time their recall was less specific, but the overall tone of the communication became more important.

The communication continua. By utilizing the continua to code encounters, this study could be replicated by health communication scholars in a larger sample of women with breast cancer. Because the continua were not based solely on research with women with breast cancer, they could also be used to code encounters between providers and people with various illnesses. Different hybrid approaches might be discovered in different settings and with different patient samples.

Patients' information needs. The patient provider transcripts support the fact that medical providers spend a great deal of time explaining minute biomedical details of procedures and potential therapies; however, the patients generally retain only the big picture. Although some of this explanation may be required by informed consent laws,

potentially some of the details could be reduced or omitted in some encounters and

supplemented with written materials patients could read at a later time. The amount of

medical information providers gave to patients was extensive and was present in every

encounter. Although some patients want to be told "everything," others might reach a

saturation point and should be asked if they have had enough. Lovie at one point during her

very long and detailed encounter with the oncologist began to yell. This exchange is toward

the end of the encounter and the research nurse has entered the room.

Dr.:	If you decide you don't want to participate then we still, we're going to continue chemotherapy anyway because that's a standard of care.
Lovie:	Well, I'll take it.
Dr.:	If you feel like you want to be as aggressive with your disease as possible then this is something to consider.
Lovie:	Okay.
Dr.:	But you don't have to make a decision today, without really understanding…, sit down with your family, and make sure that everybody lists down the questions and we'll talk again.
Lovie:	Okay.
Dr.:	I told her I'd be back on the 18th but maybe we should see her next week or something? (to research nurse)
Nurse:	We have to have you done within 84 days of your surgery, and your surgery was on January 27th, so we're getting kind of close to that timeframe. So, what we'll do is we'll bump you up.
Dr.:	What we'll do is we'll keep the appointment for January 18th but she will give you her contact information in case you have decided you want to or…
Lovie:	I WANT TO. I WANT TO. I AM GOING TO DO IT!

At this point, Lovie had reached her decision. Although the providers clearly did not want to rush her into making a decision, Lovie wanted them to know she already had. This was the only time she raised her voice during the entire encounter. Many patients may not feel comfortable interrupting providers, or raising their voice during a visit, so providers need to look for non-verbal cues that patients have reached their limit. From my observations, this may include patients rolling their eyes, closing their eyes, starring into the distance, looking down or placing their head in their hands.

Previous studies clearly show that individual cancer patients have different levels of need when it comes to medical information (Arora, 2003). Field notes, observations and transcripts, attest to an incredible effort to provide comprehensive information to each patient. However, asking women what they want and need might uncover more effective approaches. Further research in this area, conducted by medical and/or communication scholars, could include a questionnaire asking women to identify which part(s) of the medical encounter were most helpful to them, especially in regard to reaching a decision about their treatment. This should be done immediately following the encounter, because recall of specific communication tended to fade over time.

Aiding patient recall. The lack of specific recall of medical topics in this study may be partly due to the fact that 12.5 (median) major topics were introduced during each encounter. In comparison to medical encounters in primary care settings, in which the provider searches for a chief complaint (Beckman & Frankel, 1984), or at most 2-3 issues for discussion (Smith, 2002), visits with new breast cancer patients are much more complex. Health communication scholars could conduct future studies to address whether this is true in other settings where cancer patients are seen (e.g. private clinics).

Due to the voluminous amount of medical data presented to patients, additional memory aides could prove helpful in increasing recall of medical information. For example, while providers used some standard visual aids (reports), they also drew pictures and flowcharts during the encounter that could be created in advance. The surgery team at the Hecurcan Center created a flowchart for that purpose soon after this study ended. The goal for any such aid should be to increase communication and not serve as a substitute for face to face discussion. There is an element of narrative co-creation involved in drawing an individual pathway for the patient, so the provision of paper with some possible pathways drawn on them might be helpful. The patient and provider could then customize a pathway together. The act of drawing places providers in a different state of mind, and may help them to see their patients' points of view in a more holistic way (Younie, 2009).

Addressing patients' unmet needs. Patient initiated narrative moments should serve as a signal for providers that their patients have something important to say which has not been addressed. Providers who listen and keep silent during this time, on average 60 seconds, may then understand the underlying concerns of their patients (Beckman & Frankel, 1984). This is also an opportunity for the provider to evoke more narratives from the patient. Providers may not see this as a cue and may try to regain control by returning to an interview format. Mishler, (1984) notes that the medical interview is biased in favor of a medical interpretation of what is happening. "The pervasiveness of the medical bias in interpretation of medical interviews makes it difficult to propose an alternative perspective, but it is all the more important to do so" (p. 55). By using a more narrative approach providers gain an alternative perspective.

By presenting traditional medical interviewing as a continuum, providers can shift from traditional to narrative strategies depending on patient needs and cues. A strictly narrative approach may not be the best way to communicate with patients in all situations. A patient who has a breast mass may just want to get an opinion from the provider of what the mass might be, and what needs to happen next. The patient's family and friends may have different needs. A worried parent might discuss the situation as a narrative with the provider. Because physicians do not have to use traditional medical interviewing or narrative exclusively, they can combine both techniques as each unique situation arises. This also eases the transition to more narrative approaches for providers who were only taught medical interviewing techniques during their formal training.

Implications for provider training. Current and future providers should be exposed to a range of provider-patient communication interaction types. The continua can be used to address how traditional interviewing and narrative approaches can be combined. The results of this study have already been presented to current staff at the Hecurcan Center and additional trainings are being scheduled with select medical students and residents. Extending training on a continuum of communication approaches to all medical school students affiliated with the Hecurcan Center is a long tern goal of this study. The continuum would include narrative methods, traditional medical interviewing, as well as hybrid approaches

As a member of the breast team, I have already begun to apply more narrative methods in my own practice. I am able to intervene, when a provider misses a narrative cue in the clinical setting. I stop the provider and elicit a narrative from a patient, or assist the provider to move into a more narrative mode when a patient initiates a story.

The importance of emotional connections. The only attribute of the provider communication that patients retained in the long term, was the tone. They remembered positive thoughts and actions. Making a strong emotional connection to a provider has been shown to improve communication (Arora, 2003; Hall et al., 2002; Walker et al., 2001), and this appears to have occurred based on the emotional responses reported during the interviews, and especially in the follow up interviews. Cars echoed the Arora's (2003) finding that providers' communication should support a caring atmosphere. She stated that with her medical providers "I wasn't a number; I was a person to them." Betty remembered her provider's "kindness."

Patients' use of narratives. In this study, patients' used narratives to interrupt providers when they had something important to say by utilizing patient initiated narrative moments. However this type of interruption requires a great deal of agency on the patients' part. Not all patients will speak up, and sometimes over, their providers. When patients are invited to ask questions, for example during understanding checks, they often miss the opportunity to have their needs addressed. Although it is easier for patients just to say "No" to the provider's statement "Do you have any questions so far?" it may not be in patients' best interests to miss an opportunity to express their concerns. Providers need to ask more open ended questions, such as "What else would you like to discuss at this point?" Patients can then respond narratively to any concern that they have, whether it relates to the previous discussion or not. This takes the burden of remembering and using correct medical terminology off of the patient. Although patient-led traditional medical interviewing was found in this study, it requires substantial agency on the part of the patient. Patients need to learn correct medical terms and how to apply them to their situations. They must also be

willing to lead the interview. Neither of these is required in a narrative format. Patients' can be taught to recognize these understanding checks as opportunities to have their underlying concerns addressed by the providers.

Patients' evaluations of provider narratives. A woman diagnosed with cancer faces a long and complex journey through the medical system. There are many ways in which her possible paths are presented by providers. What is most interesting is not how many of the treatment decisions which were discussed in these encounters actually occurred, but for what reasons. Cars, who said she would never accept chemotherapy at her first visit was convinced by her second visit, by her oncologist, that she, in her circumstances, needed chemotherapy. She was not convinced about the need for radiation treatments and did not have any. Franny ultimately decided not to continue to take Femara (a hormone blocking medication used her prevent breast cancer re-occurrence) because the medication caused her to have severe joint pain, that affected the quality of her life too much.

The bottom line is that patients are making narrative decisions about what treatments they will accept. They do not have the technical expertise of 14 years of medical training to guide them, nor can many hours of explanation provide them with this. They are making decisions based on narrative fidelity, or how well a story appears to be true based upon their experience, and narrative coherence, or how well the story is constructed and is like other stories in their life (Fisher, 1987). Why then don't providers emphasize creating a better story? The heart of the matter has to do with prior training and power sharing. Providers have to be willing to co-create stories with their patients, and the systems that they work in need to support their decisions.

This study sheds light on the complex needs of women with breast cancer and ways to improve communication. Patients ultimately decide what treatments they will accept and what they will decline. Providers are experts, but need to act more as guides, as wise storytellers and compassionate listeners.

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Appendices

Appendix A

Demographic Information Collection Tool and Interview Guide

(Nelson, et al., 2004)

(All the questions have don't know or refused options)

1. What is your age? _____

2. What is the highest grade or level of schooling you completed?
    ☐ Less than 8 years
    ☐ 8 through 11 years
    ☐ 12 years or completed high school
    ☐ Post high school training other then college (vocational or technical)
    ☐ Some college
    ☐ College graduate
    ☐ Postgraduate

3. Are you Hispanic or Latino?
    ☐ Yes
    ☐ No

4. Which one or more of the following would you say is your race?
    ☐ American Indian/Alaska Native
    ☐ Asian
    ☐ Black/African American
    ☐ Native Hawaiian/other Pacific Islander
    ☐ White
    ☐ Other: _____
    ☐ Prefer not to answer

5. What is your combined annual household income?
    ☐ $0 - $9,999
    ☐ $10,000-$14,999
    ☐ $15,000-$19,999
    ☐ $20,000-$34,999
    ☐ $35,000-$49,999
    ☐ $50,000-$74,999
    ☐ $75,000-$99,999
    ☐ $100,000 to $199,999
    ☐ $200,000

Appendix B

Semi-Structured Interview Guide

1. Opening statement of introduction by researcher

2. Verbally explain consent (voluntary nature of project, right to refuse to answer any question, to stop at any time, their responses are confidential and not linked to their demographic information etc.)

3. Imagine you are back in the room with your doctor …

4. Tell me whatever you can remember about the conversation you just had with your doctor.

   4a. Probe: What did he/she want you to do?

   4b. Probe: What do you recall about how he/she described your situation?

   4c. Probe: Give me some examples

5. Was it easy to talk to the doctor about your concerns?

   5a. Probe: What concerns or questions did you talk about with your doctor?

   5b. Probe: How well were your questions answered or concerns addressed?

6. How would you describe the interaction between your doctor and yourself?

   6a. Probe: How did you feel about it?

   6b. Probe: How well do you think it went?

7. Thank participant

8. (As needed) Stop recording

9. Answer any specific patient questions utilizing appropriate staff members