Understanding Patients' Voices

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Understanding Patients' Voices. A multi-method approach to health discourse
by Marta Antón and Elizabeth M. Goering

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A multi-method approach to health discourse

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Acknowledgements

Introduction*

This book stems from a multi-year study of disease management among people living with diabetes that was conducted by an interdisciplinary research team at the International Center for Intercultural Communication (ICIC) at Indiana University Purdue University Indianapolis (IUPUI). The book consists of a collection of articles that serve as a model for the interdisciplinary study of the relationship between language use and chronic disease management. The primary objective of this collection is to present the research team process from conceptualizing the project to collecting and analyzing the shared data set using a variety of methodological approaches.

The goal of the book is three-fold: to illustrate the application of particular research methods that can be fruitfully applied in the study of health discourse, to share research findings that enhance our understanding of the role of language in chronic disease management, and to highlight considerations related to working in interdisciplinary teams and translating research into practice in diverse cultural settings.

The volume is organized in three parts. Part I describes the research design process including the conceptualization of the research goals framed by the literature on health discourse and chronic disease management, as well as a detailed account of the methodology deployed for data collection. Part II contains five chapters illustrating different approaches to the analysis of the data. Each of these chapters presents a general introduction to a specific methodology or methodological approach, along with a research project that applies that method to our shared data set, analyzes the benefits and limitations of that methodology for the study, and provides recommendations for future application of the methodology in health related research. In addition to the chapters that illustrate specific methodologies in practice, Part III consists of three chapters that explore macro-level issues related to conducting interdisciplinary, multicultural health discourse research and translating the research findings into practice. By including

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*   Chapters with no authors listed were written by the primary authors of this book, Elizabeth Goering and Marta Antón, and represent the work of the interdisciplinary research team at the International Center for Intercultural Communication (ICIC) at Indiana University Purdue University Indianapolis (IUPUI).

the complete sequence of the research, from conceptualization to practical application and adaptation to other contexts, this collection provides a holistic overview of the research process, hopefully opening the doors for others to approach the study of health discourse from a variety of disciplinary and methodological perspectives.

In recent years, there has been growing interest in the study of health discourse, and this collection adds to the increasing body of literature that examines health discourse from a linguistic perspective. Previous books in this field of study have focused on doctor-patient interaction (e.g., Ainsworth-Vaughn 1998; Hunter 1991; von Rafler-Engel 1989), illness narratives (e.g., Charon 2006a; Frank 1996; Hawkins 1993) or particular illnesses and medical conditions (e.g., Capps and Ochs 1995; Edwards 2005; Goodwin 2003; Hamilton 1994; Higgins and Norton 2010; Stommel 2009). Gwyn's (2002) book on communicating health and illness offers an introduction to the use of discourse analysis in such studies. Chapters on topics such as body, disease, and discourse, lay talk about health and language, power in medical encounters, the media and health scares, metaphors of sickness and recovery, and narratives in voicing illness synthesize knowledge for readers from a variety of disciplines. The current state of the field is presented in a recent handbook on language and health communication (Hamilton and Chou 2014), which summarizes linguistic contributions to health communication research in areas such as patient-provider communication, the role of technology, authentic interaction in health contexts, and health narratives.

Other work has taken a critical theoretical stance to the study of language and health. Ramanathan's (2010) book, *Bodies and Language. Health, Ailments, Disabilities*, applies feminist and other philosophical perspectives to understanding patient and caregiver perspectives to chronic and terminal conditions. Personal accounts and experiences of patients with cancer, diabetes, and epilepsy are probed. Caregiver perspective is used in understanding Alzheimer patients and autistic patients. McPherron and Ramanathan's edited collection, *Language, Body and Health* (2012) continues in the tradition of critical theory drawing from several discourse frameworks (i.e., biomedical, societal, poststructuralist, autobiographical) to analyze "language-related issues concerning chronic and terminal ailments."

Conversational analysis has been used as a method to study language in health contexts in some work on health discourse. For example, Heritage and Maynard's edited collection, *Communication in Medical Care: Interaction Between Primary Care Physicians and Patients* (2006), provides a comprehensive treatment of the analysis of medical encounters, i.e. patient – healthcare provider interactions.

The collection of articles in our book stems out of a research study with the overall goal of examining the relationship between language use and chronic

disease management by looking at how health literacy and psychological constructs such as locus of control, agency and affect are expressed through language in patients' talk. The shared data set that forms the foundation of this book was collected as part of a multi-year, grant-funded study on chronic disease management among people living with diabetes. The study, carried out by the ICIC at IUPUI, was conducted by an interdisciplinary research team with participants with expertise in linguistics, communication studies, sociology, and endocrinology. In-depth interviews with 43 English-speaking subjects and 22 Spanish-speaking subjects provided the data for the study. For this book, members of the research team were invited to write chapters that highlight the application of a particular methodological approach to the data or show applications and adaptations of the research findings. The book contributes to the field of health discourse in three ways: (a) it illustrates and integrates multiple methodologies that can be used to theorize language use in health discourse; (b) the research is interdisciplinary, bringing together the strengths of joint expertise in language, communication, and health disciplines; and (c) the focus of the book is on patients' voices.

A main distinctive feature of the work presented here is the use of multiple methodologies to analyze the language used by people living with a chronic disease such as diabetes. A common criticism of research on medical encounters is that it is atheoretical about language (Ainsworth-Vaughn 2001). The collection of essays in this book lays the foundation for theorizing the linguistic features of patient talk. In addition, the chapters illustrate the potential of a wide range of methods in the study of health discourse, and they provide examples of those methods in practice. This line of research is rooted in the assumption that if one were able to codify the linguistic features of patient talk, one would be a step closer to identifying linguistic patterns associated with effective or ineffective disease management. Identifying the linguistic patterns that characterize individuals who are effectively managing their disease, as well as patterns that indicate problems with disease management would, indeed, be a valuable tool for healthcare providers. This volume introduces and illustrates five different methodological approaches. The purpose is not to compare these methodologies, but to show how they can be usefully applied in this effort.

Another unique feature of this project is its focus on patients' voices rather than the voices of healthcare providers. Past research has been criticized for typically focusing on the perspective of the healthcare professional rather than on the person living with a health issue (Vermeir, Hearnshaw, Van Royen and Denekens 2001). As a result, the provider's voice, or the voice of medicine, takes precedence over the voice of the patient's lifeworld (Hamilton 2001). In contrast, this book systematically examines the language used by patients as they describe, through in-depth interviews, their experiences living with chronic disease.

A final distinctive feature of this book is its interdisciplinary, multicultural, and translational scope. From conceptualization to data collection to data analysis, the project has been carried out by a team of researchers from a variety of disciplinary backgrounds. The book highlights insights that can only be gained by synthesizing multiple disciplinary perspectives. In addition, we have included chapters that analyze and explore the practical issues associated with working as an interdisciplinary team, adapting the research design to multicultural contexts, and translating research findings into practical interventions.

As mentioned above, the book is divided into three parts. Part I consists of two chapters. The first chapter presents an overview of health discourse and chronic disease management, reviewing the literature that approaches chronic disease management from linguistic and health discourse perspectives in order to establish the value of exploring disease management using linguistic methodologies. Chapter 2 describes the methodology developed for collecting data for this study and introduces the data set that is analyzed in each of the other chapters in Part II. The data set consists of transcribed in-depth interviews conducted with 43 English-speaking (ES) and 22 Spanish-speaking (SS) individuals living with type 2 diabetes. In the interviews, open-ended questions were used to elicit life story information about living with diabetes. In addition, interviewees were asked questions about medication adherence, sources of information used to help manage their disease, literacy levels, and basic demographic information. This chapter does not address methods of data analysis, which were varied and will be appropriately described in each of the chapters in the second part of the book.

Part II includes five chapters that showcase the use of various methodologies to approach health discourse data. Chapter 3 illustrates the use of statistical analyses in the study of health literacy and patient talk. Traditional statistical methods often are inappropriate for analysis involving the discrete variables and smaller sample sizes that are typical of qualitative research. However this chapter introduces ordered probit modeling, a non-linear estimator that can be applied to ordinal dependent variables and is useful for merging findings from discourse analysis into a multivariate model of adherence for people living with diabetes. Variables related to general literacy, health literacy, age, income, patients' expression of agency, and patients' expression of affect are found to be significantly associated with adherence. When these associations are combined into a multivariate model, profiles of more adherent and less adherent diabetics emerge. The multivariate model produced through this analysis suggests that an individual who is younger, has a lower income, and uses language that expresses more dissatisfaction and insecurity may be more likely to be less adherent. Identifying profiles such as this and specific patterns of language use that may serve as indicators of

successful management are useful tools in optimizing care for people living with diabetes.

The next chapter (4) illustrates the application of corpus-based methodologies within the study of health discourse. For this study, the interviews were treated as a linguistic corpus and processed following the procedures that are considered standard in corpus-based text analysis. The focus of this chapter is the comparison of the linguistic features of the language used by adherent versus non-adherent subjects. In other words, the study sought to identify the linguistic markers of the propensity to healthy action by patients. To assess this, the texts were separated into adherent and non-adherent groups using self-reported adherence measures. Two-sided T-tests were used to test for significant differences in the means between the two groups for each of the linguistic features counted. The results revealed statistically significant differences in the use of second person pronouns and possessive determiners, first person pronouns and possessive determiners, present progressive, subordinating conjunction-causative, passive post nominal modifiers, and Wh-pronoun-relativizer-with gap in the object position. As a second step, a functional analysis of these linguistic features in the contexts in which they occurred when used by these two groups of patients was conducted. The results of this analysis yielded important differences in the ways in which these patients used language to portray themselves as belonging to these groups. Further implications of these differences in patient talk are explored, and possible applications of the methodology in similar research are discussed.

Chapter 5 applies metaphor analysis to data from patients' interviews. Metaphors have long been recognized as a primary way in which we come to understand the unknown. Using metaphor analysis, this chapter examines the meaning-making associated with diabetes by providing a step-by-step explanation of the process of metaphor analysis, and then applying that process in an exploration of metaphors related to living with type 2 diabetes. The results identify categories of metaphors patients use to talk about: (1) diabetes as a disease, (2) the reasons a person gets diabetes, and (3) what it is like to live with it. In addition, the study compares the metaphors used by patients who are managing their disease effectively and those who are not.

Chapter 6 analyzes patient interview data using sociocultural theory and activity theory as a framework to interpret agency in self-management of diabetes from an ecological perspective. Individual agency in health self-care cannot be detached from the individual historical and cultural trajectories of patients. It is important for healthcare providers to know more about the context surrounding patients' lives. This chapter analyzes linguistic and content cues about a patient's agentive behavior towards diabetes self-management in life-story narratives. A

sociocultural approach towards the study of agency in health care gives voice to patients and highlights the role of contextual and culturally localized mediation by the healthcare providers, as well as the patients' reciprocity to the actions and resources put forth by the healthcare system. First, grounded theory analysis produced a taxonomy of the linguistic expressions used by our participants to denote degrees of agency in managing the disease. Then the themes that emerged in our patients' stories as facilitating or constraining agentive behavior towards managing diabetes are discussed from a sociocultural perspective. In particular, we highlight the individuality of patients' stories and the role of previous personal experience with the disease, personal outlook on life, the experiences of others (family and friends), access to health care in their native language, and the perceived importance of the disease within the context of the patients' daily lives.

The following chapter exemplifies contrastive methodologies. Chapter 7 focuses on health literacy and use of health information sources by Spanish and English-speaking patients. An important part of managing a chronic disease is having access to and understanding necessary and culturally appropriate information. Yet, health information fails to reach many Latinos. Limited health literacy has been associated with less primary prevention and poor health outcomes. This chapter argues that understanding health literacy, particularly in the case of ethnic minorities, requires complementary approaches. Data from semi-structured interviews, including survey questions, life-story narratives and reading comprehension tests, are used to describe English-speaking (ES) and Spanish-speaking (SS) diabetic patients' perceptions of sources of health information, to identify the actions patients report taking in seeking health information, and to test reading comprehension of medical information among SS patients. These three approaches to health literacy reveal disparities in access and use of information sources, as well as disparities in reading comprehension of health information. The results from the present study show that a multi-method approach to understanding which information sources patients value and use and how they process the information provides a deeper understanding of the role of health information for different ethnic groups. Practical implications for informed interventions to narrow the gap in accessing and understanding sources of information among ethnic minorities are discussed.

Part III collects three chapters that explore the interdisciplinary and translational aspects of the research project. Chapter 8 examines the challenges involved in adapting the methodology of this study for use in other cultural contexts. The original research project included both native English speakers and native Spanish speakers, and issues involved in adapting data gathering and data analysis tools across those two populations are discussed. A follow-up study has involved replicating the methodology in China, and the complexities faced in that process are

also explored. Chapter 9 explores potential applications of the research findings in the practice of providing health care for people living with diabetes. Finally, Chapter 10 reflects on the experience of working on a major, grant-funded health communication research study as an interdisciplinary team and provides practical recommendations for facilitating successful interdisciplinary collaboration.

When taken together, these chapters provide a sampler of a variety of quantitative, qualitative, and contrastive methods that have considerable potential in the study of health discourse and offer practical guidelines on conducting interdisciplinary team research on health discourse in multicultural settings. In addition, the findings provide useful insights into chronic disease management.

Research design

CHAPTER 1

Health discourse and chronic disease management
An overview

Elizabeth M. Goering and Marta Antón

1. Chronic diseases: A global challenge

The World Economic Forum and Harvard School of Public Health released a report in 2011 that highlighted the human and societal costs of chronic diseases. According to that report, non-communicable diseases, most notably cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes, account for 63% of all deaths and 48% of "healthy life years lost" worldwide (Bloom et al. 2011, 7). In addition, the report estimates that over the next 20 years, these diseases will cost the global economy more than $30 trillion along with a "cumulative output loss" of $47 trillion (Bloom et al. 2011, 6). While the numbers can be overwhelming, the encouraging news is that these chronic diseases can be prevented and managed. Many of the risk factors associated with these diseases are controllable, and many of the complications faced by people living with them can be avoided through proper treatment and preventive care. Consequently, a key to reducing the personal and societal impacts of non-communicable diseases is facilitating the management of chronic conditions.

This research focuses on one particular chronic condition: diabetes. According to the Centers for Disease Control (2011), 18.8 million people in the United States have been diagnosed with diabetes, and an additional 7 million cases are undiagnosed. The International Diabetes Federation (2010, para. 4) argues that "diabetes is a leading threat to global health and development," and it estimates that worldwide more than 300 million people are affected by diabetes. Diabetes is an appropriate focus for this study not only because of its prevalence, but also because it is a disease for which there is considerable agreement within the medical community about how best to manage it. Therefore, diabetes is well-suited for a study on discourse and chronic disease management.

2.   Chronic disease management

Over the past 50 years, considerable research has focused on chronic disease management. According to Charmaz and Olesen, over the decades, the study of chronic illness has "moved through three significant foci" (1997, 458): interactions between patients and providers, coping with practical problems associated with chronic illness, and the subjective experience of living with chronic disease. This research utilizes a variety of labels, including compliance, adherence, disease management, self-management, and self-care. Much of the early research used the term "compliance" (e.g., Bower and Taylor 2003; Burgoon et al. 1990; Frankel and Beckman 1989; Haynes 1979; Klingle and Burgoon 1995; Moisan et al. 2002; Morris and Schultz 1992, 1993; Parrott, Burgoon, and Ross 1992; Raynor 1992), a term that implies that the medical community is in the best position to describe appropriate treatment regimens, while the patient is expected to "comply" with directives from healthcare providers.

Because of its problematic focus on the binary relationship of expert vs. novice and its conceptualization of knowledge as something discrete that can be possessed and passed on by authority figures (Martins 2005), the use of the label "compliance-gaining" has diminished, and many researchers now prefer the term "adherence" (e.g., Becker 1985; Dunbar 1998; Dunbar-Jacob and Schlenk 2001; Jackson 1994; Knecht 2000; Murray et al. 2004). Knecht (2000, 18–19) articulates the distinction between the two terms as follows: "The terms 'compliance' and 'adherence' should be distinguished, because compliance means only strict observance of instructions, while adherence refers to more flexible self-care and control of situations." The term "adherence" does seem to recognize that knowledge is not something held by experts and transferred to patients; rather, the label implies that knowledge is dynamic, contextually-based, and produced through meaning-making practices involving healthcare providers and patients alike (Martins 2005). Furthermore, the label takes into account "intelligent noncompliance" (Weintraub 1981) on the part of some patients.

While the term "adherence" seems to be a more appropriate label than "compliance," there is some resistance even to the use of that term, particularly related to chronic illnesses, because of the unique position of the individual living with a condition such as diabetes. Research shows that adherence rates for chronic conditions are generally lower than for short-term medical regimens (Klingle and Burgoon 1995) and, indeed, making sense of and responding appropriately to treatment recommendations over the life cycle of a chronic illness is obviously very different from "adhering" to directives related to an acute illness. Consequently, alternative terms, such as "self-management" (Erdem and Korda 2014;

Forjuoh et al. 2014; Helduser et al. 2013; Lorig et al. 2013; Thomas and Bryar 2013) and "self-care" (Kickbusch 2004; Knecht 2000; Pryor and Mengle 1987; Sakraida and Robinson 2012) have been offered as substitutions for describing the situation of individuals with chronic illnesses. These terms clearly imply a different balance of power between healthcare providers and patients than either adherence or compliance, and they acknowledge that living with diabetes is an ongoing process. A U.S. government report defines chronic disease management this way:

> Through a combination of enhanced screening, monitoring, and education; the coordination of care among providers and settings; and the use of best medical practices, disease management seeks to identify chronic conditions more quickly, treat them more effectively, and thereby slow the progression of those diseases.
>
> (Congressional Budget Office 2004, 1)

Much of the current research in self-management of diabetes focuses on the development and assessment of self-management programs designed to prepare people living with diabetes to take control of all aspects of their chronic disease management, to provide them with the knowledge "to care for oneself and the ability to make treatment related decisions, monitor symptoms, set goals, and develop successful relationships with health care providers" (Sakraida and Robinson 2012, 787). Some of the key themes explored in this body of research include the relationship between technology and self-management (Ruston, Smith, and Fernando 2012), health literacy and self-management (Sakraido and Robinson 2009), the assessment of particular self-management programs (Forjuoh et al. 2014; Lorig et al. 2013; Thomas and Bryar 2013), and the exploration of factors that affect participation in and completion of self-management programs (Erdem and Korda 2014; Helduser et al. 2013).

Even within these conceptualizations, however, is the assumption that there are preferred, medically-sound ways of living with chronic diseases such as diabetes, and an individual who desires to successfully manage his/her diabetes should do certain things while avoiding others. Consequently, for our purposes, "chronic disease management" is conceptualized as a combination of knowledge and adherence. A person living with a chronic disease can only manage that disease if s/he knows what "best medical practices" related to the disease are and follows or adheres to those recommendations.