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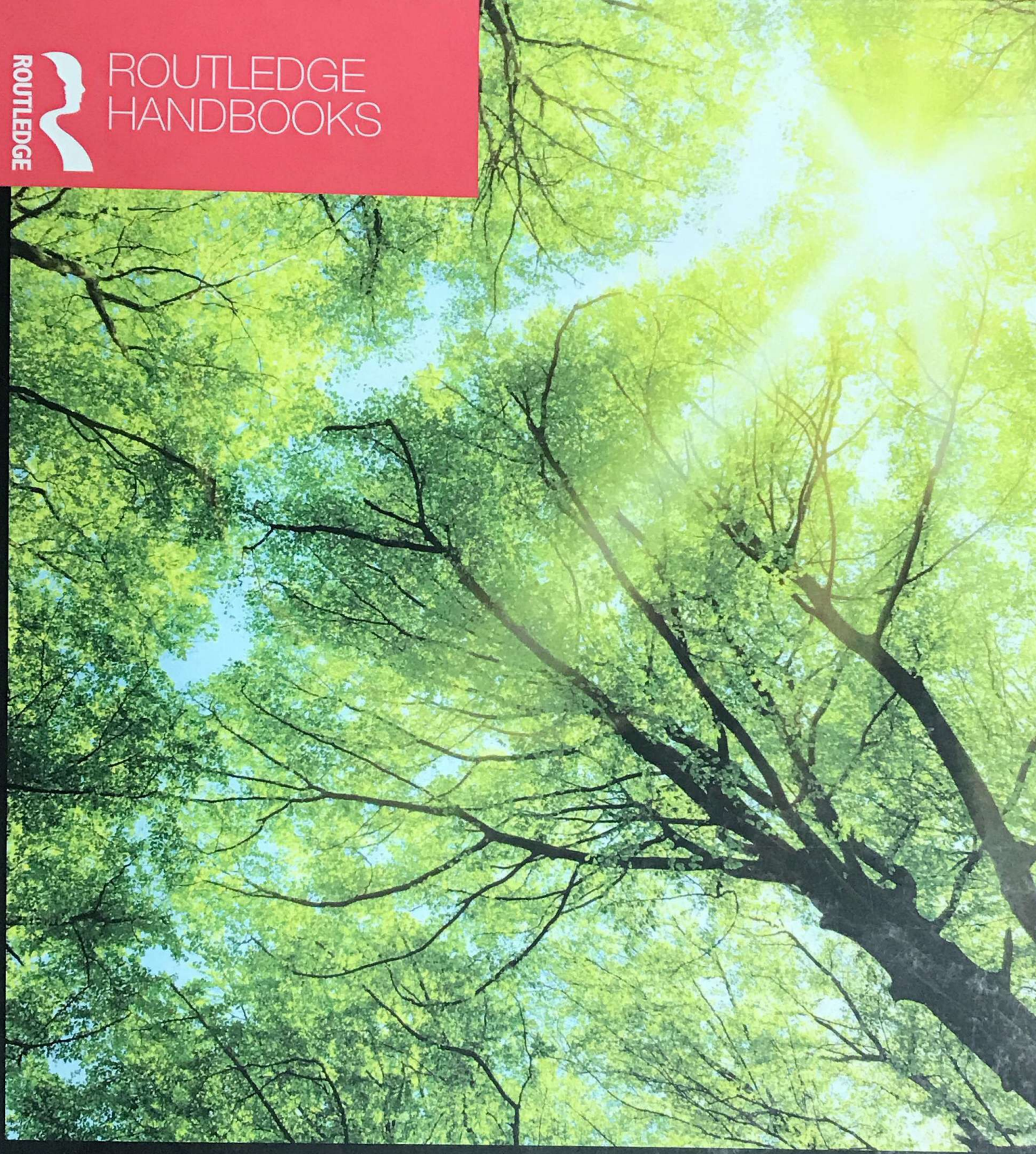


The Routledge Handbook of Language and Health Communication

Edited by Heidi E. Hamilton and Wen-ying Sylvia Chou

First published 2014
by Routledge
2 Park Square, Milton Park, Abingdon, Oxon OX14 4RN

and by Routledge
711 Third Avenue, New York, NY 10017

Routledge is an imprint of the Taylor & Francis Group, an informa business

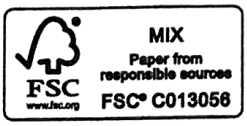
Aaron Cicourel's chapter is reprinted with permission from Alessandro Duranti and Charles Goodwin (eds). 1992. *Rethinking Context: Language as an Interactive Phenomenon*, 291–310. Cambridge University Press.

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

Library of Congress Cataloging in Publication Data
The Routledge handbook of language and health communication /
edited by Heidi E. Hamilton and Wen-ying Sylvia Chou.
pages cm. – (Routledge handbooks in applied linguistics)
1. Communication in medicine. 2. Medicine--Terminology. 3. Applied linguistics.
4. Therapist and patient. I. Hamilton, Heidi Ehernberger, editor of compilation.
II. Chou, Wen-ying Sylvia, editor of compilation.
III. Title: Handbook of language and health communication.
R118.R68 2014
610.1'4--dc23
2013023481

ISBN: 978-0-415-67043-2 (hbk)
ISBN: 978-1-315-85697-1 (ebk)

Typeset in Times New Roman
by Saxon Graphics Ltd, Derby



Printed and bound in Great Britain by
TJ International Ltd, Padstow, Cornwall

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A linguistic analysis of diabetes patients' talk

Reported adherence to healthy behaviors

Ulla Connor and Kathryn Lauten

Introduction

Non-adherence to prescribed medication and healthy behaviors is a pressing issue in today's healthcare system. Much research has been conducted in this area under a variety of labels, including *compliance, disease management* and, most recently, *adherence.* In an effort to better understand adherence, researchers have examined a wide range of variables, including psychological characteristics, health beliefs, and demographic information. The extensive literature is summarized in several excellent review articles. Rather than offering an additional review of the adherence literature in this chapter, we refer readers to van Dulmen et al. (2007).

In spite of the extensive research, factors related to predicting and explaining adherence remain elusive. Several possible explanations exist for this lack of powerful predictors. A frequently expressed concern is that research typically examines adherence from the perspective of healthcare professionals rather than from the perspective of people living with a particular health issue. In response to this concern, van Dulmen et al. (2008) have called for patient perspectives to be included in future research.

In this chapter, we present a study in which linguistic analysis was applied to patient life stories to provide a better understanding of patient-level factors related to adherence. Over the past four decades, researchers have examined a wide range of variables in an effort to better understand adherence. Drawing from health literacy and adherence research, we base our linguistic analysis on three psychosocial constructs consistently included in the literature: *control orientation*, based on locus of control research (Wallston et al. 1978); *agency*, based on self-efficacy (Bandura 1977); and *affect* or attitude and emotion (Martin and White 2005). By transforming these constructs into linguistically definable features and developing analytic systems to describe them, we offer researchers and caregivers new ways of understanding patient narratives. Through the analysis of patient talk, our research addresses the need to connect psychosocial constructs of adherence defined through a linguistic methodology and extensive research on health literacy and outcomes. In the rest of the chapter, we will discuss the state of the research in health literacy, as well as in adherence, followed by our research methods and analysis of patients' life story data.

Health literacy

Healthcare researchers are using multiple methods to investigate a variety of health literacy topics. A significant boost to the study of health literacy in the US came from the Institute of Medicine (IOM) 2004 Health Literacy report, which defined health literacy as 'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions' (32). This is based on an individual's skills with health contexts, the healthcare system, and the education system, as well as social and cultural factors at home, work, and in the community.

Edwards et al. (2009) provide a meta-synthesis of the literature and propose a model of information seeking/giving that leads to an empowered patient. Their model points to the importance of other types of literacy beyond functional literacy, namely *interactive health literacy* and *critical health literacy*. Interactive health literacy involves the social and personal skills that enable individuals to derive meaning from different kinds of communication and apply it. Critical health literacy entails advanced skills used to critically analyze information and to control life events. According to Edwards et al. (2009), poor health literacy is associated with decreased ability to participate in shared decision-making.

Numerous studies have documented the difficulties that patients with low health literacy levels have reading labels on pill bottles, understanding patient information leaflets, reading educational materials, and understanding informed-consent forms (e.g., Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs 1999; Doak et al. 1996; Gazmararian et al. 1999; Mayeaux et al. 1996). Research has also shown that poor health literacy is more common among patients who have low educational levels, as well as among immigrants and older patients (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs 1999). Functional health literacy has been related to poor oral comprehension among patients, particularly in the technical, explanatory dimensions of clinician–patient dialogue (Schillinger et al. 2004). Subsequent research has tested intervention strategies for more effective physician–patient intervention in communication by using regular comprehension checks (Schillinger et al. 2003).

In sum, the existing research points to a strong relationship between patients' literacy skills and how much they know about their disease; there is a clear connection between the ability to obtain information and turning that information into knowledge. This suggests a direct pathway for the development of literacy skills and health management. Patients who know how to access information about complex health issues should be better able to take care of themselves. Yet, research results indicate that additional skills, such as speaking and listening, need to be made part of health literacy.

Our linguistic discourse analysis of patient life stories contributes to an expanded notion of health literacy that considers speaking and listening and their complex interactions with certain psychosocial variables. These two foci – health literacy and psychosocial constructs – are charted in our health outcomes framework, known by the acronym PLAIN Health. The components of this working model are the *Process* of turning information into knowledge, *Literacy* (in its more common definition of reading and writing ability), the capacity to turn knowledge into *Action* (encompassing control orientation, agency, and affect related to health behaviors toward adherence and good health outcomes), *Intercultural/Interactive communication* with healthcare providers, family and friends, and *Numeracy*. The term PLAIN Health highlights factors with the most impact in this arena and reinforces the call to use more 'plain language' in communications with patients.

Adherence and psychosocial variables

To better understand both the *Process* of turning information into knowledge and the way that knowledge gets turned into *Action*, our team recognized the importance of integrating a linguistic system for coding psychosocial constructs of health behavior into the working PLAIN Health model, as psychosocial constructs have consistently proved relevant in other health behavior and adherence research. Linguistic indicators were thus identified for the three constructs that have been studied extensively in relationship to health behavior: *control orientation*, *agency*, and *affect* or attitude and emotion. Studies have shown that none of these constructs individually can account for adherence. Rather, their interaction must be studied within specific disease states (O'Hea 2003). By transforming these constructs into linguistically definable features and developing an analytic system to code them, caregivers will have new ways of understanding patient narratives, as well as an adaptive system to apply to open-ended questions about health management.

Control orientation

One of the most studied psychological constructs related to adherence in chronic diseases is locus of control (LOC). According to Rotter (1966), who introduced LOC as a psychological construct within his Social Learning Theory, a person who perceives an event as 'following some action of his own but not being entirely contingent upon his action' (1) is said to have *external* control, while a person who perceives an event as 'contingent upon his or her own behavior or relatively permanent personal characteristics' (1) is said to have *internal* control.

Rotter's seminal theories on LOC were later applied to healthcare and renamed Health Locus of Control (HLOC) (Wallston et al. 1978). In spite of the considerable research on HLOC and medical adherence, most studies report only moderately significant relationships between these two variables. Some suggest that the inconsistent findings may be, at least partly, the result of the surveys used to measure LOC.

One way to address these problems is to seek indicators of HLOC in the discourse of people with diabetes rather than through surveys. An inherent problem in survey research is the potential for social desirability bias; that is, respondents try 'to answer as "good" people "should" rather than in a way that reveals what they actually believe or feel' (Vogt 1999: 268). A patient's naturally occurring talk is less likely to be tainted by such bias. Thus, identifying specific linguistic features of control orientation that occur in responses to open-ended questions should provide an expanded framework for studying the relationship between control orientation and diabetes management.

Agency

Agency has been defined as the 'capacity to make a difference' (Castor and Cooren 2006: 573). Several researchers (e.g., Glasgow et al. 2001; Hadjistavropoulos and Shymkiw 2007) have attempted to identify the factors affecting individuals' health-related agency, or their ability to take actions that facilitate the self-management of chronic health conditions. Many have focused specifically on the management of diabetes (e.g., O'Hea et al. 2009; Wangberg 2007). Our use of the term agency, based on an individual's actual actions, is closely related but not identical to self-efficacy, which is based on one's *belief* in the ability to do what is needed to attain an outcome (Bandura 1977). Both agency and self-efficacy are concerned with a person acting positively in order to improve his or her health.

As with control orientation, the most common measures of agency and self-efficacy have been surveys (e.g., Anderson et al. 2000; Bandura 1977). We maintain, however, that the actual words of patients living with diabetes may contain more accurate indicators. Therefore, identifying specific linguistic features of patients' actions can provide a useful framework for expanding the study of the relationship between agency and diabetes management.

Affect

The expression or suppression of affect or emotions in relation to coping with illness, especially terminal illness, has been studied from numerous perspectives, perhaps most frequently in psychology (e.g., Keeling et al. 2012; Boinon et al. 2011; Schuettler and Kiviniemi 2006; Petticrew et al. 2002). While this research suggests that there is indeed a relationship between the expression of emotion and disease management, there have been relatively few studies that focus specifically on the role affect plays in adherence to treatment and self-care recommendations for chronic diseases such as diabetes.

To our knowledge, there has not been a systematic linguistic analysis of affect, although a subcategory of Martin and White's (2005) Appraisal Theory provides a linguistic system for its analysis. Because of the comprehensiveness of Martin and White's Appraisal Theory and its validation through empirical testing in other discourses (e.g., Hood and Forey 2008), we place it as the foundation of our analysis of the role of affect in patient accounts about living with diabetes.

Research methods and data

The data on which we report here came from an investigation of adherence among people with diabetes that was conducted by an interdisciplinary research team at the Indiana Center for Intercultural Communication (ICIC) at Indiana University-Purdue University Indianapolis (IUPUI) consisting of linguists, communication studies specialists, sociologists, and an endocrinologist. In-depth interviews were conducted with 43 English-speaking subjects and 22 Spanish-speaking subjects living with diabetes in the Indianapolis area. The data presented here are for the English-speaking interviews only. Of those, 21 were male and 22 were female. Twenty-three were non-Hispanic white, 15 were non-Hispanic black, one was Hispanic, and four classified themselves as Other. The mean age was 51.2 years, and the mean duration living with diabetes was 7.6 years.

The interviews had two sections. The first consisted of several questions asked to elicit life story information from the patients. Subsequent segments of the interview included questions about medication adherence, information sources and use, and health literacy level, as well as basic demographic information. The length of the transcribed interviewee talk on the open-ended questions section ranged from 608 to 11,274 words. The mean number of words was 3,055 (standard deviation 2212.03) words.

The three psychosocial constructs (control orientation, agency, and affect) were identified through analysis of patients' responses to 14 questions about diabetes and its management such as, 'In what ways has your thinking changed regarding diabetes since you were first diagnosed?' 'What do you do to manage your diabetes?' and 'Have you ever had any difficulties communicating with your provider? If so, please explain.' In addition, there were four questions about life decisions at the time of high school graduation, such as 'How did you end up doing what you did after high school?'

The initial coding systems for control orientation and agency were developed using six randomly selected transcripts. The coders carefully read the sample transcripts, making gestalt assessments of the variable that had been assigned to their team (i.e., high, medium, or low agency; internal vs. external control orientation) and highlighting specific phrases in the transcript that represented their assessments. The coders compared the individual coding of the six sample transcripts. The degree of agreement among individuals on the gestalt coding was computed as an indication of intercoder reliability. The percentage of agreement was 87.5 percent for agency and 94.5 percent for control orientation. This level of intercoder reliability was deemed acceptable, and coders then turned their attention to the linguistic instantiations of each construct. The system developed by the research team was applied to the remaining transcripts.

The affect analysis started from an existing framework and took a slightly different path. Six coders analyzed sample transcripts using the coding guidelines from Martin and White's (2005) Appraisal Theory. The group then came together and discussed the appropriateness of the guidelines for this dataset, as discussed in the 'Coding analysis of affect' section below.

Coding analysis of control orientation

After the gestalt assessment of internal vs. external control orientation, a linguistic feature system was compiled to distinguish internal and external patient talk. These linguistic features include semantic roles (i.e., agent for internal; patient, recipient, and beneficiary for external), metaphors, idioms, characterizations of self, claims of knowledge or ignorance, and the use of vague vs. detailed language. These particular features were found to be the most prominent linguistic factors between subjects with internal and external control. A list of features appears in Table 6.1 with relevant examples extracted from the data. A detailed explanation of each feature category is given in Connor et al. (2012).

Coding analysis of agency

The linguistic realizations denoting a subject's agency were also identified. Agency was operationalized as the degree of action the patient reported taking vis-à-vis adherence to current diabetes regimen recommendations.

In the first round of analysis, a subject's gestalt agency was analyzed (i.e., without consideration of the type of action taken or not taken). In this preliminary analysis, the subject received one agency score in a tripartite system of *high*, *moderate*, or *low* agency. Managing diabetes is complicated and involves adherence to medications and medical procedures, as well as adherence to lifestyle behaviors such as diet and exercise. After completing the first round of open coding, agency talk was found to differ, sometimes greatly, depending on the domain of diabetes management (e.g., exercise). Therefore, in the final analysis, agency was coded across six domains for each subject: Medication Adherence, Information and Support Seeking Behavior, Food Management, Exercise Management, Medical Management, and General Diabetes Management. In the final system, a subject's agency could fall into one of four categories for each domain: *high*, *moderate*, *low*, or *not articulated* for when nothing was said about his or her actions in a particular domain.

A subject's level of agency was determined by particular linguistic cues used to describe action or inaction with regards to managing diabetes. The language of agency is manifest in specific lexical and grammatical categorizations; however, agency can be understood in broader terms as well. Specifically, coders considered the ways in which subjects expressed

action (i.e., behaviors subjects reported actually engaging in), stance (i.e., attitudes toward or assessment of their actions), and intensity (i.e., degree of intensity or commitment with which subjects reported performing an action or the degree of intensity of subjects' assessment of their actions). The linguistic realizations of agency and examples from the data can be found in Table 6.2.

Table 6.1 Prominent linguistic realizations of control orientation

Linguistic features coded as external control orientation	*Linguistic features coded as internal control orientation*
Semantic role	*Semantic role*
"she [wife] had me keep a little where I took my blood sugar every day" (Patient)	"I check my feet every night before I go to bed." (Agent)
"My daughter fixes my food." (Beneficiary)	
Metaphor	*Metaphor*
"It [diabetes] was hid back there and like hid out something [...] then it jumped on me and said I'm here now."	"I can whoop it and fight it [diabetes]."
	"If you work out diabetes gets mad [...] it hurts diabetes when you working out."
Idiom	*Idiom*
"If that's [manage diabetes] what I am kinda meant to do [...] if god wants me to do it then alright I'll do it."	"I'm really on my Ps and Qs."
"That's [low blood glucose levels] just the way it happens sometimes."	"The idea is to stay with it [managing blood glucose levels]."
Characterizations of self	*Characterizations of self*
"Unfortunately I'm a sweetaholic I love sweets [...] if they didn't make sweets I probably wouldn't be a type two."	"I'm the type of person that's willing to learn things."
"I'm not like a real exercise person."	"I'm the type of person who will go from one extreme to the other [i.e. able to change habits quickly]."
Claims of ignorance or forgetfulness	*Knowledge of diabetes*
"I don't really know what it [diabetes] is."	"I know everything it takes to get healthy [...] I know the right foods to eat [...] I know the exercise I need to do."
"When I go out I forget to bring the medicines with me."	
	"I'm fairly well educated from the outset on the disease."
Vague language in relation to medicine and diabetes	*Detailed/descriptive language and/or medical jargon*
"I'm taking two medications and things like that."	
"It's [blood glucose levels] up to two hundred or two fifty or whatever."	"There's type one [...] which is the autoimmune reaction where the body basically decides uh pancreas or the islets of langerhans are a foreign body and decides to destroy them."

Table 6.2 Prominent linguistic realizations of agency

	High agency	*Moderate agency*	*Low agency*
Propositions	"I exercise." (domain: exercise management) "I also keep track of you know how much portions I'm suppose to have." (food management)	"I do try to exercise." (exercise management) "I try to eat well." (food management)	"It's [exercise] stopping." (exercise management) "I went on an eating binge." (food management)
Intensity and stance			
Single adverbs of extent/degree and manner; Adverbial clauses of time	"I've been taking my medications constantly." (medication adherence) "I've been seeing him [doctor] *quite frequently*." (medical management)	"I took medicine *occasionally*" (medication adherence) "I've had it [blood glucose level] as low as sixty when I'm watching it." (medical management)	"I didn't take it [medication] *anymore*." (medication adherence) "I crave sweets *constantly*." (food management) "I used to have problems *consistently* [with low blood sugar]." (medical management)
Premodifying stance adverbs	"I *really* started managing it [diabetes]." (general diabetes management)	"I *pretty much* follow a 1500 to 1800 calorie diet." (food management)	"It's *very hard* for me to avoid it [sweet food]." (food management)
Hedges *(we found that hedges suggest moderate agency thus examples for high and low do not appear)*		"I see my doctor *kind of* on a regular basis." (medical management)	

Coding analysis of affect

In order to determine linguistic realizations of emotion, the subcategory 'affect' of the attitude meaning system was adopted from Martin and White's (2005) work on Appraisal Theory. Our modifications of Martin and White's system are described in detail in Connor et al. (2012).

In our transcripts of patient accounts, we were interested in the emotions of subjects toward their disease and its management, as well as toward their healthcare providers. All instances of affect were coded within one of four domains: *diagnosis*, *state of being diabetic*, *management of disease*, and *providers/system*. Each instance of affect was then coded for one of the following categories: *unhappiness*, *happiness*, *insecurity*, *security*, *dissatisfaction*, *satisfaction*, *disinclination*, or *inclination*. Instances of affect were further coded using a subcategory, as recommended by Martin and White (2005). Table 6.3 lists all of the categories (in italics) and subcategories (in parentheses) used in this study.

With refinements to the system, transcripts were coded and recoded accordingly as changes were made. Coded linguistic evidence for expressions of affect included nouns, verbs, and adjectives, as well as multiword phrases within the context of the utterance and agreed upon

on a case-by-case basis as to whether or not they expressed affect according to the coding guidelines. Examples of multiword phrases include 'not another thing' and 'that's a bunch of baloney'. Each coder analyzed the transcripts independently, and then came together to discuss and compare results and to establish inter-rater reliability. Each case of affect was coded, categorized into domains, and counted. The total instances of affect in each transcript were divided by the total number of subject words in the transcript and multiplied by 1,000. If the two coders did not have the same counts, their results were averaged, which resulted in some fractions. Table 6.3 provides examples of each affect category. The domain used for coding is indicated before each example.

Table 6.3 Linguistic realizations of affect

Unhappiness (misery)	(diagnosis) "I was really -- I don't use the word depressed but I was you know I was *mad* you know..." (state) "I'm *just in constant* pain."
Unhappiness (antipathy)	(provider) "... I mean I got some of the clinics over [there] that I *don't like* going to because some of the people over there some with *attitude*..."
Happiness (cheer)	(management) "...when my sugar is lower ... it makes you *feel good.*"
Happiness (affect)	(provider) "I really *like* her."
Insecurity (disquiet)	(diagnosis) "I was *mad.*" "We didn't know how to deal with it." "It was a *disaster* for me to find out." (state) "...for me to tell people, it was kind of *embarrassing.*" (non-medication management) "I'm *scared* of needles."
Insecurity (surprise)	(diagnosis) "It's kind of *shocking.*" "It *threw me for a loop.*" (state) "I *never realized* how bad or how uh drastic uh diabetes can be."
Security (confidence)	(state) "I'm *alright.*" (collective management) "I'm doing *really well.*"
Security (trust)	(providers/system) "... science and medicine have a *better understanding* of how to control it [diabetes]."
Dissatisfaction (ennui)	(state) "I've been very *frustrated* by the whole thing." (diagnosis) "I was goin' to say maybe the first time when I first found out about it I was *kinda aggravated.*"
Dissatisfaction (displeasure)	(management) "'cuz it's *hard* when you have kids and you have to go home and cook them a meal and then you're trying to have a salad..." (provider) "...which if she's an endocrinology doctor she *shoulda known* that to begin with."
Satisfaction (interest)	(management) "I'd go through spurts where I'd *REALLY try.*" "...that's when I really started managing it *like I should.*"
Satisfaction (pleasure)	(provider) "The doctor made me feel real *comfortable.*" "He was *really good* at his job." (non-medication management) "It's *really about the healthiest diet* you can have."
Disinclination (fear)	(state) "The one thing that probably *frightens* me more than anything is losing my eyesight as a result of [diabetes]."
Inclination (desire)	(management) "I'm *extremely motivated.*" (management) "*I'll pick it back up* in the summer."

Analysis and results

In this section, we provide examples of coded excerpts from the transcripts. Then, we describe the quantitative results of the application of the three linguistic systems to our dataset and the correlations of results with self-reported adherence.

Examples of transcript coding

Guidelines for transcription were adopted by the team based on Jefferson (1979, as cited in Schiffrin 1994). In the following excerpts, a plus sign indicates a pause of less than a second; a number in parentheses indicates the length of a pause in seconds if more than one second; a colon indicates that a word was drawn out; non-verbal utterances are inserted within double parentheses; all capitals are used for extra loud words; 'I' stands for Interviewer; and all subject names have been changed to pseudonyms.

The following examples illustrate the application of the coding system to transcript excerpts. In each example, a complete coding of the excerpt is presented. However, these are only short excerpts from much longer interviews. A complete transcript analysis would show many more linguistic features being expressed in each interview. The second example provides the longest excerpt and gives an idea of the richness of the complete dataset.

The first two examples are both coded as internal control, but present the contrast between high vs. low agency coding and positive vs. negative coding. In the first example, Cory, diagnosed eight months before the interview, was coded overall as internal control, high agency in most domains, and positive affect. As the coding in Table 6.4 shows for this excerpt, his language is very specific in terms of what he does to manage diabetes, using phrases that indicate moderate to high agency for actions that adhere to recommended health behaviors. His outlook presents a positive 'can-do' attitude.

Excerpt 1

Interviewer (I):	What are you supposed to do to manage your diabetes?
Cory:	oh + they did give me a medication metformin I think it's called metformin my doctor game me metformin and I take it once a day thousand milligrams once a day in the evening. I try to anticipate that at some point in time I'll never have to take anything because I intend to lick this thing with my diet and exercise and I think that at the time I start a nice exercise regimen
I:	uh huh
Cory:	that the medication won't even be necessary.
I:	[...] What do you think about your ability to manage your diabetes [...]?
Cory:	Absolutely I absolutely think that I can manage it.

Table 6.4 Analysis of transcript excerpt for Cory

Coding	*Example from transcript excerpt*
Control orientation coding	
Metaphor	"I intend to lick this thing [diabetes]" (Internal)
Detailed/descriptive language and/or medical jargon	"my doctor gave me metformin and I take it once a day thousand milligrams once a day in the evening" (Internal)
Agency coding	
Propositions	"I take it once a day" (High)
Single adverbs of extent	"I absolutely think" (High)
Affect coding	
Inclination – desire	"I intend to lick this thing" (Positive); "the time I start a nice exercise regimen" (Positive)
Satisfaction – interest	"I absolutely think that I can manage it" (Positive)

In this second example, Delores, diagnosed six years before the interview, was coded overall as internal control, low agency in most domains with instances of high agency, and negative affect. As Table 6.5 shows, she assumes a controlling role over her disease management, using high agency direct propositions when describing her actions, but often qualifying her actions with hedges and adverbs that indicate lower agency. The majority of her expressions of affect are negative as she dwells on her fear and unhappiness of having diabetes.

Excerpt 2

I: What do you think about your ability to manage your diabetes?

Delores: [...] it's hard when you have kids and you have to go home and cook them a meal and then you're trying to have a salad and a plain chicken breast [...] It's just hard to um + like I said get home at six and have a meal on the table we don't get home to nine ten o'clock at night and you know by then it's fast food ((laughs))

[...]

o:::hhh I don't know + um >I just think like I said the fear of it at the beginning< made me want to do the right thing + and follow + and lose this weight and not be diabetic and not be on insulin

I: right

Delores: and you know not have all these horrible things happen because I'm diabetic you know as far as my um ( ) but putting that with reality in real life is two different things

I: yeah

Delores: and it worked for awhile because my kids were also panicked too you know and like I said just as time went on + and + so I don't care if I drink this pop + ((high pitched stylized voice for next two words)) it's bad + but + I ((next word stylized)) exercise and whenever I drink coffee I make myself drink a glass of water ((laughs)) the same you know and it just I just kinda played with it and make excuses so I can have something that I want ((laughs loudly)) so you know like at Thanksgiving I didn't eat the roll and the +

dressing and the + sweet potatoes and the + mashed potatoes but I wanted a piece of that pie so + I had a little sliver of pie and I had my green beans and I- I was pretty happy with that you know I didn't have to have the whole + meal even though I cooked the whole meal for everybody else ((laugh)) so I- you just kinds + you know play games with yourself I guess

I: yeah

Delores: if I have this I won't have that

I: yeah what other types of games ((Delores laughs)) do you play with yourself regarding the management of your diabetes ((I laughs))

Delores: ((laughing)) we::ll ++ that's basically it with the food and a- again + with the exercise I- I start out strong I may exercise two weeks steadily and then something – ((stylized nasal voice for the next two words)) it rains so – I have to pick my daughter up and I just totally forget it and then three four days later I go I was walking ((next two words stylized)) what happened and you start over you know.

Table 6.5 Analysis of transcript excerpt for Delores

Coding	*Example from transcript excerpt*
Control orientation coding	
Semantic role	"I make myself drink a glass of water" (assuming role of Agent – Internal)
Agency coding	
Propositions:	"You're trying to have a salad" (Moderate); "I exercise" (High); "I didn't eat the roll" (High); "you start over" (High)
Single adverbs of extent hedging	"I may exercise two weeks steadily" ("steadily" suggests High however "may" suggests Moderate due to hedging)
Premodifying stance adverbs	"I just totally forget it" (Low); "I just kinda played with it and make excuses" (Low); "it's just hard to um + like I said get home at six and have a meal on the table" (Low)
Affect coding	
Dissatisfaction – displeasure	"it's just hard to um + like I said" (Negative)
Insecurity – disquiet	"the fear of it" (Negative)
Inclination – desire	"made me want to do the right thing"; "and follow"; "and lose this weight" (Positive)
Disinclination – fear	"and not be diabetic"; "and not be on insulin"; "not have all these horrible things happen" (Negative)
Dissatisfaction – displeasure	"I don't care if I drink this pop"; "it's bad" (Negative)
Satisfaction – interest	"I was pretty happy with that" (Positive)

The third and final example is much shorter to show the contrast between internal and external control coding. Table 6.6 will only present the control orientation coding. In this example, Pam, who was diagnosed less than two years before the interview, was coded overall as external control, moderate agency in most domains, and negative affect. As Table 6.6 shows, she characterizes herself as being the recipient of diabetes due to her genetic make-up, showing no evidence that she had any role in getting the disease nor control over her craving for sweets.

Table 6.6 Analysis of transcript excerpt for Pam

Coding	*Example from transcript excerpt*
Control orientation coding	
Characterization of self	"it's been passed on uh gene-wise" (External); (sweets craving controls her) (External)

Excerpt 3

I: [...] tell me how you were first diagnosed with diabetes and how you felt

Pam: [...] it's hard to deal + with it for me because I know that it's been passed on + ((clears throat)) uh gene-wise

I: what do you think of YOUR ability to manage your diabetes?

[...]

Pam: [...] the eating part is what I have a problem with and the craving for the sweets oh my GOD

[...]

Pam: sweets craving gets on my nerves.

The next section presents the results from the quantitative aspects of the mixed methods analysis.

Quantitative results

Control orientation

Coders applied the linguistic system of control orientation described in Table 6.1. Thirty-five of 43 (81 percent) were coded as external orientation, suggesting that the majority of interviewees talk about their diabetes as something beyond their control, while 8 of 43 (19 percent) were coded as internal orientation. Table 6.7 presents the frequency and percentage of individuals in each of the agency categories after coders had applied the linguistic system.

Table 6.7 Numbers and percentages of individuals in each coding category per agency domain

	High agency N (%)	*Moderate agency N (%)*	*Low agency N (%)*	*Not articulated* N (%)*
Medication adherence	29 (67)	8 (19)	2 (5)	4 (9)
Information and support seeking behavior	21 (49)	8 (19)	9 (21)	5 (12)
Food management	16 (37)	19 (44)	8 (19)	0 (0)
Medical management	32 (74)	7 (16)	4 (9)	0 (0)
General diabetes management	10 (23)	26 (60)	4 (9)	3 (7)
Exercise management	12 (28)	12 (28)	9 (21)	10 (23)

Note: *The patient transcript contains no reference to this agency domain.

Agency

Generally speaking, the words of these interviewees indicated a moderate or high degree of agency. Of the interviewees, 32 of the 43 (74 percent) exhibited High Medical Management in their talk about scheduling and attending doctor's appointments, monitoring blood glucose levels, and checking skin and feet. Twenty-nine of 43 (67 percent) were classified as having High Medication Adherence. The domains in which the lowest agency was heard in patients' talk were related to managing diet (19 percent as Low Food Management), exercise (21 percent as Low Exercise Management), and information seeking (21 percent as Low Information and Support Seeking Behavior).

Affect

Instances of affect in each domain were counted by two coders who achieved high reliability. Those totals were then used in the quantitative analysis. Given the scope of that tabulation, we present only a synopsis of some of the more interesting results. Dissatisfaction (Displeasure) was expressed the most overall (524 instances). Dissatisfaction (Displeasure) for Non-medication Management received the highest overall instances (237 instances), suggesting predominant overall negative feelings about such things as diet and exercise. The second highest coding was Satisfaction (Pleasure) for Providers/System (208 instances). While Dissatisfaction (Displeasure) toward Providers/System (137.5 instances) was also relatively high, many examples referred to previous doctors. Once patients changed doctors, Satisfaction or an expression of Dissatisfaction with the insurance provider or healthcare system was reported. Security (Trust) was expressed the least overall (14 instances). Insecurity (Disquiet) was expressed most often in terms of diagnosis (81 instances) and the general condition of having diabetes (127 instances). These numbers were far greater than those for Security (Confidence) for diagnosis (3 instances) and general condition of having diabetes (23.5 instances). Overall, subjects expressed more negative emotions than positive ones about the management of diabetes, but expressed more positive emotions than negative ones about their healthcare providers.

Adherence to medication

After the quantification of the linguistic features, results were subjected to statistical analysis to better illuminate patient-reported adherence to medication. The linguistically identified constructs for each patient's control orientation, agency, and affect served as independent variables. The dependent variable was patients' self-reported medication adherence. Medication adherence was measured through a self-report response to the question 'How many times did you miss taking medications as prescribed during the previous month?' A subject was 'adherent' if the response was two times or fewer. In our dataset, 32 of 43 (or 72 percent) were 'adherent'. The Fisher's exact test (two-sided) was used to analyze the relationships between adherence and the independent variables. The following is a discussion of the statistically significant variables that are most relevant to the linguistic system presented in this chapter.

There was a statistically significant relationship to adherence for those who, through talking about living with diabetes, exhibited High Food Management according to our linguistic analysis system. This suggests that those who talk about controlling their diet (a critical component of Type 2 diabetes management) in an agentive manner also adhere to

their medication regimen. An example of such agentive talk is, 'I also keep track of you know how much portions I'm suppose to have.' In contrast, those with less agentive talk (e.g., 'I try to eat well', with 'try' exemplifying the lower agency level) were less adherent to their medication regimen. Interestingly, since our model also examines the influence of health literacy on adherence, those who exhibited highly agentive talk with regards to seeking out information and support were also highly adherent.

We now turn to the expression of affect in these interviews. Of all the categories, expressing Dissatisfaction was the most significant variable when correlated with adherence. Thus, negative feelings are more likely to indicate lower adherence tendencies than positive feelings are to indicate higher adherence. While the former conclusion may seem intuitive (i.e., someone who is really dissatisfied with medication, care, diet, and exercise would be less inclined to follow a medication regimen), we suggest that the latter conclusion is less intuitive. To recognize that positive expressions do not necessarily indicate adherence is critical to understanding the patient and not assuming that positive affect means everything is going well.

Consistent with previously published LOC research, control orientation was not significant on its own in relationship to adherence. We believe, however, that understanding control orientation is critical when examining the interactions of these constructs and providing intervention recommendations through targeted communication, as described in the following section.

Recommendations for practice

Since daily self-care health behaviors are recommended to patients with a chronic illness like diabetes, it is important for healthcare providers to have a good understanding of the extent to which patients follow these recommendations. Providers also need clues to understand how to communicate effectively in a patient-centric manner. The coding system addresses both of these needs. It can be used to create profiles of patients that define their control orientation, agency, and affect. Once the profile of a patient is coded, providers can then provide patient-centric communication that has been tailored for that specific profile in a way the patient identifies with and responds to. For example, in its simplest form, a profile shows that a person displays external control, high agency and negative affect, or internal control, low agency and positive affect. More complex profiles give further information that breaks down agency and affect into domains so a person may show internal control, high agency in taking medication, but low agency in diet and exercise, or negative affect toward ability to manage diabetes, but positive affect toward healthcare providers. Tailored communication can be incorporated into face-to-face communication as well as written newsletters, emails, and text messages.

To train healthcare professionals to assess control orientation, several features of the system can be integrated into instruction about what to *listen* for when a patient speaks. For example: Are things described as happening to or for the patient (external), or is the patient a responsible initiator of the action (internal)? Do metaphors and self-characterizations reflect being dominated or relinquishing responsibility (external), or dominating and taking responsibility (internal)? Does the patient use vague language or claim to not know or forget what to do (external), or does the patient give detailed reports that show knowledge of diabetes and its care (internal)? (see Table 6.1).

To assess agency, healthcare professionals can be taught to listen for such things as: the use of 'try' with a verb, which indicates lower agency; adverbs that reveal intensity of an action;

and hedges like 'kind of' which show lower agency (see Table 6.2). Because the affect system is based more upon what is expressed rather than the linguistic manifestations of content, it requires less training than for control orientation and agency and is rather intuitive (see Table 6.3). Communication is then altered according to the results of the assessment for each patient.

Recommended strategies for people with an external control orientation include using the influence of important people in their lives and imposing an external authoritative structure. Based on results of this study, we recommend that phrases such as 'Your doctor holds the key to your health' or '9 out of 10 people with your health condition have benefited from this medicine' would resonate with those with external control orientation.

Recommended strategies for people with an internal control orientation include allowing them to take responsibility for their health and being clear about expected results to help avoid frustration with perceived failures. Phrases that focus on the individual being in control, such as 'You are in the driver's seat' or 'Consider these benefits of your medication and you may find they would address your concerns', would be appropriate for people with internal control orientation.

Agency has significant relationships with adherence and health outcomes. Thus, the goal of health improvement communication is to increase agency. This includes recommending 'Baby Steps' (DeWalt et al. 2009) and increasing exposure to others' experiences of success regarding the same behaviors. A recommended way to frame advice to increase agency would be, 'From this list of good food choices, pick just one you like. Next time you reach for a food high in carbs or sugar, eat this chosen one instead.'

Similarly, if negative affect is detected through linguistic cues – a variable shown to be related to poor adherence – then professionals could alter their tactics to better understand negative emotions and build up positive feelings by offering words of encouragement such as, 'You are not alone. Many people find it frustrating to watch everything you eat, but you'll feel the difference from just taking one step today to eating better.'

We believe that understanding how the three constructs interact in order to create communication recommendations that address all three states is an effective communication approach. Future intervention studies are needed to test these recommendations.

Future directions

While strictly qualitative research in patient discourse provides valuable insights to the patient experience, the strength of the multi-method approach presented in this chapter is that the qualitative data from the open-ended interview questions can be transferred into quantitative results. Thus, we were able to study the relationships between patient-reported adherence and their talk patterns. In future studies, we will use this approach on longitudinal data to identify trends that emerge in patient behavior over time. Additionally, we will use the quantitative results from this study to design research with larger numbers of subjects to better understand how the constructs interact in a health outcomes model. Finally, the linguistic features presented in this study need to be integrated into intervention strategies for healthcare professionals' use.

Summary

In this chapter, we have described an interdisciplinary, multi-method approach to understanding and explaining patients' own accounts about their health and their relation to health

outcomes – adherence, in this case. Our working model, PLAIN Health, guided this linguistic research by forging close connections with praxis/process literature, health literacy, and patient adherence.

Through patient talk and the linguistic analysis of life stories, we identified patient profiles based on key psychosocial variables found in the literature on patient behaviors. Through a qualitative analysis, we first operationalized the linguistic features. These features were then quantified, enabling us to conduct statistical analyses to determine the relationships between discourse and behavior. In the field of health discourse, a great deal of previous research has presented qualitative case studies. The approach presented here provides an analytical system that we believe has important practical implications for translational intervention work.

Acknowledgments

This project was supported by a grant, 'Project for Health Literacy and Patient Adherence,' from the Eli Lilly & Company Foundation, 2007–2010.

Related topics

Diabetes; adherence; self-care; locus of control; agency; affect; applied linguistics.

Further reading

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