

# Three Approaches to Understanding Verbal Cues from Older Adults with Diabetes

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## Abstract

The older adult population is growing in epic proportions. With this growth, chronic disease is also increasing, especially the chronic disease of diabetes. Older adults often have difficulty communicating with health care professionals about their illnesses and often have low health literacy and poor understanding of their illness processes. Advanced Practice Registered Nurses (APRNs) serve a vital role in not only caring for this burgeoning population of older adults with diabetes, but also are the key to ensuring good communication and understanding of the disease process with their patients. This article discusses the importance of the lifeworld in older adults with chronic diseases such as diabetes and presents multiple qualitative analytic approaches utilized to better understand the intricacies of these conversations with older adults with diabetes. The key conversation points are then discussed to assist APRNs on how to cue into certain words within the conversation that will allow them to better understand their patients' diseases in respect to their lifeworld. This in turn will allow for better education of the patient and for better patient self-management.

## INTRODUCTION AND BACKGROUND

The World Health Organization (WHO) estimates that there will be over 2 billion older adults worldwide by the year 2050 [1]. This boom of the aging population will increase the incidence of chronic diseases such as cardiovascular disease, chronic respiratory diseases and diabetes. In the United States (US), 7 out of 10 deaths are the result of chronic disease and the care of those with chronic disease accounts for 86% of US health care costs [2]. The increase in the aging population also brings an increase in the population with low health literacy. The Centers for Disease Control (CDC) estimate that approximately 9 out of 10 adults have difficulty understanding health information that is readily available to them and among those adults, the population 65 and older, have the smallest percentage of people with proficient health literacy skills and the largest group with below basic health literacy skills [3]. This situation complicates the interaction between advanced practice registered nurses (APRNs) and older persons with chronic disease.

The global expansion of the chronic disease of diabetes has risen to epidemic proportions [4, 5]. As of 2015, the WHO lists diabetes in the four chronic diseases accounting for 82%

of deaths from chronic disease [6], while the CDC lists it as the seventh cause of all deaths in America [7]. In the US, one research review states that diabetes not only increases with age to more than 18% of the population, it is undiagnosed in almost a third of people over 65 [8]. Other studies [9, 10, 11], assert that geriatric diabetes has specific features distinguishing its impact and management from other age cohorts and it has been largely understudied. These issues underscore the importance for APRNs working with older persons to better understand features affecting patient engagement and management, which can be difficult in the best of times with diabetic patients or clients [12].

More than thirty years ago, Mishler [13] demonstrated the importance of recognizing the role of the patient's lifeworld in understanding how the patient viewed and talked about a disease or condition. The lifeworld, as described by Mishler [13], is the patient's view and experience of events and problems in their own life and how the patient describes them, which is dependent on their position within the social world. This view is in contrast to the position of medicine which is grounded in science and rules that work against looking at each patient as an individual with unique circumstances [13]. As Hyden and Mishler [14] remind us,

this lifeworld often surfaces in the illness narratives [15] that can arise in medical interviews as interactions, but whose contribution to understanding the patient may not be recognized or valued. Understanding the lifeworld of persons with chronic disease may help all health care providers in promoting engagement and self-care: this understanding is too often seen as limited [16]. This lifeworld may also include the experience of low health literacy and the patient not understanding their condition.

Cultural values affecting self-care can be identified in lay discourse [17, 18], particularly as they impact health beliefs and health literacy [19]. However, it is not always easy to elicit information about the lifeworld: one study found that roughly one-third of 300-plus patients were reluctant to discuss self-care with their providers, perhaps because they did not want to acknowledge or admit unhealthy behaviors [20]. Another study [21: p. 810] found that older adults

‘...experience a range of negative feelings related to their conditions and are only comfortable talking to people who understand their everyday experiences with managing chronic conditions.’”

The purpose of this study was to employ multiple qualitative analytic approaches to conversations conducted with older adults with diabetes to better understand the effects of their lifeworld on the participants’ diabetes. This will help inform APRNs in the benefits of analyzing and using insights from their patient’s lifeworld when treating and educating patients with diabetes.

### **SAMPLE**

A large data collection of conversational interviews was accessed to better identify how multiethnic older people with chronic disease incorporate their lifeworld into accounts of illness. Three different, although complementary, methods of qualitative analysis were utilized to wring the greatest possible amount of information out of a set of 20 audio-/video-recorded and transcribed conversational interviews with 10 multiethnic older persons with diabetes [22]. These interviews were taken from the Carolinas Conversations Collection (CCC). The CCC is an online, password-protected, digital web portal available to researchers, hosted by the Medical University of South Carolina and sponsored by the National Library of Medicine/ National Institutes of Health [23]. The CCC was developed to meet the need for spoken data for research purposes from older persons from a

range of racial, ethnic and linguistic groups. Its two cohorts are:

- Cohort One: men and women who are 65 years and older, with chronic conditions most frequently linked in the two Carolinas to causes of death. Members are not cognitively impaired and have two conversational interviews, one with community partners of similar age and, whenever possible, similar gender and ethnicity, and one with young clinical professionals.
- Cohort Two: men and women who are 65 years and older, with cognitive impairment, most frequently dementia of the Alzheimer’s type. Members of this cohort may have one to ten conversational interviews over time, with researchers and student visitors to their residential communities.

The initial goal of the investigation was to learn what everyone had in common in their interviews. Information was also sought about what kinds of language cues could signal different aspects of that topic to a clinician, and ways in which the older person, or patient, chose to express themselves.

Two interviews took place with each consented participant from the CCC interviews from Cohort One. Names are given aliases to protect identities.

### *Interviewer training*

Interviewers were given a brief training session on using (a) cognitive mapping, a visual story prompt [24] adapted from mapping one’s environment and used as an elicitation technique; and (b) some or all of 8 semi-structured questions adapted from Kleinman’s (1988) questions [15] to explore explanatory models of a disease. The interviewers were reminded that their real job was to listen and let the person go in any direction they wished.

The interviewers were directed to talk through their own cognitive map which they sketched for the participant. Once this was completed they were to ask the participant to take a few minutes to sketch a map portraying the world they live in as people with X medical condition, speaking about places, people, and daily events that are important to them, namely, their lifeworld. The purpose of cognitive mapping is to discover and analyze concepts related to people’s spoken accounts. This mapping approach turns control of self-disclosure over to the conversation partner.

During and after sketching their map, the interviewers asked the participant to expand the narrative they began with the cognitive map utilizing Kleinman’s [15] questions. The

questions, adapted from Kleinman [15], included the following as seen in Table 1.

**Table 1**

Secondary prompts adapted from Kleinman[15]

<p>* <b>Disease understanding and causation:</b> What do you think about your <i>medical condition</i>? What do you think caused your <i>medical condition</i>? What do your family/friends say? What worries them?</p> <p>* <b>Disease onset timing:</b> Why do you think it started when it did? What do your family/friends think? What did they notice?</p> <p>* <b>Disease expectations:</b> How bad is your <i>medical condition</i>? How long will it last? How do you think it will affect you in the future?</p> <p>* <b>Disease process and impact:</b> What do you think <i>medical condition</i> or its treatment is doing to you? To your body?</p> <p>* <b>Disease treatment:</b> What kinds of help or treatments are you getting? How are they (each treatment or medicine) working for you? What other things do you do to help deal with your <i>medical condition</i>? Where do you get help? (Often, this will provide an opportunity for the partner to discuss or explore role of spirituality)</p> <p>* <b>Disease complications:</b> In a typical week, where and how does the <i>medical condition</i> affect your life? What problems do the treatments cause you? How do you handle these sorts of things?</p> <p>* <b>Disease concerns:</b> What fears or worries do you have about your <i>medical condition</i>?</p> <p>* <b>Disease successes:</b> Who or what helps you most with your <i>diabetes/breast cancer</i>? What things you do for yourself seem to be helping? What would you teach others who have <i>medical condition</i>?</p>
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### Methods for analysis

Three methods were chosen to study the language used by older patients with chronic disease to reflect findings ranging from the most general to the most specific, and to exemplify emerging trends in communication, language analysis and health informatics. These methods are: 1) ‘big data’ topic analysis and visualization [25]; 2) computer-assisted qualitative content analysis [26]; and, 3) discourse analysis [27,28]. Topic analysis, visualization, and computer-assisted qualitative content analysis have been applied across all twenty conversational interviews; discourse analysis is highlighted with the two contrasting interviews by one of the participants anonymized as Ms. Badger. Ms. Badger was chosen at random; her communication and concerns are typical of the other 9 interviewees and her interviewers provided a response to diversity similar to the other interviewers.

## FINDINGS

### “Big data” topic analysis

Big data topic analysis may be defined as the use of specialized techniques and algorithms used to manipulate datasets too large for typical software to store or analyze, such as electronic health records [29]. In this case, the number of words creates a big data set and is combined with

visualization, which is the representation of the analysis of a dataset as images that can increase understanding findings and provide new insights.

Big data analysts often use topic models, which are a suite of algorithms for discovering main themes that pervade a large and otherwise unstructured collection of documents [30]. These algorithms are statistical methods that analyze words of the text documents to discover themes that summarize the texts; each theme is presented in the form of a group of related keywords. Topic modeling algorithms do not require any prior annotations or labeling of the documents – the topics emerge from the analysis of the texts [31]. Topic models enable the analysis of large amounts of textual information at a scale that would otherwise be impossible by human annotation. A topic model was developed and applied to summarize the textual data obtained from the collection.

Each topic that the topic model identified is in the form of a group of phrases that are ordered by their importance to the topic. The phrases are statistically correlated, which could be the result of being mentioned together in certain conversations. For example, the major topics (shown in Figure 1) included these terms: “blood pressure”, “blood sugar”, “heart attack”, “family history”, “sister died”, “mother asthma”, “tossed salad”, “herb tea”, etc. At a quick glance, this topic pertains to a theme of illness, family history related to the illness, and healthy diet that may be beneficial for alleviating illness symptoms. A word cloud is used as a way of visually representing these themes [32], shown below in Figure 1. A Word Cloud can be used as a way of visualizing qualitative data sorted by topic appearance and frequency, with the perceptions of people sorted by their proportion in talk [33].

During a big data analysis process, the technique of sentiment analysis is also performed to determine the positive and negative sentiments and overt or inferred emotions around the extracted topic phrases [34]. Generally speaking, sentiment analysis aims to determine the emotional attitude of a speaker or a writer with respect to some topic or the overall contextual polarity of a document, which means its negativity or positivity [35]. Sentiments were categorized into three categories: positive, negative, and neutral. In visualization, color-coding is usually applied to represent sentiment. In Figure 1, positive sentiment was coded with the color blue, while the color red represents negative sentiment. Gray denotes neutral sentiment. The results of the sentiment analysis permit one to see the participants’ attitude when mentioning a particular issue. For



home and do whatever I have like I pray over my food - as I take my medicine in the morning, when I come back from the gym

M: um hmm.

-- I um, I'm uh, border sugar diabetic

- I take pills for that

- **and**, ah my pressure is it's you know right on the border line

- I take a water pill for that **and then** I have cholesterol (overlap)

M: your blood pressure?

-- yeah my blood pressure (overlap)

M: oh, so it's a little bit high?

Pronouns were highly frequent in the list of most frequent words. Since these texts are conversational interviews, *I* and *you* are obviously used to disclose or to ask questions; *that* signals a series of details to come or refers to a condition (I think *that* X, I take something for *that*); and *they* refers either to family members or to providers. *My* is the word for which to listen as it signals awareness, interests and 'ownership' (Table 2). *My* acts as a cue that tells the clinician what lifeworld features are "owned" by the patient, the concept referred to as human agency by Bandura [41]. It is often worthwhile to listen for and elicit discussion about some of these items to establish common values and lay groundwork for introducing motivating features of diabetes self-management [42] or for use in motivational interviewing, which begins with reflective listening [43].

**Table 2**

Co-occurrence of MY with keyword themes in texts (alphabetically by theme)

Keyword Theme	Frequency	Keyword Theme	Frequency
Age	14	'kids'/grandchildren	113
body part	106	Medication	47
comorbidity/condition	140	provider/doctor	79
diabetes	15	relative/close friend	142
exercise/(daily) activity	40	things/possessions	71
foods/eating/meals	39	treatment (for condition)	36
God/faith/religion	36	external support	5
job, work, money	25	verifying moods/feelings	48

*Microanalysis of semantic fields*

To compare semantic fields across two texts, WMatrix® automates the use of log likelihood to create a constant comparison and assign significance. (Log likelihood is a

type of linear regression). Sections were extracted from each text which specifically discussed diabetes and were compared to the set of those extracts against the whole set. Not surprisingly it was found that the extracts mentioned the fields of food and diet significantly more often, and also found that the extracts were significantly more likely to mention words in the field of investigation, such as *check/checked/checking* related to monitoring blood sugar or blood pressure. The extracts were significantly less likely to include laughter or words in the semantic fields of happiness, work and employment, or report what others had said. This lack of positive sentiment seems to echo other documented descriptions of the emotional burden of living with diabetes [44]. The lack of positive sentiment or emotions in descriptions of diabetes management may signal diabetes distress, the hidden worries and emotional burden of living with diabetes often overlooked by providers [45].

*Discourse analysis*

Discourse analysis involves the close reading of a text, utterance by utterance, for its function as well as its content to identify how people use language in particular contexts to make meaning [46]. Discourse analysis, an approach familiar in nursing research [47], looks at how people use language in its functional component parts as words and phrases during the interaction, in ways that either directly mark or infer one meaning within a range of meanings, relationships or contexts [48]. In health communication research, discourse analysis has been used to examine a variety of communication practices that give us insight into the perspectives of patients, characteristics of provider-patient interactions, shared decision making, shifts of control in interprofessional behavior and other social and clinical activities in health care [49]. Though there are a number of approaches to discourse analysis, the following examples are grounded in interactional sociolinguistics [50], which examines how people invest background knowledge, particular social and cultural positions, identities, and contexts in the talk of face-to-face interaction. These word choices people make often show the position or stance a person assumes in discussing themselves and other people [51]. In two contrasted transcripts, an older African American woman, anonymized as Ms. Badger, with diabetes was interviewed separately by a White younger interviewer and an older African American interviewer. Excerpts were chosen to compare common features in the way Ms. Badger uses language to tell her story and reveal evidence of her lifeworld in speaking choices beyond the content or topics.

**EXAMPLE 2. AN UNDERSTANDING OF A HEALTH EPISODE AND A HEALTH SERVICE**

P: Um hmm. But, anyway, I been back and forth in the hospital in between time.

I: Oh, really?

P: Um hmm.

I: What was, uh, do you mind asking, if I ask what for?

P: Um, well, I had a DNC at one time.

I: A what?

P: A DNC.

I: What's that?

P: That's cl-cleaning you, yeah, your body out, down below.

I: Oh, okay.

P: Um hmm. And, I had other little compliment... little complication things going on with me. But, anyway, they clear all that up.

I: That's good.

P: And, um, it was a blessing. I bless the Lord and I thank the nurses and the doctors for what they have done for me, cause they didn't have to do it, but they did it.

In Example 2, from her conversation with a young White medical student interviewer, Ms. Badger recounts an illness episode during her working life, identified in the phrase *in between time*, a reference of context recognizable to a reader of the entire interview, but that might mark a less recognizable context to an outsider. When asked about the reason for her hospitalization, she is able to name a gynecological procedure, own it with the use of the “I” pronoun (as contrasted with something done to her), and explain it in terms *cleaning you, yeah, your body out, down below* that shows a commonplace understanding offered the listener. This cue is not taken up for sharing, but instead the Interviewer responds with “*Oh, okay*”, a practice in institutional turn-taking that can mark the end of a topic [52]. By contrast, *the other little things going on with me* are not named, may not have been understood, nor are they possessed by use of the “I” pronoun, so understandably they can be cleared away as if they were objects taken care of by

the external providers. The invocation of faith in the last sentence introduces one of Ms. Badger’s primary coping mechanisms, her spirituality, as well as a qualifier she will echo later regarding race. As she talks to the young White interviewer of her gratitude to the predominantly White staff at the hospital she names, this older African American woman who grew up in the era of segregated South Carolina hospitals uses a phrase that raises issues of entitlement. In the phrase *...they didn't have to do it, but they did it*, she suggests the care she received was more than that to which she was entitled, as well as better than expected. The phrase also echoes a phrase used in the Black Church to mark God’s steadfastness even when we are unworthy: *He didn't have to do it, but He did.*”

Example 3, again from the same conversation has her showing her hesitancy to respond directly about her medical conditions with *ums* or even to admit something is wrong – and then she reconstitutes her doctor’s comments which she minimizes – these were *little thingies*.

**EXAMPLE 3. MINIMIZING CHRONIC DISEASE**

P: And, so he wrote up everything for me to give to my boss, and tell him that to disregard me from the school guard, cause see I think she has had enough. Say, body just can't take it now.

I: Did he say, did he say anything in particular, that was wrong with your health or (overlap)

P: Um, (overlap)

I: was it just (overlap)

P: um, my doctor was telling me all kind of little thingies, been so long, I forgot now. But, um, my nerves was bad.

I: Your nerves?

P: Um hmm. And, um, I had a little heart failure. Um hmm. And, um, --- (long pause) that all, what else he tell me that was wrong? He say, "You got to stop," he just didn't tell me then, (overlap)

I: Um.

P: that I had to cut the driving out.

I: You had to stop driving?

P: Um hmm.

I: Around that same time.

P: Well, I drive a little while.

I: Um hmm.

P: I'll say about half a year, I drove.

It is hard to forget chronic disease -- but she has at least three of them and she does not name them all nor does she constitute them as serious. However, she cannot have forgotten them since they did not go away. She still has heart problems – and depression or anxiety – and she has diabetes, a condition that is unnamed throughout the entire second interview. When she names heart failure, she minimizes its importance and what she sees as its impact on her. The practice of using words that minimize the importance of health conditions or behaviors has been previously noted in conversation analysis [53]. Note that she is prompting herself – and explaining that he (her doctor) says she has to stop working and stop driving. However, when the interviewer echoes her, she admits she went on driving – and working - for another half year, ignoring her provider's advice. She positions herself in the lifeworld as not completely accepting or acknowledging that these diseases may have an impact on her ability to function in her lifeworld. This position is not an unfamiliar reaction from persons who might define themselves by their jobs.

Example 4 is taken from the conversational interview by a woman whose age and race were concordant with Ms. Badger.

**EXAMPLE 4: THE STORY OF MY INSULIN**

P: So, um, when I came out of the hospital, I had to go back to him, so, he could adjust whatever was going on.

I: Um hmm.

P: So, he checked my medication. And, he put my insulin pills, just a little higher.

I: Yeah. That's what I was thinking (overlap)

P: Um hmm.

I: sometime they have to do that. Get it adjusted they said to (overlap)

P: So, he say, "Let me adjust this a little higher."

I: Um hmm.

P: And, she say, he say, "If anything changes from this, you call me."

I: Yeah.

P: And, he say, "If I have to run over to your house, I'll just do that."

I: Um hmm.

P: And, say, let's, let's, let's put your insulin up a little higher and see if something you eating could cause that (overlap)

I: Could be causing some problems. (overlap)

P: Um hmm. (overlap)

I: Yeah. Yeah. (overlap)

P: Say, let's, let's work on that a little bit.

I: Um hmm.

P: And, so, we work on it. And, so, afterwards, I guess about two weeks or three weeks afterwards, I was coming to my self, little by little.

I: Um hmm.

P: And, he have helped, good about it you know. So, um, he give me some medicine for my fever and he, here I had, I was on high blood pressure medicine, (overlap)

I: Okay.

P: And, uh, that heart medicine, I was on that too. So, I hadn't been back in the hospital ever since. And, that happened in nineteen and ninety-eight.

In this concordant interaction between two persons similar in age and race, the Interviewer uses echoing and "Um hmm's to build the story, signal her engagement in the narrative, and interest in the details. As a result, the diabetes barely mentioned in the interaction with the White, younger health professional student emerges despite her initial attempts at minimizing. Additionally, the older Interviewer exhibits no judgment of Ms. Badger's behaviors, while in response Ms. Badger expresses more efforts as personal human agency. In several other places in this narrative, Ms. Badger indexes her spirituality with a praise- or bless-reference, and it is taken up as a cue and paraphrased back to her by the Interviewer. The echoing as Ms. Badger narrates the Story of My Insulin prompts more details, but she still does not name the disease she has difficulty managing. The practice evokes the phrase

heard here in the Carolinas: “If you don’t name it, you don’t claim it.”

### 5. DISCUSSION

Advanced practice nurses need to know that when they are speaking with an older person with chronic disease, they will have access to multiple levels of information, beyond what seems to be the obvious content of topics. The three approaches provide a window into intersecting levels of social interaction and interpersonal communication:

Level 1:        *What* they talk about        (Big data Topic analysis)

Level 2:        *What cues* signal meaning    (Computer-assisted qualitative content analysis)

Level 3:        *How* they talk about it    (Discourse analysis)

The three analytic techniques that were selected, like the three levels above, move from the most common to the most specific. At level one, people are as interested in speaking about family, diet and their activities as they are about the medical details of diabetes and co-morbidities, but more particularly if prompted with signs of interest and active listening. For example, the sub-topic of blood pressure emerged repeatedly. To understand on another level, qualitative content analysis showed word and phrase frequencies and semantic fields that identified items of more primary importance to speakers. These patterns tell us of pronouns that can signal ownership ‘*my*’ and ‘*I*.’ Use of strings of “*and*”s in a narratives show the elaboration of details that need unpacking, similar to the use of the word ‘*so*’ that something important is being prefaced or summarized that needs attention. The use of computer-supported qualitative content analysis enables an associated quantitative analysis that supports coding into categories and lets us identify semantic fields that are statistically significant for potential relevance in considering self-management. For example, the clusters of meaning group around family, diet, activities, and the experience of co-morbidities with far less detail or meaning associated with the biomedical tasks of testing blood sugar or taking medications, tasks that may be done but not completely understood. The focus on future tense lifeworld in word use rather than words and phrases about life in the present shows a lack of attention to current self-management. On the third level, Ms. Badger spoke in more detail with the echoes of her references to spirituality increased the importance of her

faith as a means of coping with the uncertainty of her disease.

The importance of these findings of clusters of meaning provides clues to APRNs that particular speaking practices may reveal how little people understand of their disease, are unwilling to hear, or cannot accept. In the conversations, where there were very few references to “my diabetes”, their lack signals a gap in what may be omitted, lost in impatient changes of subject, dropped as cues of topic importance, or misunderstood. The details of the lifeworld can be used as motivation in increasing understanding and self-management while changing behavior. Ms. Badger has a life in her church that she values, where there is a health ministry whose involvement might be encouraged, but the health professional student did not pick up the cue. Ignoring the lifeworld will continue to contribute to continued poor self-management if persons living with chronic disease have their social contexts ignored [54]. Those social contexts were identified throughout the three levels of what and how people chose to say about the main topic, a chronic disease which few of them “owned.” In summary, APRNs who are open to the contributions of medical informatics can keep up with the development of big data and the growing trend toward drawing on this type of analysis, to select and adapt findings that can help us understand what the patient brings to the interaction. APRNs open to the multiple levels of language use and its cues will elicit more meaning than others, using reflective listening to follow up on cues, silences, and repetitions to position the patient as having useful information about their own lifeworld that could be used for self-management.

### LIMITATIONS

This study has multiple limitations including a small sample size and a narrow geographic location. This study also only looked at persons with diabetes. Repeating this study with a larger, more geographically diverse population with multiple chronic diseases may provide more insight into conversational cues as they pertain to a person’s lifeworld and their chronic illness.

### IMPLICATIONS FOR PRACTICE

The current study highlights three qualitative methodologies utilized to analyze the conversation of persons with diabetes to better understand their lifeworld. Advanced practice registered nurses (APRNs) will be dealing with a progressively aging population who have multiple chronic illnesses and will need to employ a range of strategies to

encourage self-management of the patient's illness. A large proportion of these chronically ill individuals will also have low health literacy. Approaching chronic illness self-management from a lifeworld perspective, that is better understanding of a patient's verbal cues regarding their life and illness, will allow the APRN to better understand patients' health and social needs as well as their understanding of their illness. This study begins to reveal key conversational points that APRNs should be attuned to when speaking with patients. Both the analysis and interpretation of findings benefit from an interdisciplinary collaboration, a partnership that should be considered for future research as well as enhancement of communication in clinical practice. Utilizing multiple approaches such as big data techniques to analyze patient interactions will open APRNs to a growing number of potential strategies with which to relate to a diverse patient population with unique lifeworld experiences.

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