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# Putting the Patient Back in Patient Care: Health Decision-Making from the Patient's Perspective

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### Abstract

This research explored health decision-making processes among people recently diagnosed with type 2 diabetes. Our analysis suggested that diagnosis with type 2 was followed by a period of intense emotional and cognitive disequilibrium. Subsequently, the informants were observed to proceed to health decision-making which was affected by three separate and interrelated factors: knowledge, self-efficacy, and purpose. Knowledge included cognitive or factual components and emotional elements. Knowledge influenced the degree of upset or disequilibrium the patient experienced, and affected a second category, agency: the informants' confidence in their ability to enact lifestyle changes. The third factor, purpose, summarized the personal and deeply held reasons people gave as they made decisions concerning their health, eating and exercising. We propose this model, grounded in informant stories, as a heuristic, to guide further inquiry. From these stories, the patient is seen as more active and the interrelated influences of knowledge, agency, and purpose, synergistically interact to explain changes in health behaviors.

### Keywords

Type 2 Diabetes, Health Decision-Making, Qualitative, Knowledge, Purpose, Agency, Relationships, Patient-centered, Lifestyle Changes, Adherence, Grounded Theory

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## Putting the Patient Back in Patient Care: Health Decision-Making from the Patient's Perspective

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Adherence to medical regimens is low, a significant problem when health and even life are at stake, and there is public concern regarding health care policy and cost (Leung, Carlsson, Colditz, & Chang, 2016). People may follow doctors' orders 70 to 80% of the time when treatment brings symptom relief (Buckalew, 1991; Conrad, 1985; Donovan & Blake, 1992; Nieuwlaat et al., 2014; Segal, 1993), but adherence decreases as symptoms become less acute and as regimens lengthen (Buckalew, 1991; Conrad, 1985; Donovan & Blake, 1992; Maningat, Gordon, & Breslow, 2015; Nieuwlaat et al., 2014; Sackett & Haynes, 1976; Segal, 1993). Efforts toward prevention are even less successful. Patients are estimated to follow through with lifestyle change only 15% to 30% of the time (DiMatteo, 1995; Hernández-Ronquillo et al., 2003). These findings are especially relevant for the management of type 2 diabetes, a costly metabolic disorder (NCD Risk Factor Collaboration, 2016; American Diabetes Association, 2013) that begins with only subtle symptoms and requires the person to enact changes to what they eat and how often they exercise. It would be beneficial to understand the conditions that influence a person's decision to adhere or not adhere to a prescribed medical regimen.

Efforts to research and understand health behaviors generally fall into one of two categories: compliance and health decision-making. The compliance literature tends to be quantitative and supports a view of the patient as the passive recipient of medical advice (Hernández-Ronquillo et al., 2003; Kardas, Lewek, & Matyjaszczyk, 2013; Stone, 1997; Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). A much smaller number of studies approach the patient as empowered to make health decisions, and consults them on how they manage health concerns (Pound et al., 2005; Vermeire, Van Royen, Coenen, Wens, & Denekens, 2003). Viewing the patient as an active decision-maker and attempting to

understand health decisions from their view might reasonably provide some insight into how to help them more effectively, and improve their health and healthcare delivery.

The researchers interviewed people who had been diagnosed within the past two months with type 2 diabetes. This illness was selected for several reasons: a) the disease's growing international economic and personal cost (NCD Risk Factor Collaboration, 2016); b) personal interest of the researchers who have family members with type 2 diabetes; and, most of all, c) the treatment regimen, with its emphasis on healthful lifestyle changes, provided opportunity to explore what affects people's health decision-making. Our purpose in this research is to develop a model, grounded in patients' stories that may guide further research into health decision-making and adherence.

### **Relevant Background**

Healthcare research constitutes a vast and growing body of knowledge. This section will provide some background on diabetes, which underscores not only cost and consequences of unmanaged type 2 diabetes, but also the benefits of intensive lifestyle intervention (ILI). We will also review the established models use to understand the patient and health decision-making, and consider more recent research on the experience of the patient.

#### **Diabetes: Disease and Decisions**

Diabetes has risen steadily in the United States. In 1948, about 1% of the population had diabetes. Current estimates are that 30.3 million people in the U.S., 9.4% of the population, have the disease (Centers for Disease Control and Prevention, 2017), while 382 million people globally are estimated to have diabetes (Aguiree et al., 2013). Roughly a third of those with diabetes are asymptomatic, undiagnosed, and untreated (Centers for Disease Control and Prevention, 2017; Dwyer-Lindgren, Mackenbach, van Lenthe, Flaxman, & Mokdad, 2016; NCD Risk Factor Collaboration, 2016).

The consequences and costs of diabetes are significant. Diabetes can lead to vision, kidney, and nerve damage (Centers for Disease Control and Prevention, 2017; Forbes & Cooper, 2013). Poor blood flow, along with neuropathy results in diabetics being 10 to 12 times more likely than the general population to have a lower-extremity amputation (Fosse et al., 2009; Gregg et al., 2014; American Diabetes Association, 2016). Additionally, neuropathy results in problems for the autonomic nervous system that include poor night vision, heat exhaustion, orthostatic hypotension, constipation, diarrhea, fecal incontinence, bladder dysfunction, and sexual dysfunction (Tesfaye et al., 2010). People with diabetes are also at higher risk of death from heart disease and stroke (Balcioglu & Muderrisoğlu, 2015; Gu, Cowie, & Harris, 1998; Forbes & Cooper, 2013; Hayama-Terada et al., 2016; Mostafavi-Pour-Manshadi, Naderi, Dehghan, & Azizi, 2016; Paneni, Beckman, Creager, & Cosentino, 2013). Research in the past decade has found strong evidence for the role of insulin resistance in Alzheimer's disease (De la Monte & Wands, 2008; Ojo & Brooke, 2015). Diabetes not only damages health, it is also expensive. According to the American Diabetes Association (2013), one-fifth of healthcare dollars are spent on diabetes. The total cost of diabetes to the U.S. (healthcare, disability, lost work time, and early mortality) has risen from around \$100 billion (Goldberg, 1998; The National Institutes of Health, 1999) to \$245 billion (American Diabetes Association, 2013).

Although type 2 diabetes leads to significant health problems, lifestyle choices can influence disease progression. The landmark 10-year Diabetes Control and Complications Trial (DCCT) found that tight control over blood glucose resulted in a 75% reduction in eye disease, 50% reduction in kidney disease, and a 60% reduction in nerve disease among type 1 diabetics,

with some healthful effects persisting at a thirty-year follow up (Diabetes Control and Complications Trial, 2016). It is generally believed that similar findings would apply to a population with type 2. To this point, research indicates that intensive lifestyle intervention (ILI) leads to significant weight loss and a remission of type 2 diabetes (Gregg et al., 2012), if not a corresponding reduction in cardiovascular disease (Celli et al., 2016; Després & Poirier, 2013; Look AHEAD Research Group, 2016). Other support for the importance of ILI comes from a meta-analysis from Alouki, Delisle, Bermúdez-Tamayo, and Johri (2016). They conducted a systematic review of peer-reviewed studies published between 2009 and 2016 and found that lifestyle interventions were a cost-effective approach to preventing diabetes. Although there are many significant consequences to unmanaged diabetes, evidence supports that it is possible to stop, or even reverse, its advance with lifestyle changes. Because of the significant benefits from ILI, it is important to understand how people make decisions about their health, and what factors influence their thinking.

### **Models of Patient Behavior**

Healthcare researchers have developed several approaches to understand patient behavior. These models, and modern interest in understanding patient behavior, emerged in the 1950's (Rosenstock, 1974). In that decade, researchers developed more effective vaccines and the federal government worked to address gaps that existed in healthcare delivery in the United States (Hinman & Orenstein, 2006; Rosen, 2015; Rosenstock, 1974). However, despite improving treatments and effective vaccines, some people did not take anticipated steps to improve their health (Rosenstock, 1974). Social scientists then attempted to understand the person-as-patient and developed models to account for health decision-making (Janz & Becker, 1984; Rosenstock, 1974). Among the more significant are these six: the Health Belief Model (HBM), the Transtheoretical Model (TTM), Social Cognitive Theory (SCT), the Theory of Reasoned Action (TRA), the Theory of Planned Behavior (TPB), and the Health Action Process Approach (HAPA).

One of the earliest models (Rosenstock, 1974), the HBM focuses on beliefs and proposes a person will modify their behavior if: (a) they believe they are vulnerable to a particular illness; (b) the consequences of acquiring the illness are believed to be severe; (c) the benefits of reducing their susceptibility exceeds the barriers to or costs of the treatment; (d) there are cues to trigger the preventive health behavior; and (e) according to what are described as modifying social psychological, demographic and structural variables (Rosenstock, 1966). Of these elements, benefits and barriers have been found to best predict health behaviors (Carpenter, 2010).

The TTM, also called the "stages of change model," views behavior change as a naturally occurring process. Prochaska and DiClemente studied individuals who quit smoking and created a sequential process to describe steps they observed: (a) pre-contemplation, (b) contemplation, (c) preparation, (d) action, and (e) maintenance. The original model was expanded to explain a broad range of behaviors (Norcross, Krebs, & Prochaska, 2011; Prochaska & DiClemente, 1982, 1986; Prochaska & Velicer, 1997).

Bandura's (1986) SCT proposes that actions are the result of interactions from three interrelated factors: the person, environment, and behavior. The person includes cognitive factors such as beliefs, expectations, knowledge, and attitudes. The environment includes social norms and social support systems. The behavioral dimension includes skills, practice opportunities and self-efficacy (Glanz, Rimer, & Lewis, 2002). SCT is used broadly in the health sciences to explain and influence the adoption of healthy behaviors from condom use and abstinence, to physical exercise and health communication (McAlister, Perry, & Parcel,

2008; Patterson et al., 2008; Tougas, Hayden, McGrath, Hugué, & Rozario, 2015; Young, Plotnikoff, Collins, Callister, & Morgan, 2014; Zhang, Jemmott III, & Jemmott, 2015).

Other models emphasize rational decision-making. TRA assumes people gather information, think through consequences, and then act rationally (Ajzen & Fishbein, 1980; Fishbein, Middlestadt, & Hitchcock, 1994; Sheppard, Hartwick, & Warshaw, 1988). The TPB, also rooted in TRA, proposes behaviors are based on four influences of social cognition: intentions, attitude, subjective norms, and perceived behavioral control (Ajzen, 1991). The TPB has addressed health behaviors from physical activity and dieting (Nejad, Wertheim, & Greenwood, 2004; Sniehotta, Scholz, & Schwarzer, 2005) to consumer decision-making, environmental choices, and behavioral economics (De Leeuw, Valois, Ajzen, & Schmidt, 2015; Greaves, Zibarras, & Stride, 2013; Kautonen, Gelderen, & Fink, 2015; Montaña & Kasprzyk, 2015).

Finally, the HAPA (Schwarzer, 2008) is a more recent patient model. It emphasizes motivational factors and the intention to move forward with the behavior change (Schwarzer, 2008; Sheeran, 2002; Smith, Murray, Greaves, Hooper, & Abraham, 2014; Sutton, 2008). Other aspects of this theory, such as the assessment of risk, action planning, discernment of expected outcomes, and maintenance, are based on previous models such as the TRA, TTM, TPB, and SCM, as well as the Protection Motivation Theory (Rogers, 1975) and the Transtheoretical Model (Prochaska & DiClemente, 1982).

Our review of these models finds that each has strengths and weaknesses (Armitage & Conner, 2000). To summarize broadly, they focus on individual, cognitive processes. The patient experience and the decision to act is portrayed as the product of a series of steps, the careful consideration of pros and cons, or the result of a private, decisional process. It is a “highly individualistic view of decision making” (Siminoff & Thomson, 2016, p. 172) and Spring (2008) asserts health decision-making is critical and still not well understood by practitioners nor researchers. Thus this review of decision-making models provided some context but did not guide our effort. Our aim is to begin fresh, hearing about patient decision-making, from the voices of patients, as they contended with making lifestyle changes. This research does not argue against the utility of previous models nor attempt to replace them, but rather seeks to suggest other factors, grounded in patient narratives, for consideration.

## Research on Patient Decision-Making

In August 2017, we conducted a literature review of scholarship maintained by the PsychARTICLES, PubMed, and Web of Science databases spanning the years of 2004 to 2017. Our first search contained the keywords *patient*, *decision-making*, and *diabetes*, which returned 780 studies. A second search using the keywords *patient*, *perspective*, and *diabetes* located 1694 studies. A closer examination of those studies found that relatively few considered the patient’s perspective on life with diabetes and how they made decisions concerning ILI.

Some research addressed the conflict that exists between the doctors’ goals for patients and the patients’ rights to self-determination. Shortus, Kemp, McKenzie, and Harris (2013) interviewed healthcare providers and used a grounded theory approach to understand doctors’ views of patient involvement in diabetes care planning. Providers described a tension between aggressively addressing health targets balanced against respecting patient autonomy and their right to make decisions about how to live their lives. A quantitative study using a questionnaire found that patients preferred shared decision-making versus doctor-dominated prescriptions. This was especially true among younger and better educated patients (Marahrens et al., 2017). Researchers in Kuwait have also tried to understand reasons for non-adherence to diabetes medication in an Arab culture. Their qualitative study involved interviewing physicians in

Kuwait, and led them to conclude that physicians believe patients lack requisite understanding for effective health management (Waheedi, Jeragh-Alhaddad, Awad, & Enlund, 2017)

A small number of studies consider a more patient-centered view of illness and lifestyle change. Booth, Lewis, Dean, Hunter, and McKinley (2013) conducted focus groups with patients recently diagnosed with type 2 diabetes and health professionals in order to identify barriers and facilitators to ILI. Barriers included the following: difficulty changing lifelong habits, negative perceptions of the new regimen, the social impact of the required changes, a lack of knowledge about healthy living, motivation, and practical concerns such as food costs and access to gyms. Motivators were far fewer. Participants noted that feeling healthier and setting and achieving goals were facilitative. Also in 2013, qualitative research looked reasons emerging adults with type 1 diabetes, gave for non-adherence. Five of the eight participants interviewed reported consistently making choices to not follow their regimen. They explained their decision as being the result of burnout, following alternative standards, social support problems, or self-efficacy and emotional problems (Pyatak, Florindez, & Weigensberg, 2013). Johansson, Ekebergh, and Dahlberg (2009) described their phenomenological work concerning being diagnosed with diabetes. Their analysis of seven participants' writings revealed a fight to not *become* one's illness and a striving to manage the diabetes without the illness becoming an all-consuming concern. No research was located that looked at a process of health decision-making from a type 2 diabetes patient's perspective.

Diabetes is metabolic disease that has high personal and economic cost. Evidence supports that ILI, though challenging, can mitigate the progression of symptoms. Lifestyle changes may be prescribed by the physician, but they depend upon the patient. Our current understanding of the patient and health decision-making involves models that attempt to describe the process as a function of steps, decisions, catalysts and obstacles. Little research, however, considers the decision-making process from the perspective of the person recently diagnosed with type 2 diabetes. This study is intended to fill this gap.

## Researcher Context

In qualitative research, the authors are part of the instrumentation, and can influence processes and outcomes (Maxwell, 2013). It is helpful, then, to know something of the authors' experiences with the topic.

**Bill Garris.** I am an Assistant Professor in Counseling and Human Services at East Tennessee State University. My academic and professional orientation draws strongly from marriage and family therapy. I am personally interested in health and nutrition and believe that, macrosystems challenges notwithstanding, individuals can make healthy lifestyle choices. At times my personal and professional interests merge in the area of family systems and health. Type 2 diabetes runs in my family and I have witnessed first-hand the negative health consequences of unmanaged type 2.

The catalyst for this particular project was when a first-degree relative and another close family member were both diagnosed. One family member made significant lifestyle changes which improved their and blood glucose levels; the other did not. I was very curious about what might account for the differences in how they both responded to the same diagnosis, information, and prescription for ILI. Inasmuch as diabetes has a genetic component, I also appreciate that I am learning for my future self what motivates lifestyle change. Other than this personal experience as a proximal outsider and being curious, I did not have many preconceptions about what to expect from the research and no insider perspective to the issue. The aim of the research was to describe from the patient's perspective what influenced their thinking and decisions early in the disease and to develop a model from this that might offer a

more effective way for healthcare providers, and diabetes educators in particular, to motivate patient change.

**Amy Weber.** I am a doctoral student at both Arizona State University and East Tennessee State University, working towards doctorates in Behavioral Health and Public Health, respectively. My interest in health and nutrition stems from personal experiences and my educational background. I also have a keen interest in the behavioral attributes that both precede and supervene health decisions, as well as the implications of those behaviors. While earning my Master's degree in Public Health, I worked on a project to identify behaviors that cause children and adolescents to be predisposed towards overweight and/or obesity, and developed potential strategies for modifying these behaviors.

## Method

### The Sample

First, the research was approved by the Iowa State University IRB and the IRBs of two other hospitals that allowed their patients to be contacted for the research. We then reached out to healthcare providers associated with these hospitals in a Midwestern state and Southern state. After explaining the research and soliciting their cooperation, we gave healthcare providers brochures to share with patients. These brochures described the research to prospective participants in lay terms, and included a form the patient could return to their provider if they were interested in being contacted by the researcher to learn more about the research process. Return rates on the form were 15% and no demographic information was collected on people who did not return the form. We met with 27 who returned the forms.

Table 1. Demographics

#### Gender N (%)

Male	9 (43%)
Female	12 (57%)

#### Age category

25-40	1 (5%)
40 - 55	6 (29%)
55 - 70	11 (52%)
>71	3 (14%)

#### Race

Black	5 (24%)
White	16 (76%)

#### Relationship status at time of interviews

Married	14 (67%)
Single (never married, divorced)	5 (24%)
Widowed	2 (9%)



Because the grounded theory study aimed to develop an understanding of how people made health decisions while they were in the process of adjusting to a new diagnosis, we used theoretical sampling around the principal criterion of having been diagnosed with type 2 diabetes within the past two months. Secondarily, we considered the informant's ability to communicate effectively. This was a more subjective judgment and we did not concretely identify what this threshold would look like. Of the 27 individuals contacted, three declined participation and three others were deselected because we determined that they could not explain themselves well. The remaining 21 participants provided sufficient data for category development and saturation. Of the 21, 13 were from urban and rural areas in a midwestern state, and eight were from an urban center in the Southeastern United States. Participant details are described further in Table 1.

## **Data Collection**

Research design followed an iterative process of collecting and analyzing the data (Sparkes & Smith, 2014). After interviewing subjects, transcribing the interviews, coding and analyzing the data, questions would arise, leading the researchers back to the field to collect more data. Consequently, initial interviews tended to be more exploratory and generative. Inquiry later in the process invited comment on emerging categories, and data confirmation, particularly as categories became saturated.

The researchers generated data through semi-structured, face-to-face interviews. The interviewer began, asking "what actions that have you taken since the diagnosis," and followed with "what influenced those decisions?" There were other variations, such as "what motivates you to keep with the regimen," "tell me about when you get off track, and what is going through your mind in at those times," and "what is it that leads you to then conclude that you should get back on track?" The interviews were conversational and somewhat idiosyncratic as we followed where the informants led.

The interviews were audio recorded and transcribed verbatim, with participants' personal details deidentified. The transcripts were open coded, analysis of the coded transcripts led to further questions, and the researchers returned to the field. Ultimately, each informant was interviewed at least three times, while some were interviewed up to five times in order to conduct member checks, which helped to clarify or confirm what the researchers were finding in the data.

## **Data Analysis**

Our approach to data analysis followed the grounded theory approach originated by Glaser and Strauss (1967) and refined by Strauss and Corbin (1994). In grounded theory methodology, the coding and analysis processes are interrelated and referred to as open coding, axial coding, and selective coding (Strauss & Corbin, 1990). In the early stages of inquiry we focused on "open coding," that is, reading through the transcripts repeatedly and breaking the data down into tiny meaning units, while remaining noncommittal to an organizing narrative (Charmaz, 2014; Merriam & Tisdell, 2015; Saldaña, 2015). These codes were subsequently analyzed and written about in the transcript margins as part of the memoing process. Basic elements of the model took form when we grouped meaning units together and then collapsed into broader groupings called categories. We developed categories and then related them to one another in the process of axial coding. After we "opened up" the data and established links among the categories, subcategories, and properties, we engaged in "selective coding": developing a theory, based on the categories and their interrelationships, that described the

phenomenon under investigation. The researchers were the instruments of analysis and we did not rely upon a qualitative analysis software program.

We used three specific tools to integrate and refine the theory. First, we put outlines of categories, subcategories, properties, and dimensions on cards and tried to conceptualize the emerging theory visually, demonstrating with proximity and distance how the categories interacted with one another. Second, we sought to aid integration by writing a storyline connecting the categories. Finally, we reviewed the story for internal consistency and logical development. When the development of properties and dimensions were inadequate, we reexamined the memos and transcripts, or returned to the field to gather more data. We carried out these step with two additional peer debriefers who read and discussed the transcripts and analyses along with us.

### Results

The model that emerged from the interviews and analysis begins with disequilibrium ushering participants into a place of health decision-making (HDM), our central organizing category. HDM is then affected by three primary categories: knowledge, agency, and purpose. These categories not only influenced the HDM process, but also mutually influenced one another. For example, as a person had more, or certain types of, information about diabetes (knowledge), this enhanced their sense of control over the illness (agency). Alternatively, having a sense of agency or control over the events in one’s life increased the likelihood that one would seek to acquire helpful medical information (knowledge). Thus, the categories were conceptually separate from one another, but interrelated. As we begin to share results, we will note again that transcripts were de-identified and names the reader sees are pseudonyms. Table 2 provides an overview of the concepts that emerged from the data.

Table 2. Concepts

Key Concept	Definition
Knowledge	The information that the participants had about their illness
<ul style="list-style-type: none"> <li>● Factual</li> <li>● Feedback</li> <li>● Emotions</li> <li>● Experiential</li> </ul>	Information about the illness Information specific to the person An emotional response to diagnosis Personal knowledge acquired from having witnessed someone suffer
Agency	A sense of empowerment over health that stemmed from a belief that they could influence the outcome of the illness
<ul style="list-style-type: none"> <li>● Possibility thinking</li> <li>● Mindset</li> <li>● Choice</li> </ul>	The view that health was not predetermined Acceptance of diagnosis with a certain amount of resolve Locus of control and a perception of options

Purpose	An existential-level reason for living that infuses life with meaning and rationale for staying healthy
<ul style="list-style-type: none"> <li>• Mission</li> </ul>	A source of purpose that draws from a metaphysical sense of calling one perceives in their life.
<ul style="list-style-type: none"> <li>• Relationships</li> </ul>	A source of purpose that variously draws from caring for other people or avoiding imposing on others

### **Disequilibrium: A Shock to the System**

As participants described the process of being diagnosed, nearly all experienced some degree of disequilibrium. Disequilibrium was both a cognitive and emotional response. Participants were, variously, concerned, shocked, afraid, and angry as they dealt with the new diagnosis and considered the changes required of them. The degree of disruption varied depending on the amount of prior knowledge they had about diabetes and the extent to which other concerns already claimed their attention (concurrent challenges), which served as intervening variables.

Only 3 of 21 participants had almost no prior awareness or knowledge about diabetes. Not having any context in which to understand their diagnosis, their reaction was muted and tentative. Illustrating the nonplussed response that accompanied a lack of background knowledge about type 2, Quinn responded, “Shit! [laughter]. Well, I didn’t know anything about diabetes. I’m learning quite a bit. If I had known all about this and then found out, I probably would have been a little more upset that this had happened.”

A moderate amount of diabetes knowledge was associated with a greater negative, emotional response. This was illustrated in several interviews. Participants’ parents had died from diabetes-related causes. Friends had diabetes. The participants tended to evince more distress.

In contrast, higher levels of knowledge seemed to contribute to a more stoic acceptance as illustrated in the interview with Kelly, a healthcare practitioner.

Kelly: I diagnosed myself, basically. I was doing a screening program through the hospital. And two years in a row my fasting blood sugars came in a little high...Both of my parents are Type 2 diabetics, most of my aunts and uncles are, so it was just a question of “when.”

Kelly’s tone of voice, and acceptance or resignation, was echoed by others. More prior familiarity with diabetes seemed to lead to muted emotional response to the challenge.

Finally, people with stressors they deemed greater than diabetes seemed to minimize or mask the disequilibrating effects of the diagnosis. Bernice, 71, was just diagnosed with Type 2, but appeared unfazed. “...Just another one of those things that you cope with in life. I seem to be doing pretty well with it... I didn’t really ask to have the diabetes, but I’ve got it and I accept that fact.” She was much more concerned for her spouse who was living with Alzheimer’s. In the months during which the interviews took place, her husband would also suffer heart attacks. Her flat emotional response served to illustrate how concurrent challenges were associated with more muted disequilibrium.

Diabetes management begins with a diagnosis, which often initiates disequilibrium. The degree of disequilibrium or upset was affected by prior knowledge about diabetes and other issues a person may be contending with simultaneously.

## The Central Category: Health Decision-Making

After disequilibrium, participants proceeded to make decisions about how to respond to being diagnosed. Health decision-making (HDM) came to serve as the central category for the investigation. When pressed to explain the reasons for the decisions they made, three broad themes emerged from the data: knowledge, agency, and purpose.

**Category one: Knowledge.** Knowledge referred to the information that the participants had about their illness. Interviews and analysis revealed four different subcategories of knowledge: factual knowledge, feedback, affective knowledge, and experiential knowledge. We consider each in turn.

**Factual.** Typically, being diagnosed with type 2 began a long educational process. Doctors provided pamphlets, clinics offered group classes and counseling, and hospitals hosted weekend-long seminars. Most people craved more information about their illness at this time. As Steve remarked:

Steve: I found that if you have information, you get over your fears initially and you get something you can do about it. And once I found something I could do about it, like exercise, I guess I just took it by the horns.... Let me say this. I wish that education would have started... the moment I got out of the doctor's office because I was just like a sponge.

Interviewees identified understanding the consequences of diabetes and practical steps to manage their health as important factors in decision-making. Four of 21 informants emphasized the role of factual knowledge in decision-making to the near exclusion of other factors. Patient education simply directed their actions. "[Change] is more about education," explained Sam. Information describing the course of disease progression, in particular, appeared to prime people for change. These participants indicated that a combination of early diagnosis, warning about future consequences, and concrete steps to avoid or delay those consequences were necessary and sufficient to prompt change.

**Feedback.** Feedback, a second type of knowledge, is information specific to the person. Informants frequently spoke about the role of feedback in shaping their actions. Feedback took two forms: symptoms and health numbers. Informants attended to symptoms and talked about "listening to one's body." Others were affected by official numbers. As Betty noted: "My A1C was 7 point something...Seeing it in black and white on paper. I saw my blood results back and there it was. ...It's black and white and you can't get away from it." Clear boundaries and quantifiable demarcations for health and illness served as signposts for participants.

**Emotions.** Emotions also influenced HDM. All participants discussed having some emotional response to diabetes, notably anger, sadness, and fearfulness. The emotions varied in intensity, and varied in the degree to which they moved informants to act. Although informants experienced anger and sadness as they contended with diabetes, fear was mentioned by 17 of 21 participants and was viewed to be highly motivating, a point illustrated in the comment from Betty: "Part of my motivation is fear of what will happen if I don't take care of it. And I think fear is a good motivational factor. It's in the back of my mind..."

Fear emanated from a variety of concerns: impotence, amputation, blindness, and death. Being older and unpartnered added vulnerability.

Mary: I guess vulnerable is the word I would use because I feel as though I am at risk. Something might happen, and I don't have anyone right here and I don't want to be a burden on the children. So I want to keep myself in good shape.

Several other older, single females also echoed similar themes. A diagnosis, combined with being single, added to a sense of susceptibility and portended a loss of independence. Participants viewed this as highly motivating for lifestyle change.

**Experiential knowledge.** Finally, there was a fourth type of knowledge, acquired from having witnessed someone suffer through diabetes' consequences. This property, termed experiential knowledge, was closely associated with emotions, but separate and with different, non-overlapping indicators. Typically, experiential knowledge was marked by a vivid, disturbing visual image of someone close who was suffering the consequences of prolonged, poor diabetes management. Experiential knowledge served as a reminder and motivator to participants, and could be dimensionalized, like many other variables, along a continuum of "little effect" to "mobilizing."

Eighteen of 21 participants in the study were close to another person who had had diabetes. The salience of the experiential knowledge was affected primarily by the degree of injury the participant witnessed in the other person; needle sticks and amputations proved particularly vivid for participants. This is exemplified in Sally's explanation: "See these people out here (in the doctor's waiting room) with no legs, some with one leg; boy, that's the first thing that hits me. Then I see somebody taking a needle. Lord, don't let it come to that."

The different subcategories of knowledge were conceptually separate from one another, yet sometimes overlapped in an accumulating or synergistic way. Participants might describe seeing someone with a diabetic amputation (experiential) or seeing symptoms suggesting poor circulation (feedback) and then having great fear (emotional knowledge) and seeking resources (factual knowledge) about how to manage their health. The different types of knowledge were separate, and yet could combine to influence HDM.

**Category two: Agency.** The second category affecting HDM was agency, referring to a sense of empowerment over the illness and ability to slow the progression of the disease. Agency was supported by three subcategories: 1) "possibility thinking," in which participants perceived their future was undetermined and pliable; 2) "mindset," which was reflected a resolve a person had in addressing their illness; and 3) "choice," the extent to which a person felt capable to make decisions about their situation.

**Possibility thinking.** Participants with a higher degree of agency demonstrated a quality in their thinking described as "possibility thinking." An open prognosis, a future "not yet determined," or even future uncertainty seemed to empower participants. In contrast, forecasts and predictions seemed to foster passivity and resignation. Steve, among others, illustrate this open, possibility thinking through the use of multiple, conditional "if" statements. "If I take care of myself, if I exercise and eat right, I can manage it and it's not going to kill me. It isn't going to prematurely kill me if I take care of myself." Others communicated a similar "therapeutic uncertainty" through the use of "maybe" in their personal depictions of prognosis.

In a somewhat extreme illustration, Debbie demonstrated the power of "uncertainty" as she described starkly contrasting interactions with two different healthcare providers. She began by describing what might have been a factually accurate, if disempowering, prognosis given by her first physician. "My last checkup I had numbness in one foot... (the doctor) ... said it looks like you are going to lose your foot. It scared me. I left his office crying." Debbie decided to get a second medical opinion and relayed her experience to this other physician. This second physician did not promise a cure, but instead pronounced a therapeutic uncertainty: "it may or may not advance; we don't know." Debbie responded in a much more empowered manner toward her illness. Participants who believed the future was undetermined tended to believe they held the power to affect that future.

**Mindset.** In addition to describing "possibility thinking," informants who demonstrated agency described a certain mindset that went along with this sense of

empowerment. They used words and phrases like “acceptance,” “how I see it,” and “knowing I can do certain things” with resoluteness. Many informants accepted their new task of diabetes management with a certain amount of resolve, and, notably, a lack of emotional distress. Kurt captured the cognitive aspect of this subcategory through his use of the term “mindset,” an idea that would become the *in vivo* code for this concept.

Kurt: I guess I changed the next day, to be right truthful with you. It just needs to be done. ... That’s all you can do.

Int: For you the change was mostly a matter of intellect?

Kurt: Mindset.

When informants spoke of “mindset” it had a dispositional quality about it; accepting and responding to situations was a natural, unreflective, and instinctual response for high agency individuals and seemed to reflect a general approach to life.

**Choice.** The third category that facilitated agency over the disease was “choice.” For participants to develop a sense of empowerment with their health, it helped to not only have gritty, determined resolve, but a course of action to take. Choice contained two important properties: locus of control and the perception of options. Locus of control (Rotter, 1954; Wallston & Wallston, 1978) reflects the extent to which an individual ascribed decision-making power to themselves or to other factors. Some interviewees felt their ability to make healthy decisions was overwhelmed by a variety of circumstances while others identified with an internal locus of control. Evan described falling short of his goals and blamed weather, finances, lack of diabetes recipes, and time for all conspiring to keep him from exercising or eating well. At the other end, participants with a more internal locus of control spoke to prioritizing.

Sam: I think that a person determines the state of their health more than anything else. And with this you optimally have a lot of control. It is something you really can work with.

I think you can get to a certain level [of busyness or preoccupation with work] and don’t care of anything and let things just sort of fall where they will. I think that can be a factor.... I think priorities is a better way of expressing it. You put your health above other situations. You take care of your own health needs first.

A second important property of choice was the perception of options. Whereas locus of control described an attribution of decision-making power, perception of options was a mental assessment of what choices could be made. People might view that they had no choices to make; they simply had to act. Others thought they had great latitude. The hospital where Mary received her diabetes education emphasized that patients have choices. On the face of it, “choices” might seem to empower the patient and reduce reactivity to being told what to do. However, it is not clear that this served people well. Mary appeared to be awash in choices. Mary claimed to have made some changes to her diet, but her emphasis on choice appeared to increase her angst.

Mary: Today was teacher appreciation day and the PTA brought in little ice cream sundaes for everyone. Well, I went ahead and ate one because if I sat there like a martyr I would have been really miserable. And I really wanted it.

On the other hand, participants who applied more rigid rules to their diet made healthier choices and, significantly, with less emotional turbulence. Regarding diet, Steve stated matter of factly, "I didn't think I had a choice. I still don't."

The property "perception of choice" shared some common characteristics with the subcategory "mindset." In both cases, whether they had many choices or no choices seemed self-evident to participants, parts of an invisible, presuppositional lens. Also similar to "mindset," people who believed the only option was lifestyle revision indicated less emotional distress over their initial diagnosis and less torment over each day's choices.

Participants varied in the extent to which they believed they had options in managing their health. The five participants who reported the most significant change to their lifestyles did not allow themselves to consider they had choices. Others believed they had many options, deliberated each decision, and anguished over what they denied themselves. At least in this sense, having a reduced perception of options appeared to be associated with more successful diabetes management. Agency, with its components of possibility thinking, mindset, and choice, emerged as a second category affecting HDM.

**Category three: Purpose.** When people talked about HDM, they often invoked "purpose." It provided some existential-level reason to stay alive and well, and which influenced their health decisions. The category of purpose had two properties: mission and relationships. Purpose generally emanated from two sources. First, participants spoke of spiritual underpinnings and invoked "God," "faith," or "plan," which we will call "mission." A second source of purpose was found in relationships.

**Mission.** We define "mission" simply as a reason for living. One third of participants indicated that they viewed health and faith as intertwined. Ted, who has a leadership role in his church's youth ministry, connects faith to living as he explains, "God wants me to do something down here. He would have taken me a long time ago in certain situations if He didn't." Mission infuses life with meaning, and provides *raison d'être* to be healthy, as poor health interferes with one's calling.

**Relationships.** For Ted and others, "doing what God wants me to do" is interlocked with relationships; caring for others is the mission. Indeed, 18 of 21 participants mentioned relationships when they described their motivation to remain healthy. Relationships predominantly referred to family (16 of the 18). Spouses were mentioned, but more often children and grandchildren provided a sense of purpose and imparted greater resolve to stay healthy. Betty illustrates, "My youngest is only 24. I'm going to stick around a long time in good health. I want to be at his graduation." Another informant spoke so endearingly of how her "children" needed her that it eluded the researchers for much of the first interview that she was referring to nieces and nephews. Informants often identified their children as factors that motivated them to be well.

Relationships frequently revolved around the highly valenced notion of "need" or "caregiving." "Need" in this study was defined as contributing uniquely and vitally to the welfare of others, and helping others seemed to be the fundamental ingredient of relationships affecting HDM. The more the participants believed they were needed by others, the greater the healthful incentive they ascribed to the relationship. Sally described feeling responsible to protect nieces and nephews in a dangerous world and to see them succeed. Believing she played a unique and indispensable role in the welfare of others made those relationships important, gave purpose, and energized health-related decisions.

"Need" also cast a similarly motivating, but negative, pall: a fear of being "in need" of others. Typically this was couched in terms of being "a burden" to family. Although it was purposeful and productive to give help to others, it was flatly unacceptable to receive help from the same. Christine articulated thoughts voiced by many others: she maintained her health because she did not wish to live a nursing home. A picture window in her apartment overlooked

a convalescent home, regularly reminding her of this possibility. Living with family was not an option in her mind:

Christine: My kids have got their own life. They don't need to worry about a mother in a nursing home. And there's no way I would go live with my kids rather than [a nursing home]. NO. Their lives are their lives.... They [my kids] don't need this.

As participants talked about what influenced them to make health decisions, purpose proved important. Mission, having some reason for living that was larger than oneself, was one facet of purpose, and this often occurred in context of relationships, a second facet. Informants were motivated to take care of themselves when they believed that they were needed by others, but a fear of needing others and being dependent also presented compelling reasons to take care of their health.

## Discussion

### A Grounded Theory Model of Factors Affecting Patient Decision-Making

Our purpose in this research was to consider factors that people, recently diagnosed with type 2 diabetes, said were involved in their health decision making process. We sought to develop these categories in a way that authentically captured and honored participants' voices. We also considered how the categories disequilibrium, knowledge, agency, and purpose worked together to affect health decision-making. This portion summarizes and reviews the model that emerged from the interviews.

Upon being diagnosed, participants experienced disequilibrium, a significant change to self-perception and emotional upset. Disequilibrium was affected by the amount of prior diabetes knowledge and also any other concurrent challenges the person might be experiencing. Three factors were found to mute disequilibrium: extensive knowledge or very little prior knowledge about diabetes, and other crises. Moderate diabetes knowledge and an absence of other crises were associated with more disequilibrium. This initiated a process of health decision-making, which was affected by three other primary categories with greater theoretical heft: knowledge, agency, and purpose. These categories conspired to influence how people made health decisions.

The category "knowledge" reflected what the participants knew about diabetes. It had four properties: feedback, information, experiential knowledge, and affective knowledge. These properties reflected differences in how the participant came to acquire the knowledge and also variations in arousal generated by the knowledge.

Feedback referred to a factual self-knowledge about the effects of diet and exercise on health. Proximal blood glucose levels might influence the immediate decision to snack or not, while the more durable measures, such as the A1c and weight, provided more general guidance concerning the effects of choices. Participants with agency and purpose would use this information to guide their actions.

Information, often conveyed through pamphlets or diabetes education classes, helped participants understand how to manage their illness. This study, however, did not find that information by itself was strongly motivational. It formed options, but did not compel participants to take one path or another. However, research data suggested that information was associated with a reduction in fear, as participants learned actionable steps they could take to manage their health.



Other forms of knowledge were marked by heightened arousal and motivated action. Experiential knowledge, knowledge that was less informational and more personal, increased distress. Participants vividly recalled others' experiences with diabetes-related blindness or amputations, which usually led to fear, which we are calling an affective knowledge. Thus, an increase in negative experiential knowledge contributed to an increase in emotional knowledge. Among the four properties of knowledge, emotional knowledge may have the most influence on health decision-making; fear appeared to contribute significantly to successful lifestyle change.

Movement also required agency, a sense of empowerment over their health that stemmed from a belief that they could influence the outcome of the illness. This emergent category was termed "agency," instead of self-efficacy, because it arose from in vivo code and because of an intent to avoid imposing theory or constructs a priori upon the data. A participant perceived agency as a result of three factors: 1) possibility thinking, 2) mindset, and 3) choice. As participants experienced greater indeterminacy regarding disease prognosis, reflecting "possibility thinking," and greater resolve (mindset), their sense of empowerment increased. Participants who perceived too many choices experienced diminished agency and tended to fret over their options. But knowledge and agency alone were insufficient to induce change; participants needed to have a reason or purpose for their efforts.

Purpose emerged from two places: a sense of mission and relationships. First, many participants held a spiritual view that imparted meaningfulness to their lives. This provided a positive reframe for hardship and minimized the perceived unfairness and immobilizing anger that sometimes accompanied the diagnosis. For some, this perspective also offered a sense of control and empowerment, though other participants indicated that faith was irrelevant in their diabetes management. Second, relationships with others and being needed by others made it important to stay healthy. There was some evidence that as the relationship became more equal and mutual, the perception of purpose diminished a roughly equal amount. An overview of the model is represented in Figure 1 below. In this model, arrows are used to represent an influencing relationship. Knowledge, purpose, and agency each influence one another, but the addition of more arrows made Figure 1 overly complex.

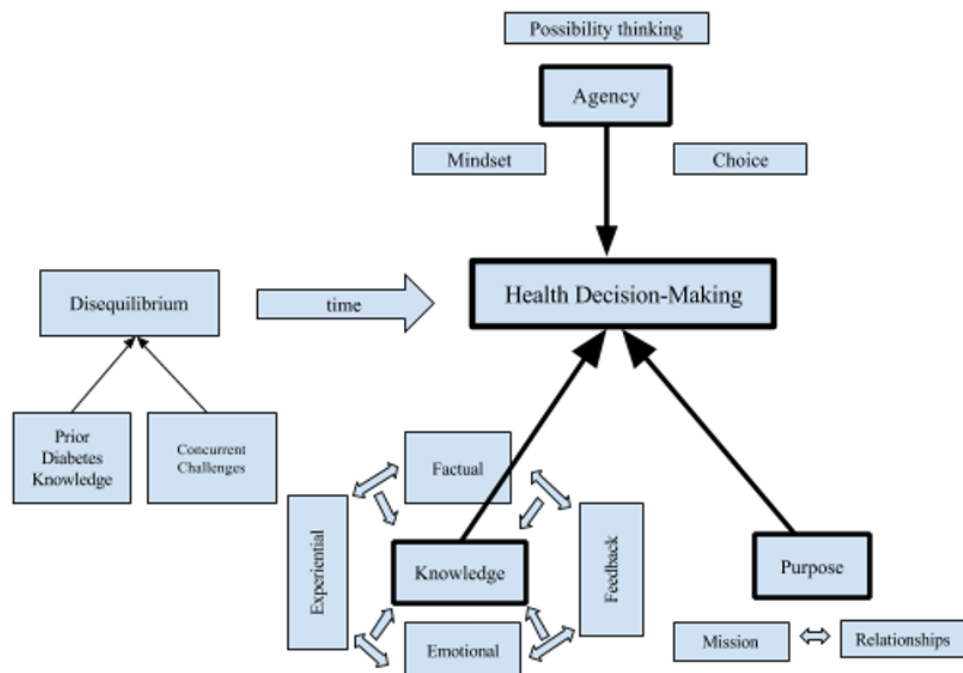


Figure 1. The major themes.

## Findings in Context

This grounded theory emphasizing knowledge, agency and purpose integrates well with other constructs from social sciences: (a) Bandura's construct of self-efficacy, (b) recent research into the demotivational aspects of choice, (c) Dweck's work on "growth mindset," and (d) the construct of eudaimonia.

The construct of agency overlaps somewhat with Bandura's idea of self-efficacy (1977b). Self-efficacy, a cognitive component within Social Cognitive Theory that has been used broadly to explain the adoption of healthy behaviors, refers to an optimistic, realistic belief that one has the power change their situation by taking adaptive action (McAlister, Perry, & Parcel, 2008; Patterson, Mausbach, Lozada, Staines-Orozco, Semple, & Fraga-Vallejo, 2008; Tougas, Hayden, McGrath, Hugué, & Rozario, 2015; Young, Plotnikoff, Collins, Callister, & Morgan, 2014; Zhang, Jemmott III, & Jemmott, 2015). Bandura (1977a) also noted that social learning theory emphasized the "informative function of physiological arousal" (p. 199). Although fear and anxiety were generally viewed to impede self-efficacy, he recognized that emotions sometimes function to steer a person away from certain consequences. Time and again in this research, participants identified fear as mobilizing.

Second, participants seemed to fare better, reporting more success in making healthy changes while also reporting less emotional distress, when they believed they had no choice but to follow the new regimen. This is consistent with writings by Schwartz (2000), reviews by Kinjo and Ebina (2015) and research by Iyengar and Lepper (2000) who found that too many choices impeded people's abilities to make decisions. Of note, Vohs et al. (2014) conducted an experiment which found making choices taxed ego and depleted subsequent self-control.

Finally, Carol Dweck has found that a growth mindset, the view that intelligence or other skills are malleable, is associated with improvement in those skills. This contrasts with a fixed mindset or the view that the skill is more of an unchanging trait (Dweck, 2006). This is somewhat resonant with the finding that an indeterminate future energized healthful decision-making over views that health outcomes were already determined. Dweck's research and model focuses on an internal trait being fixed or not; our findings drew attention instead to the future being fixed or flexible.

Finally, these results align with findings on the importance of relationships for health and eudaimonia, or well-being. The interviewed informants frequently noted that they were motivated by their personal relationships. Other research finds that relationships, notably marriages, affect health (Birditt, Newton, Cranford, & Ryan, 2015; Holt-Lunstad, Smith, & Layton, 2010; Robles & Kiecolt-Glaser, 2003; Robles, Slatcher, Trombello, & McGinn, 2014; Uchino, 2006). This research drew attention to the importance of being needed by others to give, help and assist. This overlaps with research on an Aristotelian construct called "eudaimonia," which is loosely understood as human flourishing (Fowers, 2005, Fowers, 2016; Ryff, 2014). Eudaimonia, or flourishing, often occurs in the context of giving relationships (Fowers & Owens, 2010; Ryff, 2014; Schwartz, Keyl, Marcum, & Bode, 2009; Schwartz & Sendor, 1999) and research has found it to be associated with positive health (Ryff, 2013; Ryff, Singer, & Love, 2004). This model supports the view that relationships and meaning or purpose, matter a great deal to the patient as they make choices that affect their health.

Our theory of health decision making shares some features in common with patient care models and other general models that explain changes in health behaviors. However, it deviates from these models by not focusing on a sequence of stages, cognition, or balancing costs and benefits. Instead it takes into account the complex, interrelated influences of knowledge, agency, and the generally overlooked construct of purpose.

## Implications

This study has several implications for practitioners. First, it was important for people to have a life infused with a sense of purpose. People were motivated to avoid pain and death. However, when pressed about their motivations, informants spoke about the need to fulfill a calling, a mission that was usually enriched by, if not defined by, relationships. Healthcare providers may find it useful to assess and promote patients' vital relationships.

Second, it was important to foster a sense of possibility and change - the indeterminate nature of the future. This fed a sense of agency, optimism, and action. In contrast, forecasting a particular outcome tended to foster passivity and resignation. The biopsychosocial approach, which emphasizes the dynamic interplay that the mind and environment can have on biological processes, suggests that it may be of greater benefit to patients to exercise humility over what we "know" about future events. If negative information must be given, it should likely be couched in tentative or "if-then" language. It may be practical to simply leave the future open and as one participant's physician told her: the neuropathy may "stay in just that one area the rest of your life. It may move to other areas. *We don't know.* [italics added]"

Finally, the findings remind us of the importance of including feedback in interventions. People require feedback to direct their steps. A key clinical task is to discern what constitutes meaningful feedback for the patient. Our findings suggest that measures that were quantitative were more easily translated into feedback that connoted meaningful feedback that made a "difference" for subjects.

## Limitations

This research was based on a convenience sample, with many participants being involved vocationally with the healthcare profession. All informants are subject to a volunteer bias which may make them unlike others who did not participate in the research. For instance, the findings suggest that the diagnosis of Type 2 diabetes inexorably drew all of them into an active HDM process. However, other research suggests that this is not necessarily typical, with as many as one third of people who receive irregular blood glucose readings at public screenings not following up on this alert with a physician (Jagiello, Johnson, & Plake, 2001). In contrast, participants in this research were beyond denial and were in the care of a physician.

Additionally, this study sought to identify the factors that influenced health decision-making, not establish that these factors would produce certain outcomes. As a result, specific changes and outcomes were not verified. This study was limited in scope to the patients' explanation of decision making, and developing a model based upon their narratives. Though we set out to develop a new model of health decision-making, it is likely more appropriate to think of these interacting categories as a heuristic to launch further inquiry.

Future research could conduct quantitative research to test predictions suggested by the emerging model. For instance, researchers might attempt to develop scales to measure the three categories. Following this, we might see a natural experiment that tests the relationship between the categories and participants' A1c to indirectly assess the relative influence of the different categories on health decision-making and to examine interaction effects.

Ultimately, our review of the literature suggested that the role of the patient in health decision-making had been neglected. Improvement in diabetes management might reasonably follow a better understanding of the factors that relate to patient decision-making. This research offers a new insight into HDM, one that includes familiar constructs of agency and knowledge, but also draws attention to the importance of purpose and meaning in the person's life.

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