"I'm The One That Understands What's Happening To Me":
Sensemaking Narratives of People with Type I Diabetes

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Thesis

Submitted to the Faculty of the

Graduate School of Vanderbilt University

in partial fulfillment of the requirements

for the degree of

MASTER OF ARTS

in

Medicine, Health and Society

December 16, 2017

Nashville, Tennessee

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Introduction

Healthcare research has long examined how social, emotional, and technological factors (Turner and Kelly, 2000, Okken et al, 2008) can complicate the task of diagnosis, impact the course of a disease, and pose hurdles for a patient's ability to adhere to recommended therapies (Martin et al, 2005). Yet modern healthcare practitioners have few resources to address the biological impact of non-biological influences (Borrell-Carrio et al, 2004). This is especially concerning in chronic conditions where care is largely provided outside of a medical setting and over a long period of time.

In the well-intentioned work of patient education practices, traditional biomedical research methods offer few conceptual resources for understanding *how* patients communicate their ways of knowing. This leaves aspects of a person's illness experience downplayed or discarded outright.

People living with a chronic condition experience a way of knowing that differs from the biomedical model of knowing. A way of knowing simply means the methods through which knowledge becomes apparent. (Knight and Mattick, 2006, Amin and Roberts, 2008) While biomedicine relies on scientific guidelines, patents understand and respond to disease processes through their physical sensations or limitations, and by local and cultural orientations "[which] organize conventional common sense about how to understand and treat illness" (Kleinman, 1988). In treating chronic conditions, understanding and communicating about a person's illness experience can be equally as important as addressing the course of the disease. (Pols, 2005) Unfortunately, little research has sought to examine how patients form their understanding or how they construct and perceive the task of their self-care activities.

This research aims to examine patients understanding of their illness and how they express their ways of knowing. Looking to patients' stories may give insight into the way they perceive and construct illness as well as how they enact their responses.

To do so, this paper makes two arguments: First, patients communicate their understanding through stories which reflect the current and on-going process of collaborative sensemaking regarding their illness. Second, patients actively use these stories in their self-care activities.

Subject Background

2.1 Illness and Disease

Biomedicine targets disease; a construct describing abnormalities of expected physiology (Kleinman, 1988). Elements of disease are measurable, quantifiable and thus can be described with precise language and foster universal interpretations. In contrast, illness is "what a patient feels when they go to the doctor (Kleinman, 1988). Illness is personally experienced, but socially constructed. Illness inheres physical experiences with biographical particulars and emotions, and illness begins when these experiences are linked together in culturally and personally relevant ways. Illness contains emotional, embodied, and social information, all of which impacts the interpretation of the experiencer. (Berg, 1999, Rhodes et al., 2015) So while a blood pressure reading of 140/ 90 is interpreted as "high" in any allopathic practice, regardless of location, the concern of "chest pain" is wholly dependent on who is feeling the sensation.

While healthcare research has acknowledged the broad impact of non-biological factors in patient health and health outcomes, (Berg, 1999, Casper and Berg, 1995) there has been little guidance on how to fully understand and attend to the mechanics of these influences. This is not to say that practitioners ignore social or environmental influences - quite the opposite, in fact.

Knowledge of an illness, just as any other knowledge, is socially produced (Snowden, 2005). Although often unacknowledged, healthcare providers often have a unique experience of illness beyond their clinical knowledge of disease. A person suffering from a condition 'knows' about their condition as an illness and their perspective may differ substantially from how a practitioner 'knows' about the condition as a disease. The sufferer experiences an 'introduction' of the illness into their life through the variety of physical sensations and emotional tolls. Their illness *is* the impact their condition forces upon their activities of daily life: the frustration of living within physical limitations, the change in the quality of their normal social, work, or familial roles, and the emotion-work of managing their own responses and the responses of others. A practitioner, while perhaps not physically experiencing the condition, also cultivates an emotional and practical interpretation beyond the academic concept of disease. (Berg, 1995) The practitioner may regard the illness as a puzzle to be solved or as a challenge for patients. It may be their life's work, or just another ailment they help others manage.

Both patients' and providers' acknowledgement and interpretations of disparate but relevant variables influence the conception of the illness and the approach to patient self-care activities. This is particularly true in chronic illnesses as these long-term conditions typically affect multiple areas of life. These different ways of knowing can cause frustration in the patient/provider relationship and negatively impact health and treatment outcomes (Harding, 1988).

2.2 The Challenge of Diabetes

Diabetes is a challenging chronic condition characterized by the body's inability to regulate the amount of glucose (commonly referred to as sugar). During digestion, food is chemically broken down. Glucose is a simple sugar byproduct of food metabolism that the body uses as a form of energy.

In order to make use of glucose, a body requires a protein, insulin, produced by the pancreas. If the levels of glucose run too high organs suffer irreversible damage. If they fall too low a person could enter a coma and die.

There are two distinct forms of diabetes- type I and type II. Type I diabetes is characterized by the failure of the pancreas to produce sufficient insulin, while type II is typically the result of an excess amount of fat tissue which creates a relative insensitivity to the insulin produced by the pancreas. The result of high blood glucose is the same for both types: sustained elevated levels damage internal organs, blindness, and through constriction of the blood vessels to the extremities, result in amputation of digits or limbs.

While some people with type II diabetes use exogenous insulin, many people with type II diabetes can control their glucose levels with oral medications and dietary changes. For some, their condition can be reversed with weight loss. Type I diabetes, however, is a lifelong condition and cannot be reversed. People with type I cannot produce a sufficient amount of insulin and must manually manipulate their glucose levels with insulin injections as well as diet choices.

In order to stay alive, in-the-moment medical decision making and interpretation of numbers, sensations, food, and activities is vital. Meals and snacks must be evaluated for content and frequency. As noted previously, the body depends on a continuous but balanced supply of glucose and insulin, and both rest and activity can have immediate and extreme effects. This means a person with insulin-dependent

diabetes must continuously interpret glucometer readings, physical sensations, timing, type, and availability of food, and activities in a specific way. Physical activity must be evaluated for intensity and duration. Administration of insulin may require careful titration based on a given carbohydrate algorithm and physical sensations must be detected attended to prevent dangerous glucose highs and lows. Self-care demands that these variables are continually monitored and self-care practices maintained with precision in order to avoid potentially catastrophic repercussions (Turner and Kelly 2000, Okken et al, 2008).

Because the acts of administering medication, evaluating nutrition intake and activity stressors, and monitoring one's physical state are all performances of medical decision-making, people with diabetes are themselves their principal health care provider as well as patient. In order to safely and reliably care for themselves, people with diabetes construct an internalized understanding of their physical condition as it relates to their social and emotional realities and personal values. As patient and provider, they have access to both physical sensations and medical decision-making authority which allows for the interpretation and organization of their health needs and activities in social and emotional contexts.

2.3 Patient Activities as Patient Adherence

Adherence to therapy is the subject of a large body of healthcare research (Turner and Kelly 2000, Martin et al, 2005). Just as patient and provider perceptions of a health condition is a construct of interpreted relationships with physical, emotional, and social contexts, so are approaches to management and care. Helping patients construct and execute reliable self-care routines is a principal challenge for physicians, patients, and the provision of healthcare.

A growing number of studies have recognized the complexity inherent in a patient's lived environments and the situational factors related to adherence (Okken et al, 2008, Borrell-Carrio et al., 2004), however, patient outcomes studies often evaluate patient activities and patient behavior through the lens of adherence, or measuring how closely a patient's actions meet the therapeutic recommendations of the provider. These approach patient adherence and patient comprehension as exchangeable proxies: if a patient is not performing the expected actions, then the patient has insufficient information regarding their condition or insufficient problem-solving resources. Therefore, satisfactory patient education - concerning the nature of the disease and its treatment - will translate into better adherence. This

supposition pervades the diabetes self-care research literature resulting in an emphasis on intra-personal characteristics of the diabetic patient or, in the case of pediatric patients, adult caregivers. For example, studies have examined stress and coping skills, motivation, problem-solving, health literacy and numeracy and other psychological characteristics such as self-efficacy and positive affect.

This assumption evaluates patient understanding against the biomedical perspective. Efforts aimed to improve patient problem solving skills or increase patient knowledge of disease and consequences require the adoption by the patient of biomedical ways of knowing. As noted previously, a variety of situational variables shape self-care decisions and activities, and these factors are rarely considered by scientifically-rational ways of knowing.

Analyzing patient actions through a medical lens is ontologically inappropriate and renders outcomes from such an approach epistemologically flawed. The biomedical framework truncates patient-relevant variables and evaluates patient actions within a framework different than the one in which they were formed. This disenfranchises patients by silencing the expression of their own perspectives and thus strips them of the ability to shape their care without risking negative health consequences or strained relationship with their provider, while simultaneously marooning practitioners with a single resource (approach) to help struggling patients.

This research examines interviews with people diagnosed with Type I diabetes to investigate how patients ground their understandings of their illness, and how these understandings are reflected in their current self-care routines.

Theoretical Background

3.1 Narrative Theory

In order to examine how individuals understand their illness and shape their health-related activities, it is first important to understand the way personal experiences and understandings are communicated-namely through narrative stories.

Stories are part of everyday conversation, and structure everyday thought and communication. Stories are constructed representations of past events, in any medium, selected for the purpose of focus and commentary (Maines, 1993 Simmel, 1950). Stories can be works of fiction, family legends, national histories, or personal accounts. This work specifically examines narrative stories (shorted to narratives throughout).

Narratives are a subtype of story whereby events are communicated from the particular view of an individual or group (Adorisio, 2013). As with all stories, narratives are created when previous events are selected for examination and conferred a structure, meaning, and context. However, they are unique in that they are constructed with the creator's personal interpretations and valuations of the events. Narratives integrate, consciously or non- consciously, the speaker's ways of knowing. So, while a narrative's content may relate "what happened" using the same events in the same order as other narratives, the individual's implicit appraisal of the events, the intended understanding, and even the fact that the narrator found the events 'worthy' of being storied, reveals the moral meaning (Maines, 1993). Narratives themselves are 'texts of experience' (Maines, 1993, Gubrium and Holstein, 1998). In imposing a conceptual structure, narrators transform their experiential bricolage into a decipherable, coherent, useable form to offer to the audience. Ewick and Sibley (1995), note "stories people tell about themselves and their lives both constitute and interpret those lives; the stories describe the world as it is lived and understood by the storyteller."

3.2 Narratives in Praxis

In everyday conversation, individuals manipulate colloquial language to convey their perspective. This is extremely difficult. The influence of history, biography, culture, and identity unconsciously shape an individual's way of knowing and are fundamental to their view of the world. Narratives serve as one method by which a person can share their understanding.

For instance, in order to explain why one regards their co-worker as a "strange" person, it would typically be insufficient to simply state that the coworker is "strange". Likely, the person explaining would offer examples to fully develop their meaning. She may talk about actions she has seen the "strange" person do, relate conversations she has had with the co-worker, or perhaps just describe the way she has seen the co-worker interact with the work environment or other employees. Every example is a distinct construct intended to convey her precise interpretation of "strange".

Fundamentally, every example is a story. Each example is a distinct and independent creation, formed when a speaker isolates a number of past events specifically for the purpose of explication. The speaker then communicates the events to another within temporal order. This temporal order is not just reporting the events as they occurred through time, but serves to ascribe a meaning to the events relative to the flow of time. If someone covered their mouth then sneezed, it would mean something different than if they sneezed then covered their mouth. While the actions are the same, the temporal order imposes a different relationship and interpretation of the events by characterizing the relationships of the events to each other and to other external information (e.g. it's flu season).

It is important to note that even though narratives (examples) relate interdependently, they do not typically cohere into a larger story. Narratives and their relationships communicate the speaker's way of knowing. Narratives are the *medium* of transmission. Volunteering a narrative is an invitation to bond-it invites others to share a reality. They are an explanation or an attempt to convince another person to share in one's personal way of interpreting past and present relationships within the world.

<div align="center">3.3 Healthcare Narratives</div>

A person with a chronic illness such as diabetes experiences a different reality than those without such conditions. Managing diabetes results in common situations taking on new meaning. The prospect of eating generates specific considerations and evokes a set of rules regarding the type, quantity and timing. The flow of the day may include intervals to evaluate how they physiologically feel or to check their blood glucose. Dinner invitations may require specific information about ingredients in meals while outings demand knowing the intensity and duration of activities.

As noted previously, patients and practitioners bring different ways of knowing into the clinic. The biomedical approach seeks to describe and remedy disease; thus practitioners often seek to enumerate

relevant factors (which are dictated by established biomedical ways of knowing) in order to to describe the relationship among the factors, to ultimately provide recipe for action. (May and Ellis, 2001) Patient's illness narratives also seek to identify treatment paths by identifying and evaluating relevant factors but do so within their way of knowing. Relevant factors may include maintaining relationships, or being able to do particular tasks. In describing the relationship among these factors, illness narratives may include descriptions of how chronic pain has altered the nature of established relationships, or how a disability has stopped them from performing tasks crucial to his or her identity.

Although medical practices have attempted to incorporate patient narratives into patient care (Pols, 2014, Heaphy 2017), providers are often at a loss on interpreting patient's experiences. Even if a provider has personal experience with a condition, they have few tools to incorporate and use non-biological information in a clinically meaningful manner. In practice, efforts often transform patients' ways of knowing into a form amenable to biomedical understandings. Efforts to use patient experiences have created "symptom scales and surgery questionnaires and behavioral checklists [which] quantify functional impairment and disability rendering quality of life fungible" (Kleinman, 1988).

3.4 Sensemaking

Stories are subjective creations of *sensemaking*. Sensemaking is the reflexive process of ordering and interpreting information from the environment. Sensemaking describes how individuals make 'sense' of everyday life. (Weick 1995).

The term "sensemaking" describes both the action and the theory of how people and groups create communal understanding (Weick, 1993, 1995, Feldman and Feldman 2006, Bijker et al. 1997). Since its initial conceptualization in 1972, sensemaking has become an umbrella term and has been used in research fields as disparate as deaf culture (Linderman, 1997) and reflective thinking (Teekman, 1997). Within the abundance of sensemaking research there is no single definition or approach. For the purposes of this paper, the concept of sensemaking as a theory and a process is drawn from the work of Karl Wieck, one of the early scholars of sensemaking.

3.5 Sensemaking as a Theoretical Perspective

Sensemaking theory posits that the smooth operation of everyday life occurs when those existing within a social space share a general comprehension of what is 'happening' and what the events "mean". Wieck (1995) describes sensemaking as "a social process that creates a shared awareness and understanding out of individual perspectives and interests". Social groups members seem to instinctively know when, where and how to follow invisible, unspoken rules. For example, most people in western societies know to queue at a bus stop, move their car to the shoulder of the road so an emergency vehicle can pass, or wait to for a hostess when entering a restaurant. Sensemaking examines this phenomenon of collective comprehension framing higher order patterns of interpretation and action as fundamentally irreducible to the individual. In other words, sensemaking is how a person may individually interpret information from the environment, but the inferred meaning is not an exclusive interpretation, but part of a larger group thought pattern.

3.6 Sensemaking as a Process

As an action, sensemaking is guided by plausibility. It is an effort aimed to comprehend a situation only in so far as to determine one's place in it. When faced with ambiguous or novel situations, sensemaking only seeks to know "what's going on so you can figure out what to do" (Adam, 1993).

To quickly and efficiently generate this interpretation, previous experiences and understandings are used as sensemaking heuristics. This can mean comparing present situations to similar experiences in the past, or to examine events of the near-past to figure out how a situation came about.

Although sensemaking's retrospective analysis clarifies a situation in that it ascribes a general meaning, but doesn't make it transparent. Sensemaking is an action driven to discover enough information in order for the individual to react properly, not to uncover underlying truths. For example, suppose a person driving his usual route to work encounters this scene at an intersection:
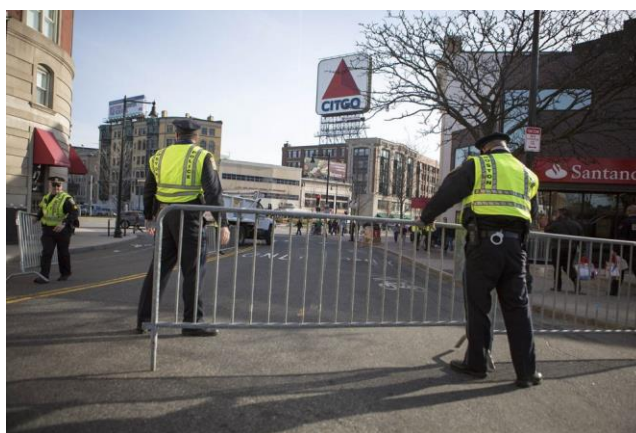
Figure 1. A scene at an intersection

In Figure 1,the environmental information includes (among other elements) the presence of the police vehicles, the movement of the other civilian vehicles, the presence and movement of pedestrians, the meaning of the signs, and the intended meaning officer's movements.

Sensemaking is not a process of production or coming up with the "right" answer, but rather a deliberation of possible and plausible explanations (Klein, Moon & Hoffman, 2006, Reynaud, 2005). The driver's sensemaking goal is to generate a reasonable interpretation of the situation which will to inform what he should do.

Previous experiences are sensemaking heuristics – either by comparing current situations with similar experiences in the past, or examining recent events to see how current situations came about. In this example, the driver may have previously seen similar barricades installed because of vehicle accidents.

Acting on this perception, the driver may understand his relationship with to the situation as that of a bystander. In the bystander role, the socially appropriate behavior is to follow the directives of the officer. Therefore, his interpretation of the situation shaped his identity which ultimately informed his actions. The cause of the barricade's existence is immaterial. The driver has made sense of the situation, decided on his role and appropriate behavior within the situation and that is sufficient.

However, sensemaking is a perpetual process. Action and knowledge are recursively entangled in sensemaking (Colville, Pye and Brown, 2012) and this recursive relationship means that the driver will continue to evaluate the validity of his interpretations and adjust if necessary. Suppose in his previous

experience, the accident was cleared and bystanders were instructed to drive around the barricades. His perceived knowledge of the situation guides him to slowly advance around the barricade. As he takes this action, he will continue to synthesize environmental inputs.

However, all sensemaking is a flawed process (Weick, 1995). If an officer blows his whistle and waves his arms, this would be unusual, unexpected information. The driver would interpret this to mean that his actions were incorrect, stop his car, and re-trigger a sensemaking process, by re-examining the environment to make *new* sense of the situation. This new examination may reveal runners on the road which indicate the barricade marks a marathon route, not an accident.

Sensemaking is an understanding (interpretation) of relationships and interactions, not renderings of objective reality. Therefore, this paper does not assume sensemaking is necessarily useful or useable but regards an individual's sensemaking processes and outcomes as real insofar as they are constructed realities for the sense-maker.

3.7 Sensemaking and Common Sense

Sensemaking is a reflexive action of interpretation powered by tacit knowledge. It satisfies the need to quickly comprehend a situation to guide one's response to it. It brings an individual to understand "what is going on here" by inferring meaning among relationships and interactions of people, explicit and tacit social knowledge, and the relationship of each of these elements with the identity of the perceiver (Reynaud, 2005, Rutledge, 2009). Sensemaking creates 'narrative sense' or a 'common" sense, sensemaking is the process that creates the built reality or life world within which the individual lives (Patriotta, 2003).

Despite the psychological veneer, sensemaking is a fundamentally social activity. Interpretations of familiar and unusual situations are reflexively negotiated and enacted through social interactions. First, elements of a situation are filtered in order to divine which pieces of information should be attended to and which are irrelevant. The importance or irrelevance of variables is evaluated through individual social and cultural understandings. Additionally, the inferred meaning of the relationships is also culturally and socially influenced. These proposed explanations are prescribed by culture, beliefs, and biography.

Second, sense-giving (encouraging a particular view) and sense-receiving (accepting a particular view) foster a shared group concept of a situation. In unfamiliar situations, individuals look to others for help in understanding equivocal events, and discuss interpretations as a way of negotiation to accept, reject, or modify understandings. (Pajak and Green, 2003, Leonardi 2001, Laroche and Laroche, 1995). As each individual in a social space seeks to interpret events to discern their appropriate role the interpretation is important so that an individual's behavior is socially predictable to those around him, and those around him are also expected to behave predictably as well. This means that rather than an individual apprehending objective reality, the process of sensemaking produces a collective cognition. This social action underpins the ability to conduct cooperative work and cooperative social action (Engeström, 2001, Fayard and Weeks, 2014). As groups of people act, they take their collective patterns of action and interpretation for granted, seeing these patterns as part of a reality that exists independently of them and which would continue even without their participation in it" (Berger & Luckmann, 1966).

3.8 Sensemaking and Health

The intimate relationship between situational comprehension and an individual's subsequent response is especially relevant in chronic disease health care. As noted earlier, patients are often their own practitioners and constantly tackle equivocal events and uncertainty concerning health-related issues. Patients must engage with a suite of variables to interpret before they can decide on an appropriate course of action. (Pentland and Feldman, 2008)

Further, as individuals typically regard their sensemaking perceptions as renderings of objective reality, especially in group contexts, interpersonal communication assumes this shared perception. (Hardwig, 1988) Therefore, while a person with diabetes may offer stories as communicative actions which for them hold obvious sensemaking and moral meanings, the act of storytelling and the story itself may wildly misunderstood by a practitioner that arranges and interprets the meaning of relationships among variables differently.

3.9 Sensemaking and Narrative

As the perception of a situation directs action, stories are particularly valuable means of gaining insight into how one understands the world. "Storytelling implies sensemaking" (Colville, Brown and Pye 2012). Sensemaking is the process of ascribing meaning to events through reflective action. Narratives are methods by which events are translated into language. When telling stories, the speaker is offering their version of reality, describing the world as they live and navigate within it. This is why the phrase 'that reminds me of a story' is perhaps the most common sensemaking gambit (Colville & Pye and Brown, 2012).

When people explain their health-related actions, they are describing activities based upon previous sensemaking episodes (Dowding, et al, 2016). Their stories reflect how they understand the illness as a part of their entire lifeworld, and how the live with and around it. Looking to patient's stories without regard to biomedical accuracy can give insight into the way patients perceive and construct illness and provide insights as to how they construct their response to self-care.

Methods

4.1 Data Collection

All data was originally collected for a study of patient work routines. Participants had received a diagnosis of diabetes (Type I), not secondary to another condition[1], and required multiple daily insulin injections and glucose monitoring with each meal. Selection criteria required that participants use a sliding scale for their insulin which required them to calculate the amount of insulin required for each administration rather than a set insulin dosage. All participants were recruited from an outpatient diabetes clinic at a large medical center. The project was approved by the Vanderbilt University Institutional Review Board.

Trained research assistants conducted the interviews in the participant's home using an opened-ended interview guide. The interview was divided into four sections: Diet and nutrition, Physiological Monitoring, Exercise, and Medication Management. The interview guide investigated participant's health routine, including how and why the participant constructed their routine in that specific way. The interview did not aim to compare participant's health actions to their provider's recommendations or evaluate the 'correctness' of the participants thought process. Audio recordings of the interviews were transcribed and analyzed in Dedoose, a qualitative software program (Version 7.6.21; Sociocultural Research Consultants LLC, 2017).

The original dataset consisted of 50 interviews approximately 1 hour long. A smaller subset of interviews were chosen for this analysis. Selection criteria for the final dataset excluded any interviews that were not conducted by the author. I further selected interviews to maximize the diversity of demographics and experiences. The final dataset included 19 interviews, 9 women and 10 men. Table 1 records demographic characteristics of the participants.

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[1] The diagnosis was not a result of chemotherapy treatments or an organ transplant

Table 1: Participant Characteristics

		Number (Percent)
Demographics	Female	9 (47%)
	Caucasian	16 (84%)
	Married	12 (63%)
Family Income	Under $15,000	1 (5%)
	$15-29,999	2 (11%)
	$30-44,999	2 (11%)
	$45-59,999	1 (5%)
	$60-79,999	1 (5%)
	80,000 or Above	10 (53%)
Education	High School or 2-year degree	8 (42%)
	4-year College Degree	3 (16%)
	Graduate Degree	6 (32%)
*does not sum to 1; some participants withheld information		

4.2 Data Analysis and Reporting

Interviews were analyzed iteratively in a manner typical of qualitative research. The process is best explained through a chronology of the analysis.

First, interviews were examined to distinguish occurrences of storytelling and non-narrative excerpts. Non-narrative passages were typically short declarative statements, a list of tasks or an expression of opinion. While they were not part of a larger story, non-narrative statements could serve to either support or clarify a story, as a point of further inquiry for the interviewer, or simply provide information or opinion (Table 2).

Next, story passages were examined in isolation. This was done by first identifying the 'elements' of the story (i.e. the people, places, artifacts, or ideas present) and characterizing the relationship of the elements as expressed explicit or tacitly by the participant. The nature of the relationships were identified in the context of the story and what the participant was using the story to explain.

For example, in discussing their weekday breakfast actions, a participant might describe waking up, checking their glucose, and then waking their child up for school. In this example, weekday mornings, glucose monitoring and apparatus, child and the school schedule may all be identified as story elements.

Table 2: Non-Narrative Relationships

Relationship	Example
Clarify a story	[after explaining a diet-related financial challenge] *Right, it just depends on, you know, what's going on at the time, what kind of time we got, you know*
Point for further inquiry	*Well my life has changed a lot ...but I wouldn't necessarily say it's because of the diabetes or management.*
No relationship to a story / independent declarative statement	*I have the long-acting insulin, which is Tresiba and then I have the quick-acting insulin, which is the one after each meal is the Humalog and then I take 1000 mg of metformin twice a day*

The participant may have discussed the school schedule as a structuring structure which acts to maintain a breakfast routine (a positive relationship between the concept of *breakfast* and *school schedule*), as a challenge to their ability to regularly eat breakfast (a negative relationship between the concept of *breakfast* and *school schedule*), or as a factor in the type of food choices available to them for breakfast (a negative relationship between *diet choices* and *school schedule*.

Finally, when appropriate, stories themselves were examined holistically to identify when and to whom the participant would tell the story.

In order to protect participant confidentiality, all reported participant names are fictitious. Pseudonyms were arbitrarily chosen to facilitate reporting the results.

Results: The Sensemaking Content of Narratives

5.1 Participant Narratives as Medium to Communicate Perspective

Participant's narratives are composed of selected elements and the relationships among them. Health-related actions are steered by perceptions of a situation. Perceptions of a situation are built on the inferred meaning of relationships among variables, referred to here as a *framework*. Therefore in describing their self-care actions, participant's narratives typically described their actions as situated in particular environments which helped them to quickly determine relevant variables. For instance, Maurice, a 63 year old musician, discussed checking his blood sugar:

> *Interviewer: And when do you check the second time?*
>
> *Maurice: It just depends on the day. Somewhere between two and four usually.*
>
> *Interviewer: Okay. And why that time?*
>
> *Maurice: Because I tend to really slump at that time and then I wonder if it's blood sugar*
>
> *or what, you know?*

The span of time between two and four p.m. and the physical sensation of feeling low have a particular relationship for Maurice which prompts him to check his blood sugar. Interestingly, he notes that he does not know why that relationship exists. A biologically-motivated answer would focus on the quantitative, computable variables such as the nutritional content of breakfast   or the rate of metabolism, for Maurice, "slumping" between two and four is sufficient evidence to declare relationship and use the relationship to stimulate action. This is because sensemaking simply provides a perspective to decide on a course of action, not determine a root cause. While his story may not meet the requirements for scientific validity, it is nonetheless valuable as it demonstrates the way he approaches his self-care and which variables he considers important.

5.2 Narratives Communicating Implicit Relationships

For the respondents, diabetes actions are often not extra-ordinary or particularly unique actions but regular, ordinary activities performed in the flow of the day. Tasks were discussed as interdependent with work schedules, hobbies, family traditions, family hassles, weekend habits, and even traffic

patterns. As such, even though participants were answering questions specific to their diabetes-related actions, many described situations rather than discrete tasks. For example, Matt, a 40 year old computer programmer described how he eats breakfast:

...when I get to work generally first thing I do is log into the PC which, because of software they have running takes fifteen minutes' minimum. So I log into the PC, it's early enough that no one else is around, so I'm able to leave the PC unlocked while it logs on. I grab, I grab the food that I brought in the morning. I go and heat it up in the microwave, grab water or something to drink. Walk back to my cube, check my sugar levels, take insulin and eat right then. And then start my daily routine at work.

Like most participants answers, Matt qualifies his response with "generally." In this sense, "generally" means that other areas of his life are functioning in a typical way. He describes his breakfast habits but also indicates that this pattern is dependent on other elements. This interdependency means that health tasks are conducted under potentially unfixed circumstances: when life is "normal" the tasks are carried out in the manner described, if life is not 'normal' tasks may be adapted.

Additionally, diabetes-related tasks may be so embedded and unremarkable they are effectively camouflaged to the participant. For example, Robhas a physically demanding job in manufacturing. Such sustained activity poses a risk for sudden and dangerous drops in his glucose levels. When asked if could feel when his blood sugar was getting too low Rob responded:

Rob :I do have that feeling where I do get low and it, it gets pretty bad sometimes, so, 3 sodas is where I limit myself to.
Interviewer: Do you have them like at certain times or..?
Rob: Yes. I do it first break, and then I do lunch, and then third break.

In light of the nature of his job, Rob has a rational, tactical approach to preventing lows which include strategically chosen items, consumed at specific times. Even though this situation is a calculated strategy that requires specific actions to sustain it (he must regularly purchase the sodas in order to consume them on his breaks) their presence and function is so familiar to Rob it did not occur to him to discuss them.

5.3 Narratives Communicating Explicit Relationships

Participants sometimes generated a narrative to teach the interviewers *how* to think before they could convey *what* they thought (i.e. their ways of knowing). For example, when asked what glucose reading she personally considered a "high" or a "low", Marcie, a 32-year old mother of two toddlers said:

> *It depends. Like, if its 100 at noon, it's like - aw yeah, I can eat now! But if it's at 8 it's like ok, am I hungry? Do I need nutrition or did I bolus too much last time? I don't want to go to bed with it too low.*

In a disease framework, self-care actions are guided by a discrete set of variables and every variable represents a single, unambiguous construct, e.g. …. Marcie, however, is managing an illness so a variable's meaning exists only in its relationship with other variables. In this short explanation, Marcie conveyed multiple concepts: the breadth of interpretations possible for a single piece of data, the variety of variables that may be relevant in that interpretation, and the importance of context.

5.4 Explanatory Narrative: Sensemaking Origins

Some narratives explained current actions by recounting the origin of their sensemaking framework. Sensemaking is an iterative and ongoing process. The sensemaking structures which guide behavior are constantly and continually 'tested' through action. When action fails to produce the expected result, the sensemaking structure is either updated or discarded.

For instance, Michelle, a 39 manager at a car dealership, provided an origin story to explain her diet-related actions. Prior to her story, Michelle stated that she chose to avoid eating carbohydrates at night. This preemptive decision is unusual and potentially dangerous as blood glucose levels fall during sleep. Nighttime carbohydrates are recommended since a sleeping person is unable to notice any physiological signs until they are in a hypoglycemic crisis. Here, Michelle explains her choice:

> *Back, I can't even remember when it happened. Insulin used to be from pigs and cows and then it switched to human insulin and so I noticed the blood sugar would drop so much quicker with this type of insulin and I would have lows in the middle of the night frequently and it scared me. And it was always because I had, maybe some spaghetti, and*

a piece of bread or something like that. That's the kind of thing that would happen in the middle of the night pretty frequently for a good amount of time…

Michelle's story begins with an initial mental model of the relationships among diet, insulin, and sleep. Every time she made a decision about what to eat before bed was an occasion to 'test' her framework. Every experience of a nighttime low was a failure of the framework. After a series of nighttime lows, Michelle faced an equivocal event: her interpretation of the relationships was either insufficient or incorrect, and actions based on this model produced surprising and negative results.

Using her previous experiences as information, Michelle reevaluated the relationships among diet, insulin, and sleep. She created a new interpretive framework, which suggested taking different action: if she avoided carbohydrates, she did not have to administer a meal bolus (a dose of insulin given with meals) and therefore she could reduce the chance of a nighttime low.

5.5 Explanatory Narratives: Sensemaking and Personal Values

Some narratives indicated how personal values shaped the way participants interpreted situations and thus the performance of their self-care. For example, John a 26 year old firefighter noted that he could still check his blood glucose and administer his insulin on the same time table at work and at home. However, at work:

> John*: You know, so I usually err, if I eat 65 carbs, I'll still just take 3 units. I don't, I don't, I don't ever round up, I round down*

When asked why he approached his care in this way, he explained:

> *I'm an engineer, so I drive the trucks. So that's not only worrying about me, but I've got to worry about four or five other people…You know, so I could, it just, it's kind of a shot in the dark really. If I take, I don't want to take too much insulin because then I know like we get a call in the middle of the night, I don't have time to go make a sandwich real quick….You know what I mean? … I would much rather it be high for those few hours I'm at work.*

Marcie also noted preferring to risk a too-low dose rather than too high.

you know I can't pass out I gotta ..so I tend to run a little higher if I know I'm gonna be

out with the kiddos.

Conversely, James, a college student, discussed how he typically acted to keep his blood glucose levels low.

The highs are just... its always something I want to do is stay away from the highs. I just

feel terrible. I get, like my chest feels tight, I get a headache. I get hot. I feel like, not that

you can breathe but it's a little harder to breathe. And you just, you just feel mad. And so

I've always pushed against that.

Especially when out with his infant son, he monitored his levels and rarely allowed any glucose spikes. In addition to avoiding the immediate distressing physical effects, he wanted to maintain his health for his son.

For Marcie and James, the variables are the same (children's wellbeing and their parenting role) but their health-activities different. It is only in their stories that they could express how such opposing actions make sense because their stories describe the relationship among the variables.

In these examples, participant's self-care actions are guided by frameworks that consider both the understanding of their body and illness (meaning how their body responds to meals and insulin boluses) as well as their significant roles and personal values. In the abstract conflict between fulfilling social roles and health concerns, the concrete actions themselves are expressions of their sensemaking synthesis.

Results: Use of Narratives in Self-Care Activities

6.1 Narratives as Tools in Self-Care

The previous section demonstrated that patients' narratives exemplify their understanding of their disease. Participants used stories of previous experiences to explain their current system of health-related actions. The stories were moments of sensemaking and therefore highlighted the complex, interrelated relationships among the areas of life the participant values. By reflecting on past experiences, participants can balance the preservation of their personally-valued aspects of life with personally-acceptable levels of health risk. Because diabetes is a chronic, life-long condition, participants call upon their previous experiences in order to continually refine the way their illness and health-related activities impact all areas of their lifeworld. In storying their experiences (imposing a structure and meaning) participants can efficiently recall the sequence of events, the inferred character of relationships among all the variables, and the meaning of the experience.

Stories then are concentrated packages of information which implicitly and unconsciously demonstrate their ways-of-knowing, by relating their inferred relationships among their body and illness, their values and beliefs, and physical and social structures. Packaging previous experiences into a story form also allows participants to share the information in a succinct and familiar format. In other words, stories are repositories of information which provide an efficient method of remembering and communicating highly complex concepts.

After sharing a story with the interviewer, participants often noted other times they had shared their stories. As a package of information, telling or withholding a story became a calculated move to achieve a particular end. In this way, the stories themselves became a tool in their self-care activities.

Participants in this study used stories as tools in one of four ways:

1. To convey their way of knowing to another person, or to reiterate particular values to themselves
2. To serve as a baseline to interpret ambiguous physiological states
3. To elicit acceptance of others
4. To engage with the medical institution

6.2 Narratives to Facilitate Shared Sensemaking

Stories which provide explanations for actions act as justifications for their chosen values. Typically, these stories served to explain how they understood their disease and why particular actions were important, not to justify special needs or requirements.

As in the previous discussion, both John and Marcie chose to keep their glucose levels high in order to protect others around them. Their stories serve as an explanation to justify and reinforces their behavior to others and for themselves; in articulating their stories, they became both the narrator and the audience. This self-validation helped rationalize and support the particular way they synthesized two opposing social roles.

In another example a 21 year old college student, Colin, worked long hours at a car factory. Unfortunately, he frequently experiences tight financial constraints which make it difficult to purchase all his diabetes medications and supplies. During these times, he would choose to purchase only the long-acting insulin (Novolin) and to mitigate high blood sugars by reducing his food intake.

> *sometimes I wouldn't even eat like maybe once a day, ...being so, the cost of it's, it's just so much, I can't really do what I want, you know? If I feel like blowing through, you know, 40 units of insulin because I got hungry, you know, ...the cost* [of insulin] *was high, so, talking about hundreds of dollars.... 300 or 400* [dollars] *on the Humalog, so the Novolog was twice as much, Humalog is half as much, and the Novolin, the Novolin was only $52.00, and I was like, yes, we're saving today.*

While it would have been easier to simply let his blood sugar levels run high, rather than reducing his food intake, in a previous story, he explained how he had lax control though high school and "*finally kinda came into senses again, I was like, oh man, I really need to take my insulin, really need to take this stuff seriously.*"

Colin's method of controlling his glucose level is extremely difficult but because he found it results in somewhat more stable glucose levels, it would not manifest in any of the routine medical tests. Thus his stories provide both a rationale for his actions but also serve to reinforce and preserve his values for himself. They provide personal encouragement to persevere in his chosen method of therapy adherence.

6.3 Narratives as Benchmarks

Previous experiences also proved essential to quickly identifying unusual or dangerous situations. In this use, stories are reference templates which help determine if one's current state was unusual or unexpected, and, of so, provided a template of how to respond. Tonya, a 37 year old manager at a home healthcare agency, a noted:

> *Sunday night we went to my nephew's birthday party and I thought I had calculated*
> *everything just fine and I came home and I was like, "I don't feel so good." And I*
> *checked my blood sugar and it was 422.*

Because she knew from *previous* parties how she should expect to feel Tonya was able to identify that her condition at that moment was abnormal and required attention.

To address an unexpected blood sugar of 422, Tonya described how she and her husband ran through a list of possible explanations by recalling previous experiences of unexpected highs.

> "*sometimes it* [the insulin pump insertion site] *will get blocked or the inset, the little*
> *needle may bend when you punch it in and you may not know it. You may know it because*
> *you're blood sugars are high, but you're just like telling yourself it's not the insulin*
> *pump.*"

She went on to explain how inexplicable highs such as the one described were difficult to interpret. Often in such situations, unknown or hidden variables were interacting with calculations.

Stories such as this frequently involved other actors such as friends or family members. Many respondents noted instances when family members were enlisted to help determine if their physiologic state was unusual and, if so, to deduce the cause. Because others were involved in past sensemaking processes, they could also serve to help identify unusual situations and possible problems, as well as help solve issues quickly because they have a basic 'role' and a shared understanding.

In these stories, both the individual and the family member compared current states of being to previous experiences with similar conditions. These shared experiences became communal stories which helped to hone both the respondent and the family member's recognition of unusual health states and facilitated a coordinated (and thus faster) response.

6.4 Narratives to Elicit Cooperation

In the previous example the participant communicated with close others to recall stories and engage in collaborative sensemaking. In public but impersonal situations, stories were used as a currency to purchase acceptance. Rather than negotiating a shared understanding, in these circumstances, sharing stories offered a completed framework for others adopt. Here, there was no need to discuss common understandings, just to purchase the participant's ability to carry out tasks, or have access to particular resources with or without the other person fully understanding why. Used in this way, narratives help to gain the cooperation of others in order for the participant to perform health-related tasks while minimizing any social stigma or negative repercussions. Therefore, a large part of the self-care process included determining when and how to publicly share stories. The variety of social situations encountered meant that each situation had to be uniquely addressed according to each participant.

> [People say] *"You can do whatever you want to do." No, sounds good, but it's not true. You cannot do whatever you want. I taught in the Peace Corp. And first, they said, "Oh, yeah, you're at a high, we really, you're in the kind of field we really like." And then, I get this call, "I saw you're a diabetic. We can't handle that, sorry." That was it.*

For one another, blunt honestly worked in both casual and work situations:

> *Yeah and just sort of people understanding that you gotta do what you gotta do. You know, so if I've gotta, if I'm at dinner and if I was still taking injections, I am not going to go to the bathroom to do that. I'm going to check my blood sugar or take my insulin right there. I don't care. One time my pump started beeping and I was in a meeting and I had it here. And the, one of the executive people looked at me and went, "Turn your phone off." And so I literally reached in my like shirt* [to pull out her insulin pump] *and I was like, "It's not my phone!!"*

Further, the value of the stories differed within different audiences. Stories considered extreme (e.g. losing consciousness) generated greater acceptance than did stories describing mild discomfort. Additionally, stories told by people considered vulnerable, such as pregnant women with gestational diabetes, were more valuable and generated greater levels of cooperation stories from college-aged men.

For example, Laura, 39 year old office worker explained that she was initially diagnosed with gestational diabetes. However her diabetic condition persisted after her child was born, and she received

a later diagnosis of type I diabetes. Complications from the two-year period between giving birth and receiving the type I diagnosis left her severely immunocompromised. However, unlike when she was pregnant, she was unable to convince her co-workers that it was important to recognize when they were potentially infectious.

> *Well, we had several that had the flu, and they were saying bronchitis and different other things, but it was the flu, and by then they were out for weeks and it was too late. I was the only one that did not have flu, but I still end up sick, I still end up, only one end up in the hospital.*

Participants discussed having to constantly evaluate their own story on others' terms to negotiate a level of necessary non-conformity that both individuals deemed appropriate.
Additionally, participants also found use in withholding these stories. In these cases, the narrator had to navigate gaining acceptance for non-normative activities with the possibility of being barred from engagement. Participants had to estimate whether the listener would place too much value on their stories. Colin noted,

> *I mean I guess I could schedule out with my supervisor, but I wish I had more time to, you know, okay, well I can check my blood sugar, you know, and here's 5 more minutes, but then, I wouldn't want to be the, the, the, you know, okay, well he, why's he doing this, you know? … Why is he getting special privileges? Oh, well this guy has diabetes too, why isn't he doing this? So I kinda try to sway away from that.*

As shown, when the narrator felt the story was going to provide insufficient funds to secure assistance, or that it would damage others' interpretation of them, the narrator would withhold or hide the story. In doing so, they were stripped of their ability to justify engaging in these actions and were therefore forced to work around anticipated patterns of action to carry out activities privately or played down the need until an extreme situation disallowed them to hide it.

Thus the participants discussed evaluating the 'worth' of their stories (explanations) against the 'value' of the acceptance as evaluated by others. So while the stories are valid and reality that the narrator may wish to share, they are aware the listener may acknowledge and appraise the story at a different value. For Kaylee, a 31 year old aesthetician describes the feeling of managing lows and discussing the consequences:

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It was very scary. And the realization of that.. at any second that could have turned to an emergency or a life threatening situation. But when you handle it, and you're like, ok, ok, I'm sweating and I'm crying, and I'm nervous but I have apple juice here so I know I'm gonna be fine, and the next morning you wake up and you're quote-fine- its like… nobody can really take that seriously. Cause it seems like "oh you handled that well, its not that threatening. Does it take having a seizure or passing out before somebody realizes that it IS dangerous….

And its my own perception about what other people see. You know if they see you going through every day and you're not complaining about your diabetes – which is good you don't want to dwell on it all the time, cause, you know, you're normal- but your normal doesn't show the bad times too. And you don't want people thinking "oh she's a bad diabetic, she doesn't have control over this."

6.5 Narratives to Engage with the Medical Institution

When interacting with medical providers, participants both gave and received narratives. Participants told their stories to signal their alignment with their provider's biomedical views or as a mechanism of resisting medical control.

Narratives that communicated an adoption of the biomedical model frequently came from participants who had little other interaction with biomedical institutions. For example, James was 23 years old when he was diagnosed with type I diabetes. With no other previous diabetes-sensemaking information available, he spent many hours researching medical literature in order to learn about the condition. As a result,

> *…when I'm at the doctors and we're talking about something, I kind of know what they're talking about and plus they know that I kind of know… when I started going to Vandy, she was very impressed that I kind of knew what I was talking about...she told me that when someone's a Type I they usually give them about three years to trial and error.*

In telling this story James indicated not just that he agrees with the medical interpretation of diabetes, but that he and the provider share the same sensemaking patterns: they both highlight

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similar variables values and interpret the relationship of the variables in similar ways. This signals his willingness to work cooperatively in addressing his medical needs and would likely work to follow the physicians recommendations.

Some participants noted experiences or understandings that were at odds with biomedical expectations. These stories included both experiences with close others who dealt with diabetes and personal experiences that came from dealing with diabetes for long periods of time. When discussing having their stories rejected in a medical setting, it was often because the provider downplayed or disregarded variables they felt were important. Because of the imbalance of social power in patient/ provider relationship, participants turned to narratives as a resource to defend their actions or validate their own understandings. Even if the provider dismissed their narrative or use it as an impetus for problem-solving rather a different way of thinking, the narratives cannot be disproved providers.

In one example, Janice, a 46 year old social worker works with children in foster care. She described several examples of conflicts between her job and her diabetes-related care and provided a story to explain why she preferred the pre-filled insulin pens to the vials of insulin. The then recounted telling the same story to her physician:

> *A lot of places I wind up locking it in my truck or whatever because, especially since I'm out seeing kids and I'm out seeing other people, and some of these homes I don't want to bring anything into…. So, now you're* [the physician] *gonna ask me to carry a needle and a pen, or a needle and a vial? Because I do transport kids, occasionally, there's no way I would do that. I wouldn't, I would not stick a syringe in my vehicle. . . I mean these are kids, some of 'em are dangerous. I mean and so, certainly, I am not gonna stick a syringe in my car. And some of 'em have their own, you know, they have drug issues and stuff like that.*

While she did receive a prescription for the pre-filled pen, the prescription had to be re-filled every 30 days rather than every 90 days.

> *You know, I think that was kinda one of the problems that I had when I was there with her …in the clinic was because I'm willing to give, but you've got to be willing to meet me halfway somewhere…. It was just like; I mean I was like, okay. You're not gonna hear me. I understand. I've dealing with, working with my; my mother's been diabetic for a*

long time so I already had a heads up on kinda dietary needs and things like that…and she was talking about lifestyle changes and I'm thinking, my lifestyle can't change too much. I've pretty set. I've got too much going on…. So, you know. I think that they're not realistic when they start talking about lifestyle changes, choices, cause they don't look at it. I think that's the big thing.

In this example, Janice's sensemaking of her health activities included her personal valuing of her job. After telling her story to her provider, she felt that her understanding of diabetes was rejected outright. By emphasizing lifestyle changes, Janice felt her physician disregarded how important her job was to her by insinuating that it was something easily altered while simultaneously devaluing Janice's diabetes knowledge by re-explaining health information that Janice already knew.

Other participants passively resisted medical authority by withholding their own stories at office visits but constructing their health-care actions on their own understanding. These respondents believed that explaining their actions to the practitioner would open them to censure or chastisement. Wayne, a 42 year old computer programmer described how he chose to test his blood glucose at a much higher rate than the providers recommended.

Interviewer: How often do they recommend you check?
Wayne: *that has actually been a bit of contention with me. When I started going to Vanderbilt I was told to check twice daily and no more than twice daily… as a matter of fact, when he ordered the prescription, it was exactly what I needed to be able to check twice a day…luckily I have no issue purchasing test strips outside of the prescription.*
Interviewer: *so how often do you check?*
Wayne: p*robably four to five times a day actually, no matter what*.

This passive resistance was not always successful. In any routine part of an endocrinologist doctor's visit, physicians download the data from the patient's glucometer. Thus for Wayne, his physician could see the date, time, and results of every glucose test. So while he did not feel the need to purposefully change the mind of the practitioner- he had the income to purchase his strips outside of the insurance mandates – deeply embedded medical surveillance practices prevented him from carrying out the action without the practitioner "finding out".

Discussion

7.1 Discussion

People managing a chronic illness like diabetes carry an invisible burden of translating their particular point of view to others. This study demonstrates that storytelling is a common medium for communicating ones sensemaking framework.

People with type I diabetes are aware that their self-care requirements influence the way they interact with non-biological variables such as time and activities, and this interaction is sometimes difficult to convey to co-workers, friends, and partners. Comparably, many non-biological variables influence the performance of their self-care work. This is sometimes difficult to convey to healthcare providers. In both situations, stories are used as an efficient and accessible means to convey interpretations of complex relationships.

7.2 Future Directions

Ongoing disease-focused education efforts continue to be a vital component of care in chronic illness, but as this study demonstrates, such information is only a part of a patient's constellation of concerns and variables. People living with a chronic illness incorporate personal, social, emotional, environmental, and technological factors in their health-focused actions. Personal experiences identify variables for consideration and personal identities guide interpretations of illness - what it is, what it does, and what it ultimately means. Even if such variables are not valid in a biomedical model of disease treatment, they are not diminished in their ability to affect healthcare practices or therapeutic outcomes.

Future patient-care research should continue to investigate how patients use stories to communicate with their providers, and how providers may incorporate patient frameworks into their recommendations. Additionally, future studies may focus on creating patient education materials that incorporate patient-identified relevant variables and understandings. This could assist providers by identifying areas where the patient may have a different framework and thus target areas where recommendations may fail. Both efforts would assist physician's ability to generate a personalized, more robust therapeutic regimen and increase adherence rates without requiring patients to conform to a particular understanding.

REFERENCES

Adam, E. (1993). Fighter Cockpits of the Future. Digital Avionics Systems Conference. 25-28 Oct. 1993. DOI: 10.1109/DASC.1993.283529

Amin, A., and Roberts, J. (2008). Knowing in action: Beyond communities of practice. *Research Policy*. 37: 353-369 http://doi.org/10.1016/j.respol.2007.11.003

Berg, M. (1999). Patient care information systems and health care work: a sociotechnical approach. *International Journal of Medical Informatics*, *55*, 87–101. Retrieved from www.elsevier.com/locate/ijmedinf

Berger, P. and Luckman, T. (1966) The Social Construction of Reality. Penguin Publishers

Borrell-Carrio, F, Suchman, A., Epstein, R. (2004). The Biopsychosocial Model 25 years later: Principles Practice and Scientific Inquiry. *Annals of Family Medicine.* 2(6): 576-582

Casper, M., & Berg, M. (1995). Constructivist Perspectives on Medical Work: Medical Practices and Science and Technology Studies. *Science, Technology & Human Values*, *40*(4), 395–407.

Collins, H. M., De Vries, G. H., & Bijker, W. E. (1997). Ways of Going On: An Analysis of Skill Applied to Medical Practice. *Science, Technology & Human Values*, *22*(3), 267–285.

Colville, I., Brown, A. D., & Pye, A. (2012). Simplexity: Sensemaking, organizing and storytelling for our time. *Human Relations*. 65(1): 5-15 http://doi.org/10.1177/0018726711425617

Dedoose Version 7.6.21, web application for managing, analyzing, and presenting qualitative and mixed method research data (2017). Los Angeles, CA: Sociocultural Research Consultants, LLC. www.dedoose.com

Dowding, D., Lichtner, V., Allcock, N., Briggs, M., James, K., Keady, José Closs, S. (2016). Using sense-making theory to aid understanding of the recognition, assessment and management of pain in patients with dementia in acute hospital settings. *International Journal of Nursing Studies*. 53: 152-162 http://doi.org/10.1016/j.ijnurstu.2015.08.009

Engeström, Y. (2001). Expansive Learning at Work: Toward an activity theoretical reconceptualization. *Journal of Education and Work*, *14*(1), 133–156. http://doi.org/10.1080/13639080020028747

Ewick, P and Sibley, S. (1995). "Subversive Stories and Hegemonic Tales: Towards a Sociology of Narrative." *Law and Society Review.* 29(2): 197- 226

Fayard, A. L., & Weeks, J. (2014). Affordances for practice. *Information and Organization*. 24: 236-249 http://doi.org/10.1016/j.infoandorg.2014.10.001

Feldman, R. and Feldman, S. (2006). What links the Chain: An Essay on Organizational Remembering as Practice. *Organization* 13(6)861 -887

Gubrium,J. and Holstein, J. (1998) Narrative Practice and the Coherence of Personal Stories. *The Sociological Quarterly* 39(1): 163-187

Hardwig, J. (1988). The Role of Trust in Knowledge. *Journal of Philosophy, Inc*, *88*(12), 693–708.

Heaphy, E. D. (2017). "Dancing on hot coals": How emotion work facilitates collective sensemaking. *Academy of Management Journal*. 60(2): 642-670 http://doi.org/10.5465/amj.2014.0101

Kimberly, J. R., Bouchikhi, H., & Kimberly Hamid Bouchikhi, J. R. (1995). The Dynamics of Organizational Development and Change: How the Past Shapes the Present and Constrains the Future. *Source: Organization Science*, *6*(1), 9–18.

Klein, G., Moon, B., Hoffman, R. (2006) Making Sense of Sensemaking 2: A Macrocognitive Model. *IEEE Computer Society* 21(5): 88-92

Knight, L and Mattick, K. (2006) '"When I first came here, I thought medicine was black and white": Making sense of medical students' ways of knowing.' *Social Science & Medicine.* 63(4): 1084-1096

Laroche, H., & Laroche, H. (1995). From Decision to Action in Organizations: Decision-Making As a Social Representation. *Source: Organization Science*, *6*(1), 62–75. Retrieved from http://www.jstor.org/stable/2635240

Leonardi, P. M. (2001). When flexible routines meet flexible technologies: affordance, constraint, and the imbrication of human and material agencies". *MIS Quarterly* 35(1): 147-167

Lindnerman, A. (1997) The Deaf Story, Themes of Culture and Coping. *Fuller theological Seminary.*

Maines, D. R. (1993). Narrative's Moment and Sociology's Phenomena: Toward a Narrative Sociology Toward a Narrative Sociology. *Source: The Sociological Quarterly*, *34*(1), 17–38. Retrieved from http://www.jstor.org/stable/4121556

Martin, L., Williams, S., Haskard, K., DiMatteo, M. (2005). The Challenge of Patient Adherence. *Therapeutics and Clinical Risk Management.* 1(3) 189-199

May, C., & Ellis, N. T. (2001). When protocols fail: technical evaluation, biomedical knowledge, and the social production of "facts" about a telemedicine clinic. *Social Science and Medicine*, *53*, 989–1002. Retrieved from http://doi.org/10.1016/S0277-9536(00)00394-4

Okken, V., Niemeijer, M., Dijkstra, A., Baars, M., Said, S., Hoogenberg, K., Orfgen, H., Otten, S, Cleophas, T. (2008). *Netherlands Heart Journal.* 16(6): 197-200

Pajak, E., & Green, A. (2003). Loosely coupled organizations, misrecognition, and social reproduction. *International Journal of Leadership in Education*, *6*(4), 393–413. Retrieved from http://doi.org/10.1080/1360312032000150760

Patriotta, G. (2003). Sensemaking on the Shop Floor: Narratives of Knowledge in Organizations. *Journal of Management Studies.* 40(2): 349-373

Pentland, B. T., & Feldman, M. S. (2008). Designing routines: On the folly of designing artifacts, while hoping for patterns of action. *Information and Organization.* 18: 235-250 http://doi.org/10.1016/j.infoandorg.2008.08.001

Pols, J. (2005). Enacting appreciations: Beyond the patient perspective. *Health Care Analysis.* 13(30): 203-221 http://doi.org/10.1007/s10728-005-6448-6

Pols, J. (2014). Knowing Patients: Turning Patient Knowledge into Science. *Science, Technology, & Human Values*, *39*(1), 73–97. http://doi.org/10.1177/0162243913504306

Reynaud, B. (2005). "Void at the heart of rules: routines in the context of rule-following. *Industrial and Corporate Change.* 14(5): 847-871

Rhodes, P., Mcdonald, R., Campbell, S., Daker-White, G., & Sanders, C. (2015). Sensemaking and the co-production of safety: a qualitative study of primary medical care patients. *Sociology of Health & Illness.* 38(2): 270-285 http://doi.org/10.1111/1467-9566.12368

Rutledge, M. (2009). Sensemaking as a Tool in Working with Complexity. *OD Practitioner.* 41(2) 19-24

Simmel, G. (1950). The Sociology of George Simmel. Translated by Kurt Wolff.

Snowden, D. J. (2005). Multi-ontology sense making: A new simplicity in decision making. In *Informatics in Primary Care*. 13: 45-53 Retrieved from http://doi.org/10.1097/NNA.0b013e3181b9228f

Teekman, B. (2000). Exploring Reflective Thinking in Nursing Practice. *Journal of Advanced Nursing.* 31(5): 1125-1135

Turner, J. and Kelly, B. (2000). Emotional Dimensions of Chronic Disease. *Western Journal of Medicine.* 172(2): 124-128.

Weick, K. E. (1995). *Sensemaking in organizations*. Thousand Oaks, CA: Sage

Weick, K.E. (1993). Collapse of sensemaking in organizations: The Mann Gulch Disaster. *Administrative Science Quarterly,* 38, 628-65