



ORIGINAL RESEARCH

Back to the Beginning: Diagnosis Experiences of Persons with Type Two Diabetes

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Abstract

Background: One in ten adults in the United States has diabetes; the vast majority are diagnosed with type two diabetes mellitus (T2DM). Even though diabetes care has significantly evolved, and a wide variety of pharmacological treatments are available, approximately one-half of people with type two diabetes do not achieve a hemoglobin A1C of less than seven percent. In addition, self-management is a consequential contributor to glycemic control. In light of the mortality, morbidity, decreased quality of life, and financial burden caused by T2DM, the author wanted to explore the diagnosis experiences of type two diabetics. Could their experiences be a contributing factor to less-than-optimal treatment outcomes?

Methods: The author interviewed nine consenting adults with T2DM in person, over the telephone, and via videoconference over four weeks in March and April 2023. The data from each transcript was analyzed independently and then compared, identifying meanings and clustering themes found throughout utilizing descriptive phenomenology as the underpinning for this study.

Results: Eight main themes emerged from the participant narratives. While distinct in themselves, many contained overlapping elements that influenced self-management, which was a theme of its own. Others included scarcity of information, emotions, experience with a provider, disease perception, minimalization of disease severity, the notoriety of Metformin, and flurry of diagnoses. Participant narratives were rich in detail and emotion.

Conclusion: The participants' personal experiences in this study suggest that care delivery at diagnosis impacts self-management. The researcher respectfully exhorts providers to consider the impact a diagnosis experience has on newly diagnosed diabetics and those following up long-term.

Keywords

Type-two diabetes mellitus, Patient experience, Diagnosis, Emotions

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Almost one-third of all adults 65 years or older have diabetes; this amounts to just over one in ten people, or 37.3 million in the United States [1,2]. While new cases have decreased from 2009 to 2020, the total number of cases continues to rise [2]. Diabetes was the seventh leading cause of death in the U.S. from 2009 to 2020 [3]. Lack of documentation of diabetes on death certificates likely causes underestimation of this ranking; also, these statistics do not adequately represent disability, decreased quality of life from disease, doctors' visits, hospitalizations, loss of income, time, and complications [4]. Diabetic complications include kidney damage, heart disease, amputations, and diabetic retinopathy; all end-organ damage from chronically elevated blood sugar levels and permanent damage can occur before the patient has significant symptoms. The American Diabetes Association [1] places the annual cost of diabetes at \$327 billion, including \$237 billion of direct medical costs; this is a significant concern for the patient, their loved ones, and the healthcare system.

Diabetes mellitus has been recognized as a disease since ancient civilizations, though it was not yet named or understood. Second-century Greek physician, Aretaeus of Cappadocia, described diabetes as a disease characterized by excessive urine, thirst, and emaciation. Hundreds of years and many minds later, Banting, Best, Collip, and Macleod are credited with discovering and improving methods to extract and produce insulin [5], paving the way for the many pharmacological treatment options we have today.

Extensive studies such as Diabetes Attitudes, Wishes, and Needs (DAWN) contributed to improved approaches to delivering diabetes care [6]. The Diabetes Medical Management plan from the American Diabetes Association (ADA), National Diabetes Prevention Program, and others provide nationally recognized treatment guidelines. The Diabetes Self-Management Education and Support (DSME) Toolkit provides resources for providers and patients, and events such as American Diabetes Month raise awareness. However, despite what medicine knows, only half of diabetic patients meet treatment goals for blood glucose levels [7].

Objectives

Self-management is considered paramount to successful T2DM outcomes, and responsibility largely rests on the shoulders of the patient [8]. Barriers to self-management include financial constraints, stress, inadequate healthcare communication, lack of knowledge regarding diet, social pressures, depression, and reluctance to take medication [9]. The determination of many extrinsic and intrinsic factors influencing self-management and adherence [6] stems from diagnosis. In addition, physicians know that provider-patient communication and attitudes while discussing diagnosis impact a patient's perception, knowledge, and self-management [10]. With this knowledge, it is reasonable to reevaluate the perceptions and experiences of patients at the time of diagnosis as a contributing factor to treatment outcomes in the light of disheartening outcome statistics for patients with type two diabetes mellitus (T2DM). Therefore, this study examines the past experiences and perceptions of persons with T2DM at diagnosis. The researcher anticipates that emerging data from this study will help improve the delivery of diabetic care.

Review of the Literature

An expansive literature search using keywords diabetes+ type +2 (two) AND patient + experience, or patient +perception, or patient + opinion, or patient + attitudes, or patient + views, or patient + feelings, AND patient + education, or patient + teaching revealed 325 articles published after 2017. The researcher removed duplicate articles and articles about gestational diabetes, diabetes in pediatric or adolescent patients, prediabetes, and studies discussing diabetes plus comorbidity. The researcher also removed four sources because they were either research proposals only or the entire article was unavailable, which left 43 articles. An additional ten articles were located using backward citation tracing; some articles older than 2017 were included because of their relevance to the topic. The review of 53 fifty-three articles revealed six themes impacting self-management with origin points at diagnosis. Key pieces consisted of overlapping

components, including communication with the provider, provider knowledge and expectations, patient knowledge, patient worldview, place in the world, self-stigma, shared decision-making, and diabetes distress/emotions. A brief description of each and its impact on self-management follows.

Communication with the provider

Physicians understand that their conversations with patients at the time of diagnosis have a long-lasting impact on patient perception, knowledge, and self-management in T2DM [10]. This is further supported by reports that clear and positive communication regarding the disease process contributes to self-management and treatment adherence [11-14]. Increased levels of self-management resulting from positive provider/patient interactions have been shown to last one to five years after diagnosis [15]. In addition, patients satisfied with provider communication are likelier to be engaged in their care and exhibit health-seeking behaviors [13]. Conversely, a negative experience with a healthcare professional is a barrier to adherence [16] experience with a healthcare professional is a barrier to adherence [16].

Provider knowledge and expectations

Providers are responsible for providing up-to-date treatment options to their patients, but knowledge must extend past treatment guidelines. A provider's understanding of cultural, racial, and religious contexts individual to each patient is listed as key by both providers and patients. A study by Goff [17] found that care providers in London caring for African-Caribbean patients felt additional training in cultural competence would improve the delivery of care to T2DM patients, while lack of consideration, or understanding, of a patients' culture was considered a hindrance in a New Zealand study [18]. Language, cultural, and religious competence add to positive interactions, realistic goal-setting, and tailored treatment plans [19-21]. The American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics issued a joint statement in 2015 recommending treatment tailored to individuals and shared decision-making. The need for shared decision-making is mentioned throughout the literature.

Patient knowledge and expectations

Patient knowledge is more than formal education; knowledge includes the patient's illness perception, previous experiences, understanding of disease terminology [18], and care goals [14]. A lack of evaluation of a patient's baseline knowledge level at diagnosis leads to inappropriate patient education [22]. In addition, knowledgeable patients are more likely to have a positive perspective and better self-management behavior [23]. Also, patients with a high

or low perception of illness perception have distinctly different treatment outcomes [24].

Patient worldview, religiosity, and perceived place in the world

A patient's worldview and real and perceived place in the world have everything to do with self-care. One example is religiosity; it can positively or negatively influence disease perception. For example, some patients report that disease occurrence is the will of their god and neglect ownership of actions, while others use religious ideals to support positive self-care behaviors [20,24].

Diabetes stigma

Self-stigma is the internal direction of actual or perceived social stigma. Interestingly diabetes self-stigma is lowest at diagnoses, peaks about a decade, and then decreases over time [25]. The decrease in self-stigma over time is thought to be associated with acceptance of the disease process as time progresses. In a study by O'Brien, et al. [26], most people with negative emotions at diagnosis could accept their diagnosis and gain knowledge over time. The concern is that increased negative emotions, self-stigma, and diabetes distress are associated with decreased self-management skills [27,28]. During this period, irreversible damage to body systems can occur if glycemic control is negatively impacted. Since diabetes distress [17,29,30] and self-stigma [28] both start at diagnosis, it is reasonable to evaluate these early and intervene if needed.

Emotions at diagnosis

Patient emotions at diagnosis are likely intense and may include anger, fear, denial, anxiety, and sadness. These emotional responses can cause a poor understanding of the disease diagnosis and influence the patient's perception of the disease [28]. Some patients have refused structured diabetes education because of their negative feelings associated with the diagnosis [31]. In addition, patients coping styles are impacted by depression, and recognition of depression and intense emotions at diagnosis helps avoid a decrease in self-management [32,33].

Methods

Descriptive phenomenology, developed initially by Husserl, is described in Polit & Beck [34] as "descriptions of human experience" in everyday life. Phenomenologists such as Giorgi and Wertz have continued to develop descriptive phenomenology to gain insights into understanding the experiences of others [35]. The systematic principles of descriptive phenomenology are the philosophical underpinning for this study. The researcher refined the data by removing anything that was not truly part of the patient narrative by participating in a bracketing interview prior to data collection and journaling throughout data analysis.

These purposeful actions assisted in the removal of researcher bias from the emerging themes [36].

The sample consisted of a convenience, or volunteer, selection of adult patients diagnosed with T2DM. Study flyers were posted at a local primary care clinic and athletic club and dispersed at a local health committee council meeting. The study also allowed for snowball sampling. Data saturation determined the study size, and saturation was achieved with nine participants. Exclusion criteria included vulnerable patients with dementia, those with mental or emotional disabilities, pregnant persons, and those under 18. In addition, patients were fluent in spoken English. Thus, there was minimal participant risk.

An informed consent adapted from the U.S. Department of Health and Human Services (2016) minimal risk model accompanied a demographic data form at the time of each interview and required a signature for consent to participate and recorded discussions. Demographic data, including age, race, gender, income, level of education, occupation, time since diagnosis, diabetes medications, and most recent hemoglobin A1C (HbA1c), was collected. Participants were encouraged to fill out all demographic information, but completing the form was optional to protect against participant fatigue. Nine 15-90-minute interviews were conducted in person, over the telephone, and via videoconference. In-person interviews were held in a place of the participant's and researcher's choosing. Interview transcriptions were identified by number, and each participant was given a fictitious name to facilitate the telling of their stories while protecting their privacy. All demographic data and consents were stored in a locked file to protect patient confidentiality and destroyed once participants provided validation of study results or once the study was submitted for publication. Participants were ages 47 to 77, two-thirds were white, and two-thirds were female. Metformin was the most used medication; none required insulin injection. The duration of diagnosis was from 11 months to 16 years and known hemoglobin A1C ranged from 5.9 to 10.3 percent. All participants had completed a high school level education or higher. Participants were given a ten-dollar gift card to thank them for their time commitment.

The data was transcribed using Google Docs voice typing and analyzed utilizing Colaizzi's seven-step method. This process included the following: familiarization with data, identification of relevant statements, identification of meanings, theme clustering, inclusive description of findings, creation of a succinct summary of the data, and participant verification [37,38].

Results

After evaluating and analyzing the data, participant

experiences were grouped into eight main categories. These include scarcity of information, emotions, experience with a provider, disease perception, minimalization of disease severity, self-management, the notoriety of Metformin, and flurry of diagnoses. The participants' experiences, while grouped into themes, overlap when considering their impact on self-management and implications for practice. A succinct account follows.

Scarcity of information

A recurring theme was the scarcity of information at diagnosis. The following statements from interviews highlight inadequacies in the patient education process. Frank, diagnosed for less than two years, said "I was just kind of in the blind. I was never told which, which one I had. So, I had to figure that out. Like I had to Google that myself and try to figure out, okay, am I type one or type two and that's, I had to figure that part out myself." Dahlia diagnosed 16 years ago said "I don't think there was ever any strict instructions by the doctor or really any help other than telling me how bad I was...". Only two of the nine participants were referred to nutrition classes. Two mentioned it took much work to evaluate the quality of the information available online though it had been their primary source of information in lieu of adequate provider guidance.

Emotions at diagnosis: Fear, terror, anxiety, betrayal, denial, and frustration

All but two participants expressed a strong emotional response to being diagnosed with diabetes. Reactions included fear of death or complications from disease, fear of failure to get diet under control, fear one might need insulin, shock, terror, anxiety, denial, and frustration.

One participant used a form of the word "terrified" ten times when discussing diabetes. While fear was paralyzing for some, it was a motivator for others. Helen said "So then when he tells me I'm full-blown diabetic, I'm thinking, oh my god. You know, so, you know, you don't wanna say your world's ending or whatever, but it's not, that's just how I felt, you know, 'cuz and it just, you know, that's when okay, of course the fear, you know, sets in. This participant avoided progressing from prediabetes to diabetes for several years with lifestyle changes and significant weight loss.

Gemma, diagnosed less than one year, said "It was a shock...I never expected it to happen to me."- She had been prediabetic for years and was monitored regularly by her physician. She went from having an A1C of less than six percent to being admitted to the hospital with blood glucose levels in the 700s. in between quarterly follow up visits. Helen expressed frustration since she was the only one of four siblings to have been diagnosed; she said "but, uh, as far as having diabetes, I said, okay, why me? You know?".

Experience with provider

Patients described positive and negative interactions with their providers at diagnosis. Several participants expressed positive interactions with their provider even when it was evident that patient education had been inadequate. Also, a positive or negative experience did not seem to correlate with glucose control when looking at the most recent self-reported HgbA1C. For example, Joe reported a normal A1c but said "But I just, sometimes I just feel do, do they really care, do they just wanna throw medicines at you...?" Another concern expressed was a lack of specialist and primary care collaboration. "... the disappointing thing was that I was a gestational diabetic, prediabetic, and my doctor was OBGYN and she didn't refer me back to my doctor to say 'hey this may be a problem where she may be prediabetic' so I never had any information between the two" and "nobody ever said - hey this is important....I felt like the boat was missed," a statement from Cassandra when discussing her experiences after gestational diabetes; her most recent A1C was 9.2 percent.

Disease perception

For several, disease perception was influenced by having a family history of diabetes, knowing others with the disease, and input from their family. Having a family history of diabetes affected participants differently regarding self-management. One participant saw a diagnosis of diabetes as expected and a way to live, while others viewed it as a warning to make lifestyle changes. Another participant, Andrew, stated his thoughts on people with diabetes before diagnosis were influenced by his experience with others with T2DM. He said, "other people I knew were always older large obese men and so that was what I always pictured in my head ... if you were diabetic, you were this older large obese person." Frank, who also expressed intense fear regarding his diagnosis, described his wife's reaction, "...my wife is one of those that she was, she was like dooms doomsday. So, she goes to worst case scenario all the time. She's like, 'oh, you're gonna, you're gonna lose your toes. You're gonna, you know, this is gonna happen. Everything'. I was like, oh my god...she's never had that like, well, things could work out. She's always been like, 'well this is gonna be the worst.' And you know, she started reading about these diabetics and feet cut on and all this stuff and she's like, 'let me see your feet. You know, like, do you have sores?' Then my wife's like, 'see, your diabetes is gonna start on your eyes now'."

Minimalization of Diabetes severity and ambiguity of terminology

While not all participants specifically mentioned that their diagnosing provider minimalized the severity of a diabetes diagnosis, a clear example follows. Cassandra was told by her diagnosing provider. "You need to take

care of this, this is something that you know if you don't take care of yourself nobody else will." She was advised to "try to take this pill, eat better, and get some exercise". She felt the burden of care was shifted completely onto her. While Cassandra relayed that she felt he was trying to help she also said "It's almost like type one is a disease and really needs to be taken care of, type two you just have to eat better and exercise and like it's not a disease at all." She also felt that relaying the urgency of managing the disease was important. She said "I never had that, and it I think you need that because it stresses the importance of taking your medicine every day- I didn't take my medicine every day- if I forgot, I forgot. Oops so what, it doesn't matter." There was also ambiguity of terminology when discussing diabetes with a provider. Several participants used terms such as borderline and full-blown diabetes. Betty said "Well once I had a 6.3 and I thought that was really bad, but I, I guess full-blown diabetes- I know they told me at one doctor's office that they don't do anything for you- no medicine or anything until you're at a 6.8 so I wondered you know- is that full blown diabetes, or that they don't get worried until then? I would think they'd want to talk to you and say You know you're going up all the time so why don't you cool it and maybe you could talk about a diet."

Self-management

Several subthemes emerged in self-management, including dealing with more than one disease, needing to do more, knowing what to do but not doing it, false hope, and hesitancy to act. Betty stated: "Well by that time I had migraines, and a fatty liver, (laughs) all kinds of things, so I just thought one more disease you know one more thing to have to mess with...". A statement from the subtheme "knowing what to do but not doing it": Also, Emma confessed, "I try to be good, but yet I'm naughty. I have mysweet things that I have hidden around here and there that I, you know, hit once in a while." Andrew's belief his A1C could improve in time without lifestyle modifications or increase in metformin demonstrated false hope.

Notoriety of metformin

There were worries about the safety of metformin, and experiencing side effects was a common theme; consider the following statement from Betty. "...she had me take two 500 mg and I got sick at my stomach every time I took them...". Dahlia said "Well, that's why I looked at the medication, uh, because I didn't know whether this was good, bad or awful." Also, "So they sent me home with um, Metformin, a thousand milligrams or something, which almost killed me...", Gemma said.

Flurry of diagnoses

Flurry of diagnoses is the perception of a cluster of ill health occurring around the time of Type 2 diabetes diagnosis. For example, one patient reported an increase

of her A1c from less than six percent to 17 percent, accompanied by vision problems requiring surgery, and influenza B occurring almost simultaneously. She felt this was a result of her Covid booster rather than a result of diabetes or as a coincidence. Another participant said she had not been sick a day in her life, but once diagnosed with diabetes she reports getting strep twice, Bell's Palsy, hypertension, and psoriasis around the same time. Yet another participant felt overwhelmed; he had been prescribed cholesterol and blood pressure medications and felt that everything went wrong at once. Joe said "once I heard...you're a diabetic, it's like everything started going bad. It's kind of like they turned on the switch and everything started going bad." (Appendix).

Discussion

The participants in this study had time since diagnosis ranging from 11 months to over 16 years; duration did not correlate with perception of better or worse care delivery at diagnosis when measured by provider-led education, referrals, and experience with a provider. This suggests that the delivery of care has not improved over time. When considering study results it is key to know that two of nine participants were diagnosed in a hospital emergency department (ED), and a specialist diagnosed one as an incidental finding of routine labs. This likely impacted their experience at diagnosis; two of these three patients did not have primary care providers at the time, causing a delay in follow-up after diagnosis. In addition, several stated that they did not seek medical care from youth to middle age unless they were sick. Disclosed reasons included lack of insurance, time, and putting others before themselves.

Patient education, emotions, provider experience, and disease perception play a role in self-management. For participants in this study, watching family members live with diabetes either lent to the idea of diabetes as a way of life or served as a warning to make lifestyle changes. Emotions, like fear, served as a motivator and paralyzer. For example, Frank expressed a significant fear of the "what-ifs" of diabetes, including amputation and death. A good discussion with his provider about how good glycemic management can mitigate those complications would have benefited him.

Conversely, fear motivated Helen to make significant lifestyle modifications though her fear persisted. Scarcity of information was almost a universal experience of study participants. Even so, two participants responded to their diagnosis pragmatically and did what they felt they needed to do to manage their diabetes; one reported a positive experience with their provider at diagnosis, while the other reported feeling criticized and given little to no instruction. Both had a family history of diabetes and prior knowledge of disease management. Differences in individual responses mean that education and care must be structured according to each patient's

situation, emotional response, understanding, and experience.

The minimalization of disease severity and ambiguity of terms to describe diabetes can alter patient perception and disease management; consequences of the lack of conveyance of urgency from a provider were demonstrated by a lack of medication adherence by one participant. Her perception, influenced by her provider, was that T2DM was not a disease compared to type one diabetes. Also, using terms such as borderline or full-blown diabetes was not accompanied by clear definitions. In addition, while self-management is vital to outcomes, the data indicates that providers had shifted the burden of care to the patient without providing a clear plan or attenuating the seriousness of T2DM. Finally, remember Andrew, who thought that disease management was temporary or just until the A1c was "under control."

There was also a lack of patient education regarding Metformin prescription. Several experienced intense and unexpected from their perspective- gastrointestinal side effects which limited their ability to leave the house or perform their jobs. Also, several patients expressed an onslaught of health issues right around the time of diagnosis. It seems the culmination of system wide damage caused by long-term uncontrolled blood sugar levels made it appear to participants as though everything happened all at once. Because of the insidious onset of T2DM, this likely is increased in younger and middle-aged participants related to seeking care only when they were sick. This has implications for both post ED visit follow-up and raising awareness of preventative care for young to middle age groups.

Limitations

There are limitations to this study. First, this was a small study with data collected over four weeks in March and April 2023 and nine participants; despite the small size, data saturation was reached. Second, the sample was homogenous, with two-thirds of the participants female. Moreover, two-thirds were white, so it is possible that data may not be generalizable to other races and cultures. Third, all demographic data were self-reported, and there is a potential for self-selection bias because of the sampling methods. Fourth, though the researcher collected the most recent A1C from participants, it is impossible to associate the education, referrals, or experience with provider with glycemic control if known. Fifth, not all participants responded to verification attempts, so it was impossible to determine whether participants agreed with the analysis. Lastly, it was occasionally challenging to separate themes emerging at diagnosis versus themes that developed for each person over time.

Recommendations

Diagnosis experiences of study participants suggest

that primary delivery of patient care was inadequate, despite current management guidelines. Therefore, the author recommends that providers consider the impact of the diagnosis experience when diagnosing and caring for diabetic persons. Proposals specific to findings from this study include education tailored to each patient, referral to a registered dietician, diabetes self-management education (DSME) classes when available, shared decision-making, use of clear terminology, and empathy. Providers should provide written information and a website recommendation for patients at diagnosis; patients also need opportunities to ask questions at non-appointment times. Referral to a registered dietician and DSME classes should be offered to every patient, even if they are not a "new diabetic," since it appears this is not always available at diagnosis. Familiarization with each patient's family medical history is necessary since study results indicate it impacts disease perception and self-management. Acknowledgment that patient emotions can either motivate or deter self-care should necessitate assessment during each patient visit beginning at diagnosis, and treatment options should be discussed and initiated when indicated. Patient education, including risks of living with uncontrolled diabetes, can be balanced by discussing an agreed-upon treatment plan utilizing shared decision-making and clear terminology.

The author also recommends improved education regarding the purpose of taking Metformin and its potential bothersome gastrointestinal side effects. Providers should start low and slow and taper people up to the maximum dose. Though his study cannot imply causation of experience with a provider with improved outcomes, it does show satisfaction with care when a provider is empathetic and thorough. Cassandra relayed that she appreciated being "mothered" or nurtured by a recent provider who sat down with her and developed a precise treatment plan. After many years of being diagnosed with diabetes, she stated that no one had ever done this before. The author contends that these recommendations align with guidelines advocated by the American Diabetes Association [39] and are suitable for every person with diabetes regardless of the duration of diagnosis.

Conclusion

In conclusion, T2DM is a national concern. Only half of diabetic patients achieve good glycemic control increasing long-term complications and death and diminishing quality of life for this patient population. The participants' personal experiences in this study indicate insufficient care delivery at diagnosis and suggest this factor impacts self-management. The author expects that study endorsements when diagnosing and treating persons with diabetes will improve care delivery and outcomes. Since several patients disclosed they only sought out care once they were sick during youth

to middle age, further studies on how to increase awareness of disease prevention are valuable in this age group.

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