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Too little, too late: Socioeconomic disparities in the experience of living with diabetes

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Abstract

The purpose of this article is to examine whether or not subjective social status (SSS) contributes to diabetes diagnosis and disease discovery experiences. Eighteen diabetic women participated in semi-structured interviews. Interview transcripts were reviewed and coded using interpretative phenomenological analysis. Several general themes emerged from the data analysis: SSS shaped different experiences through (a) situations of diabetes discovery (including the circumstances and stage of diabetes at the time of diagnosis), (b) the degree to which participants considered diabetes to be manageable, (c) the extent of diabetes-related knowledge and experience before diagnosis, and (d) opportunities to gain knowledge shortly thereafter. Due to these constraints, lower SSS individuals had particularly adverse disease discovery experiences. The findings are consistent with the theory of constrained choices. Implications for practitioners and for future research are discussed.

Keywords

Health; Medicine; Older adults; Interpretative phenomenological analysis (IPA); Subjective Social Status; Diabetes Experiences; Women

Type 2 diabetes is a leading cause of disability and death in the United States. Its complications place large demands on affected individuals, their caregivers, and the systems of health and supportive care in the United States. Further, diabetes is a chronic illness with a complex regimen requiring extensive self-care. A typical regimen includes taking medications (pills and/or insulin), exercising regularly, following a recommended eating plan, checking blood sugar, checking feet for wounds or sores, and seeing doctors and other providers. As most self-care involves purchasing goods or participating in activities, regimen experiences are shaped by one's access to social and tangible resources.

Diabetes sharply influences the health and well-being of older adults: it is the leading cause of blindness, non-traumatic lower-limb amputation, and kidney failure (CDC, 2005).

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Approximately two-thirds of diabetics die from stroke or cardiovascular disease (CDC, 2005). While many diabetics survive into old age with few complications, many others face devastating personal, social, and clinical outcomes. Research and tailored practice is needed as this problem becomes more widespread. According to age-adjusted projections, diabetes will increase 2.2 times among those aged 65–74 years and 4.5 times among those 75 years and above from 2005–2050 (Narayan et al., 2006).

Quantitative research suggests sharp socioeconomic differences in health outcomes among diabetics. Socially disadvantaged groups experience a relatively faster rate of health and functional decline (e.g. *blinded for review*). In general, individuals with fewer financial resources consume less healthful foods (Inglis et al., 2005) and exercise less (Giles-Corti and Donovan, 2002; Parks et al., 2003). Research suggests that this pattern continues after diagnosis (Nelson et al., 2002). However, little is known regarding the processes by which these socioeconomic disparities emerge and are maintained.

The diet and physical activity aspects of the regimen pose particular challenges for socially disadvantaged individuals due to financial and environmental constraints. Access to healthful foods varies greatly (Auchincloss et al., 2009; Inglis et al., 2005; Horowitz et al., 2004). It is relatively more expensive and difficult to obtain whole grain foods and fresh vegetables in minority-segregated and low income communities (Kwate, 2008; Wang et al., 2007). Horowitz and colleagues (2004) found that diabetes-recommended foods were largely absent from stores in disadvantaged neighborhoods. In addition, lower income populations perceive fewer options for safe and affordable exercise options (Auchincloss et al., 2009; Giles-Corti and Donovan, 2002).

The challenges for socially disadvantaged populations in adhering to the diet and exercise aspects of the regimen could partially explain socioeconomic differences in health outcomes; however, further research is needed to examine the challenges from a participant's perspective. We are interested in going beyond the practitioner model of regimen adherence, and instead want to understand challenges from a patient perspective. In the present article, we analyze whether or not there are differences in diabetes among women based on subjective social status (SSS).

The experience of diabetes diagnosis is a crucial period for adaptation to the illness. Until the event of diagnosis (the naming or confirmation of an illness by a practitioner), patients often are not willing to make adjustments to their lifestyles (Parry et al., 2004). This is due to the disruptive nature of rapidly imposed lifestyle changes. Research focusing on the patient's perspective has identified the diagnosis of a chronic illness to be a traumatic process (Charmaz, 1983), although in certain situations (such as experiencing severe symptoms or waiting for a diagnosis), identification of the disease can provide relief through reducing uncertainties (Esbensen, 2008; Öhman et al., 2003). Other studies that examine diagnosis from the patient's perspective frame it as a transformative process of adaptation to illness (Paterson et al., 1999; Salander, 2002).

A separate body of research considers how diagnosis timing relates to long-term chronic illness outcomes. This research also addresses how timing and outcomes vary with socioeconomic position. A qualitative study by Richards and colleagues (2002) investigated socioeconomic variations in responses to chest pain. They found that residents of relatively deprived areas were more likely to normalize initial symptoms of chest pains (due to greater exposure to ill health) and less likely to seek care due to self-blame and concerns of stigma for worse self-care practices. Several quantitative studies have examined socioeconomic differences in chronic disease among women, including the influence of socioeconomic factors on breast cancer diagnosis. Such studies found that lower SES groups were diagnosed later and had more advanced stages of breast cancer at diagnosis, which might explain the higher rates of preventable breast cancer deaths in low SES women (Gorey et al., 2003; Schwartz et al., 2003). The socioeconomic variations in stage of diagnosis were consistent with other forms of cancer such as colorectal, lung, cervical, and prostate cancers (Schwartz et al., 2003).

Prior research has addressed the patient’s experience of chronic illness diagnosis (from medical sociology) and the social disparities in timing of chronic illness diagnosis (from health services research). However, to our knowledge, no studies have examined socioeconomic differences in diagnosis experiences from a patient’s perspective, from their own circumstances and words. Our goal in the present study is to examine whether or not socioeconomic factors shape the experiences of people finding out they are diabetic. More specifically, we hope to examine threads that intersect diagnosis experiences and socioeconomic experiences, if they do at all. This analysis can inform research on social disparities in health and disease. Further, this research has practical implications in clinical settings as well as for policymakers who design and implement health promotion and disease management programs.

Method

Interpretive phenomenological analysis (IPA) is the approach used in this qualitative study. The IPA approach is situated to understand people’s social and personal experiences, such as life transformation or traumatic events (Smith, 1996; Smith, 2004; Smith and Osborn, 2003). We selected IPA to examine diagnosis because discovery of chronic illness—including diabetes—can be a transformative experience (Black, 2002). Because disease ‘naming and framing’ is socially constructed, there is great value in interpreting participants’ evaluations of their experiences.

Participants

Our data source is a parent research project entitled “Examining the role of sociodemographic and life course characteristics on diabetic experiences and outcomes,” which included 30 adults living in the greater Detroit region. The parent project concerned social experiences of health and disease and was administered to a heterogeneous study population, including 18 women and 12 men. Our present study concentrates on 18 middle-age and older women with type 2 diabetes in the greater Detroit region, including all women who participated in the parent study. To examine heterogeneity by SSS, the present study focuses exclusively on women. The experiences of diagnosis and illness over time cross-cuts several social dimensions, including gender (Brown, 1995). Previous studies of diabetes have found that men and women experience illness differently (Gale and Gillespie, 2001). As discussed by Thorne and colleagues:

> Dominant social constructions of the appropriate roles for women and for the chronically ill or disabled affects how professionals interact with their patients, the therapeutic goals set, and indeed which aspects of the disability are deemed problematic. It is important to emphasize that this process is not predicated on some neutral and objective notion of truth
>
> (Thorne et al., 2012; p. 11).

Further, there are pronounced differences in socioeconomic identity by gender. Our goal is to examine heterogeneity in illness experiences and diagnoses by SSS. We focus on women to better evaluate differences in lived experiences by SSS. We also hope to identify and develop themes that will be useful for social work practice.

We selected a theoretical sampling approach to better elucidate and interpret the themes emerging from real life events and circumstances. Theoretical sampling is described by Patton (2001) as the process of selecting “incidents, slices of life, time periods, or people on the basis of their potential manifestation or representation of important theoretical constructs” (p. 238). The sample was selected to capture both homogeneity (women living in greater Detroit with diabetes) and heterogeneity (socioeconomic status). The criteria we used to gain a heterogeneous sample by socioeconomic status were educational attainment, insurance status, and geographic area.

The sample was drawn from the Research Participant Program at the Geriatrics Center, which links older adults to research studies. This pool includes approximately 1,400 community-dwelling seniors in the greater Detroit area. The Institute of Gerontology maintains information on sociodemographic and health characteristics for potential participants, which enabled us to select individuals to contact based on our criteria.

Recruitment

As part of the parent study, 20 women were selected and were sent a letter of introduction, describing the study’s objectives and procedures. The letter specified that they would be contacted in 2 to 4 weeks directly by phone to answer questions about the study. A script was followed during the call that provided additional information about the study. A maximum of three follow-up calls were attempted for recruitment. Of the 20 women recruited, two were institutionalized (participants with similar sociodemographic characteristics replaced them). Two members of the recruited sample were unwilling to participate. The resulting sample size was 18 women. The sample lived within 60 miles of Detroit in cities and towns of diverse population densities and socio-demographic compositions. Participants ranged from 51 to 92 years of age, varying greatly in physical functional ability. Data collection took place from May to July 2008. The majority of interviews (17 of 18) were conducted in respondents’ homes to enhance participant comfort and confidentiality (the other interview was conducted in a University office as per the participant’s request). All participants signed a letter of consent and completed the interview in full. The parent study was approved by the University of Michigan Institutional Review

Board. The motivation or analysis for the present research study was not influenced by other sub-studies from the parent study.

Data Collection

Orally-administered surveys collected information on regimen adherence, health and illness status, and sociodemographic characteristics. The audio-recorded semi-structured interview followed the survey. In interviews, respondents were consistently asked the following questions:

- Could you tell me about when you learned you had diabetes?
- If you could put yourself back in that instant, what were your initial thoughts?
- How did you feel about making the changes your doctor said you should make?
- Are there things that help you stick to a diet? What kind of things get in the way?
- Can you think of anything that might help you to manage your regimen better?

Each transcript was independently coded by two researchers. General themes were developed by the research team, which consisted of the Principal Investigator and five research assistants. (The identification of themes and subthemes will be discussed in the analysis section below.) Following the interpretive coding process, the final coded passages were entered into NVivo software for retrieval (e.g. Clare et al., 2007; Söderström, 2011).

The coding strategy is described by Bradley and colleagues (2007) as a process by which coding is first conducted independently, then teams meet to reach consensus: “One approach to applying the finalized code structure to the data is to have two to three members of the research team re-review all the data, applying independently the codes from the finalized code structure. Then, the team meets in a group to review discrepancies, resolving differences by in-depth discussion and negotiated consensus” (p. 1764).

The decision to use more than one coder was made to enhance the credibility of the coding process (Green, 2005; Patton, 1999). Our rationale was to increase code credibility, reliability (including the consideration of multiple codes for a given passage) and to reduce coder fatigue. Coders met to resolve discrepancies, and reach consensus, which enhanced confirmability. Research assistants were undergraduate sociology majors with training in statistics and research methods.

Procedure to Characterize Participant Socioeconomic Status

Socioeconomic status was determined according to participant self-assessment, following the objective in IPA to better understand the experiences from the perspective of the participant’s lifeworld (Smith, 2004). Participants were asked, “How would you describe your financial situation: Well-to-do, comfortable, a little tight, or a struggle?” Among the 18 participants, none considered themselves “well-to-do”. Twelve participants responded “comfortable” while the remaining six responded “a little tight” (3) or “a struggle” (3). The 12 participants who identified as “comfortable” were categorized in the relatively higher SSS group, while the six participants who identified “a little tight” or “a struggle” were categorized in the relatively lower SSS group. Incomes in the higher SSS group ranged from

$1,000–$5,000 per month (median $3176). Incomes in the lower SSS group ranged from $1000–$4000 per month (median $1525). The groups were both racially/ethnically diverse.

Findings

Theme 1: Situations of Diabetes Discovery

During the interviews, participants were encouraged to reflect on when they first learned of their diabetic condition. Probes were provided to solicit information on who delivered the news and what recommendations were made at the time of diagnosis. Respondents were categorized as either discovering they were diabetic at a routine appointment or through symptoms/suspicions that prompted the visit. Most participants were diagnosed with diabetes during a routine appointment and were not aware of symptoms beforehand. The remaining participants who experienced symptoms prior to diagnosis overwhelmingly identified as lower SSS. Before being diagnosed, Rita (who described her current and prior financial situation to be “a struggle”) had already experienced diabetes-related symptoms:

> Rita (R): Before [being diagnosed] I remember waiting for the bus and my feet were just so painful, cold.

Rita made an appointment with a physician due to foot pain and tingling sensations. In retrospect, Rita could not recall if she was unaware or in denial of the symptoms being diabetes-related. At the time of her diagnosis, Rita recalled feeling angry with herself for waiting to go to the doctor despite having symptoms, until her diabetes had worsened (“I’m sure my blood sugar was 8 or 9 . . . .”). Rita was angry at herself for waiting even though she did not know she had diabetes.

Disease discovery can occur during inopportune times as the result of progressive symptoms developing, particularly among the socially vulnerable. Rita did not have routine medical check-ups and did not have a regular source of medical care. Routine or preventive health care appointments were sometimes considered luxuries. Prolonged symptoms, delayed diagnosis, and self-anger contributed to an overall negative experience. Self-blame of her lifestyle choices prior to diagnosis continued for decades (“I was doing all the things I wasn’t supposed to be doing and I wasn’t feeling right.”) Rita emphasized mistakes of the past over how she has since adapted her lifestyle. Rita remarked that the financial burdens resulting from becoming diabetic continue to be a strain.

Although the majority of financially secure participants became aware that they were diabetic during routine screenings, several suspected they had diabetes prior to diagnosis. This can be a way to take control over the circumstances of diagnosis. Such an example is provided by Margaret, an elderly participant with a comfortable financial situation and an advanced educational degree. She stated: “My sister, the doctor, had always said we were going to get [diabetes] because we were overweight. I had a pretty good constitution so I put [going to the doctor] off . . . .” Despite having taken control over the timing of the situation of disease discovery, Margaret still blamed herself at the time of diagnosis: “. . . . and when the doctor told me I had [diabetes] I was really mad and angry at myself. Because I knew what could happen.”

Margaret’s approach seemed paradoxical: like socioeconomically disadvantaged participants, Margaret postponed seeking care. Unlike socioeconomically disadvantaged participants, however, she sought care when she felt emotionally prepared to be labeled as diabetic—she was already aware she had diabetes. She also did not postpone seeking care due to financial concerns. Although Margaret asserted control over the timing of the diagnosis situation, she nevertheless experienced self-anger. Margaret experienced self-anger during diagnosis because of lifestyle choices even though she knew better (“Because I knew what could happen”), while lower-SSS respondents, such as Rita experienced self-anger for postponing care for financial reasons or normalizing diabetes-related symptoms. The proportionately high financial consequences are a nagging reminder. However, like the majority of other high SSS respondents, Margaret mentioned she was able to change her lifestyle following diagnosis: “But I decided I was going to follow through and I have.” Therefore, unlike Rita (who continued to experience self-blame and to prioritize past mistakes in the dialogue over lifestyle changes), Margaret emphasizes the changes she has made in her life *since* diagnosis to keep her diabetes under control. This emphasis of “managing” versus “being managed” provides a framework through which illness experiences differed according to participant SSS. We discuss how negative discovery experiences branch into negative or positive illness experiences.

Theme 2: Managing versus Being Managed

Regardless of social position, most participants reported feeling some fear, anger, and anxiety when they found out they were diabetic. However, these feelings tended to dissipate or disappear among socially advantaged participants. The prospect of making drastic and long-term changes in one’s life was particularly traumatic for socially disadvantaged respondents. Here, Sandy (with few economic resources) recalls that she had resigned herself to being sick:

> Interviewer (I): So, initially, when you found out you had diabetes how did you feel about making those changes?
>
> Sandy (S): Neglected or deprived. Like I was making a sacrifice …

Sandy then said she has since given up “fighting back” due to her age: “I don’t want to get into a war that I can’t win.” This demonstrates two related emotional reactions to the event of diagnosis: Rita experienced feelings of self-blame, while Sandy experienced feelings of deprivation-turned-surrender to the illness. Both emotional reactions are characteristic of diabetes “managing them” rather than the participants “managing diabetes”.

In comparison, study participants who were socially advantaged tended to recall feelings of manageability, optimism, and determination. One well-to-do participant (Katherine) described her initial disease discovery at a routine appointment with ease and a sense of normalization.

> Interviewer (I): When your primary care physician told you that you had diabetes how did you respond?

> Katherine (K): I thought no surprise there. I really felt that—no surprise—and I've seen enough people having to manage diabetes—she said it's Type II and it could stay like that for a long time so we will treat it with exercise and diet.

Linda, who considers herself financially comfortable, also recalls diagnosis as an event wrought with emotions. Like Sandy, Linda felt deprived or victimized upon diagnosis. Unlike Sandy and Rita, however, Linda described diagnosis as the motivation to successfully manage her diabetes:

> Linda (L): You just step up to the plate and do what you have to do.
>
> Interviewer (I): Anything else that you would like to comment on regarding when you first found out you had diabetes and your feelings then?
>
> L: Well it was kind of depressing, you feel 'why me', you know. That's about it.

Our interview respondents across the socioeconomic spectrum suggested that fear, depression, and even denial are typical emotions that emerged during the initial discovery of diabetes. Most of the participants who responded with neutral feelings or normalization of the illness at the time of disease discovery described their financial situations as favorable. Thus, socially advantaged respondents were more likely to perceive the diagnosis of diabetes as a manageable process. The analysis of transcripts revealed a pattern of comments from socially advantaged respondents such as, "so what," "no big deal," "I can handle it," and "something to work with." Differences in perceived manageability could explain much of the socioeconomic differences in subsequent adherence to a regimen.

Theme 3: Diabetes-related Knowledge

What participants knew about diabetes and the regimen prior to diagnosis also influenced the discovery experience. Generally, we found that socioeconomically disadvantaged participants had more extensive experience with diabetes (in terms of immediate and extended family having been diabetic). In contrast, participants who were socioeconomically advantaged had relatively less experience with diabetes, but held more knowledge about diabetes and its regimen.

Rita knew type 2 diabetes could lead to severe outcomes. Several of her immediate and extended family members had suffered extreme complications associated with the illness. She was unaware she had diabetes despite diabetes-related symptoms and personal experiences with diabetes. Rita described her financial situation to be "a struggle" and recalled the lifestyle that could have exacerbated her diabetes prior to diagnosis "came with the territory" of her job: "[After having the symptoms], I drank a whole lot of water . . . . I was also still working in advertising so I was drinking cocktails and eating a lot of food and doing the things you shouldn't be doing with diabetes." Despite her personal experience with diabetes, she lacked knowledge to recognize that the symptoms she was experiencing were actually diabetes-related complications. Further, she was not aware at the time that her work-related lifestyle was further aggravating her symptoms.

Through analysis of the interview data, it became apparent that having previous knowledge about diabetes and the regimen, as well as having previous experiences viewing complications unfold among loved ones, shaped the experience of diagnosis and attitudes toward diabetes. Previous knowledge prepared participants to modify lifestyles, while having known others who experienced diabetes provoked fear of extreme outcomes among participants. Socioeconomically advantaged participants had greater access to information about diabetes prior to diagnosis, while disadvantaged participants had witnessed more extreme diabetes cases, particularly among friends and family.

Milly knew little about diabetes prior to diagnosis. She had “barely enough to get by” during adulthood and at the time of diagnosis. Milly’s familiarity diabetes was limited; she had an acquaintance with diabetes-related complications. When Milly was diagnosed, her main concern was the possibility of developing devastating complications if she did not make dramatic changes in her lifestyle:

> Interviewer (I): And how did you feel about making those changes?
>
> Milly (M): I didn’t like it. But you knew you had to. My husband had a friend that he was in the Navy with that had diabetes and didn’t believe his doctor and he wouldn’t take his medicine or anything. Lost his toe, lost his foot, and then lost his leg and then he died.

It was fear that motivated Milly to adhere to her diabetes regimen. This is in contrast to Linda’s initial reaction (“you just step up to the plate”), who considered herself to be in a more financially comfortable situation.

> Interviewer (I): What were your initial thoughts [upon finding that you were diabetic]?
>
> Linda (L): Well, you’re afraid that you’re going to have to go on shots. And I have been hypoglycemic a few times. So you have to watch that real closely. That’s the low . . . .

In a concurring example, Margaret (a financially “comfortable” participant) illustrated how her knowledge of diabetes prior to diagnosis, partly due to her social connections, prepared her for the realities of the life changes that come with a diagnosis of diabetes:

> Interviewer (I): What did you know about diabetes before you found out you had it?
>
> Margaret (M): I probably knew everything about diabetes before I found out. My sister, the doctor, had always said we were going to get it because we were overweight . . . .

As suggested in *Theme 1* above, she was ready to take action to modify her lifestyle at the time of (and possibly prior to) diagnosis: (“I decided I was going to follow through and I have.”) Despite originally feeling angry with herself for becoming diabetic, Margaret did not carry with her the implicit concern of experiencing extreme diabetes-related complications. Rather, she focused on lifestyle changes. The diabetes-related information she received from her sister (a physician) reduced many barriers others face in making changes quickly. Further, she had access to financial resources and did not face the cost barriers less advantaged participants confront (e.g. cost of diabetes-related foods, enjoyable ways to exercise, and access to transportation).

Behavior and emotions were influenced by exposure to friends or family who suffered from extreme complications associated with type 2 diabetes. Participants shared feelings of aversion, stating that they “did not want to end up like their mother (or sister). Similarly, the subjects who were interviewed reflected on their family members’ experiences and discussed initial worries about having to go on insulin or fear of losing a limb. While higher SSS participants also were frequently exposed to friends and family members with type 2 diabetes, this tended to be later in the life course. Further, these participants did not tend to mention severe outcomes such as amputations or death. For disadvantaged participants such as Milly, negative feelings are often targeted around a “worst case scenario.” The concerns shared at the time of diagnosis were primarily about potential complications, and not with the process or lifestyle changes that would have to be made.

Theme 4: Opportunities to Gain Knowledge

Overwhelmingly, socioeconomically disadvantaged participants did not want to attend diabetes classes. Classes were described as less accessible or not culturally appropriate. Betsy is a participant who described her financial situation as always “a struggle.” Betsy recalled her experience attending a diabetes education class as negative and coerced: “I [didn’t] get it.” In response to her physician’s request that she attend further classes, she explained, “I didn’t want to do it. Period. That’s how I feel about it.”

In contrast, higher SSS participants reflected positively upon their diabetes classes. Katherine, who is well-to-do and had a relatively favorable disease discovery experience (discussed in *Theme 1*) reflected on diabetes classes as an opportunity to learn more about successful diabetes management:

> Interviewer (I): So your initial feelings when she told you that you had diabetes, you felt you could handle it. So what did you think about the changes she wanted you to make?
>
> Katherine (K): I didn’t know what a diabetes diet is. She said they have a very good education program at [local hospital] and you need a prescription referral and I did go there. And I was really intrigued—I thought it was great—3 different sessions for 2 to 3 hours at a time. People with different experiences there, but I learned a lot more about nutrition and particularly carbs . . . . I was very diligent when I first started.

From Katherine’s discussion of the diabetes program she attended, we can observe that although the program itself was free, there were additional accessibility concerns. First, it required a large time commitment, which might not be possible for those balancing multiple jobs and obligations. Second, classes followed a classroom instruction style, which would likely be more familiar, be less intimidating and more engaging for patients who have completed higher levels of education. Classes also required appropriate medical referrals. Finally, classes assumed access to transportation and the ability to buy and obtain ingredients and supplies required for adhering to the regimen as described. These interviews suggest that such opportunities to learn about diabetes and its regimen might be more accessible to more affluent patients. In most cases, participants who were at greatest need for these resources often did not find them appropriate or accessible.

Discussion

The theory of constrained choices could be used to examine how socioeconomic experiences relate to health and illness experiences among women with diabetes. Bird and Rieker (2008) use constrained choice theory to analyze gendered disparities in health over the life course. We draw on the theory as envisioned by Bird and Reiker (2008), except we suggest that diagnosis experiences provide insight into the processes by which health disparities are exacerbated over the life span. Further, we find that diagnosis experiences should operate as a critical intervention period. Social systems generate inequalities, which is exacerbated over the life span through developmental and demographic processes. While individuals are a part of these social forces, human agency is “constrained by the opportunities structured by social institutions and culture” (Elder et al., 2003; p. 8). Thus, opportunities for individuals to exercise agency in health behaviors such as regimen adherence could be constrained by economic realities. These constraints could be activated in multiple realms, such as constraints of information, finances, culture, priorities and access. For example, external forces such as the cost of diabetes-friendly foods could make it disproportionately more difficult for disadvantaged groups to adhere (Lutfey and Freese, 2005). Such constraints could lead to different initial experiences and timing of diagnosis as well as subsequent health behaviors, compounding into divergent health outcomes.

The findings are consistent with the theory of constrained choices. Socioeconomic constraints were demonstrated through different situations of diabetes discovery (including the circumstances and stage of diabetes at the time of diagnosis), the degree to which one feels diabetes is manageable, the extent of diabetes-related knowledge before diagnosis, and opportunities to gain knowledge shortly thereafter. Due to these constraints, women reporting lower SSS had particularly adverse disease discovery experiences. The qualitative findings provide examples of mechanisms that illustrate how diabetes experiences are influenced by socioeconomic factors. This overall finding is fundamental because one’s perspective at initial disease discovery influences the patient’s world view, level of engagement in services, and the point of departure from which self-management begins.

Women reporting relatively lower SSS presented to physicians after diabetes-related complications became apparent. Learning that one has diabetes through a routine or annual examination is a favorable method of disease discovery because it allows for earlier detection, more effective treatment options, and preventive therapies from the onset of diagnosis. Less favorable methods included discovering diabetes in the later stages once symptoms such as excessive thirst, foot pain, or blurred vision have developed into a complication prompting a medical visit. Previous research has shown that a later diagnosis of diabetes is associated with a higher risk of mortality or morbidity (Harris et al., 1992). Our findings are consistent with previous qualitative research that focused on other chronic diseases (e.g. heart disease and cancer), suggesting that socioeconomic variations in diagnosis timing partially explain socioeconomic differentials in chronic illness outcomes (Richards et al., 2002; Gorey et al., 2003; Schwartz et al., 2003).

Negative emotions at disease discovery relate to micro and macro social conditions. Differences can be seen at the individual level (e.g. relating to personal resources or mental health status) or at community levels (e.g. neighborhood resources or group-based social norms). It is valuable to realize the sources of strain and cultural/environmental contexts to best serve disadvantaged populations. The findings suggest a later and more traumatic diagnosis for less privileged respondents: relatively lower SSS women tended to report concerns regarding potential outcomes (amputations, death), while relatively higher SSS women concentrated on lifestyle change during the disease discovery process. The diagnosis of chronic disease has been identified as traumatic from a patient’s perspective (e.g. Charmaz, 1983). While our results show that initial concern at disease discovery appears over the socioeconomic spectrum, the way these emotions are activated do vary.

The analysis shows differences in emotional states at the time of diagnosis by SSS, which can provide relevant information for practitioners who provide diagnoses. While some individuals view the potential for negative consequences as a motivating force to manage diabetes, ensure longevity, and maintain good health, for others, fear can be debilitating—leading to avoidant behaviors and reduced adherence levels. Our study suggests that among socioeconomically disadvantaged adults with diabetes, fear of negative outcomes is not a motivating factor for adherence. Over time, negative feelings of self-blame and frustration can reduce self-efficacy (or the belief that one can maintain control of their regimen), particularly with diet, exercise, and patient education. This is a significant finding since it provides evidence of the mind-body connection, which has been supported throughout the literature to link emotional issues to body functioning, particularly for women (Vitetta et al., 2005). Further, it emphasizes the illness discovery stage to be an important stage for adapted identity formation (Parry et al., 2004). Diagnosis could be an ideal time for health-promoting interventions, particularly for socially disadvantaged patients.

Conclusions

This research provides unique insight into the perspectives and perceptions of type 2 diabetics during the disease discovery process and beyond. The findings are innovative in the identification of how constrained choices (in this case, socioeconomic characteristics) leads to less favorable circumstances of diabetes diagnosis. The differential diagnosis by SSS is a process by which health disparities are exacerbated in the experiences and outcomes of diabetes. Our findings emphasize the importance of the disease discovery process as an opportunity for health promotion interventions. Ideally, physicians, nurses, social workers, nutritionists, and other health practitioners should follow through with supportive phone calls or educational literature to emphasize the importance of regimen adherence. The women in our study specifically stated that their doctors did not answer all of their questions, but a sizeable body of research has similarly shown timely and integrated post-diagnosis care to be highly effective among diabetics (Parry et al., 2004).

Additionally, patient recommendations should be individually tailored to specific learning preferences, health literacy levels, and socioeconomic resources. Individuals without adequate transportation or work schedule availability may not consider a diabetes lecture a priority. Further research should investigate the openness and cultural competency of diabetes classes to different socioeconomic groups, emphasizing the opportunity to create a space for processing the information and gaining social support from other diabetics. In other studies, preferences in health education courses have been found to differ by the degree of formal education to which one has obtained and has a hidden advantage for patients with greater resources and economic security. Formal classes are often tailored to those who are educated at universities, while patients with less education might benefit from a lateral learning or peer-based approach (Whitley and Kirmayer, 2008). At the time of, or shortly following, diagnosis, patients should be provided with superior medical counseling, a practical education, a realistic plan of adherence, as well as connection to long-term support systems.

The findings are based on self-reported data and are based on current evaluations of subjective social status. Despite efforts to assist participants with recall (life history calendars), recall and interpretations of events can be subject to bias over time. Further, evaluations of SSS could have changed from the time of diagnosis to the interview period. Despite these limitations, this article offers a unique contribution to the understanding of processes of how socioeconomic disparities in diabetes outcomes and adherence, particularly relating to the experience of disease discovery and diagnosis.

Implications for Health Workers

These research findings have strong implications for community health workers, who hold a significant role in connecting both the individual patient to services, as well as partnering with the larger medical systems, to make institutional based changes. For those suffering from chronic illness, the expertise of social workers and nurses can provide vital health education, as well as assistance linking patients to natural social supports and community resources that are available. Based on the findings, it would be valuable to connect patients to one another at initial disease discovery to help set realistic regimen adherence goals that fit with the individual’s life experiences, health literacy level, and cultural background. This would be of particular importance to members of socially disadvantaged groups who may require more assistance processing what it means to be diabetic, how to access care, and utilize medical services.

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