MEDICINE’S NEW TRUE NORTH WITH E-PATIENT DAVE

THE DIFFERENCE A CDE MAKES

REDEFINING DIFFICULT

FAKEBETES CHALLENGE PATIENTS AS EDUCATORS

WRITING WHERE IT HURTS
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THE PATIENT’S PERSPECTIVE: MEDICINE’S NEW TRUE NORTH
Dave deBronkart (E-Patient Dave)
“e-Patient Dave” deBronkart, cancer survivor and patient advocate, discusses the changing nature of the patient-physician relationship, with the patient becoming an active contributor and partner in their care. Engaged and empowered patients, “e-patients,” can help raise levels of consciousness about complex health problems and what can be done to solve them.
In 1921, Canadian researchers Drs. Frederick Banting, Charles Best, J.J.R. Macleod, and J.B. Collip worked together to develop the process for extracting insulin, and subsequently led it to mass production to save the lives of children who were, quite literally, wasting away. Diabetes at the time was a death sentence, and they knew that something had to be done to save these young lives.

Profit was never the motivation of these researchers. They knew that the well-being and longevity of people with diabetes was more important than financial gain. If you want to read a fascinating story of how the miracle of insulin came about, I recommend the books *Breakthrough* by Thea Cooper and Arthur Ainsberg and *The Discovery of Insulin* by Michael Bliss.

Today, we often find ourselves stalled at the intersection of innovation and greed in the treatment of diabetes. Recently, insulin makers have come under fire for the costs that they charge for insulin. These companies applaud themselves for their record-breaking profits, reward their investors, and in turn establish themselves as beneficiaries of the very community that they have been entrusted by Drs. Banting, Best, Macleod, and Collip to keep well.

Insurance companies are guilty of putting business before healthy people as well. Preferred vendors and formularies influenced by back-door business deals have long been in place to help insurance companies turn a profit. Recently, these insurance companies have received heated criticism for limiting access to alternative therapies due to these “preferred status” deals. This has resulted in the patient community feeling as if it is not the physician who is helping them make decisions about their diabetes, but rather the insurance companies.

People with diabetes work hard to find the right combination of therapies that lead to success, but diabetes is a highly customizable disease, so what works for one person may or may not work for another. A lot of money, time, and effort is spent toward better health outcomes, and to defending the right to receive the care that best works for each individual situation. And it is a right. With the implementation of the Affordable Care Act, and its upheld constitutionality by the United States Supreme Court, people with diabetes have a right to not be discriminated against because of their pre-existing condition.

The decisions for how we live well with diabetes, and what therapies and technologies we need to do that, should be made between the person with diabetes and their trusted health care professionals. Insurance should be a partner in achieving these goals, not a barrier. In order to do that, we must give preferential treatment to the patient at the center of business and health care, hold those entities accountable who get it wrong, and reward those who get it right.

--MARTIN
We believe in our mission... to educate and develop exemplary physicians who practice patient-centered health care, discover and advance knowledge, and are responsive to community needs, especially through service to elder, rural, minority and underserved populations.

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I have been lucky throughout most of my life as a person with diabetes (PWD) to have some pretty incredible insurance. Diabetes is expensive and navigating insurance benefits can be confusing and frustrating on the best of days. Yes, I pay a staggering amount of money for premiums, copays, and deductibles, but it is far less than I would if I had subpar coverage – or none at all.

Of course it can be exasperating to pay this much money and still have to be very active in your advocacy. For example, right now I am trying to get a refill for transmitters necessary to make my continuous glucose monitor (CGM) work. I am constantly checking in with my doctor’s office to get necessary paperwork, contacting my insurance company to push the approval along, and making sure that the sup-
The first CGM sensor insertion in her office. I have pored over graphs of blood sugars seeking answers to middle of the night anomalies. I have cried with her over symptoms no one else seemed concerned about. Mostly, going to my CDE helps me stay accountable in my own care. Perhaps it’s my Type A personality or my drive for perfection that makes me feel this way. Regardless, I actually find myself looking forward to my CDE appointments. My CDE is my cheerleader. She rallies behind me when burnout strikes. She constantly guides me to be less critical of myself. She gives me perspective, and reminds me that, in the grand scheme of things, I’m doing a really good job managing this illness. Those words mean everything to me. I seek the validation she provides and it gives me the motivation to keep moving forward. I am fortunate to have the resources and health insurance that allow me to have these regular appointments with my CDE and endocrinologist.

Diabetes gives me plenty of reasons to get sad or mad or frustrated. I definitely do not need to go in search of those things. But diabetes has also given me a connection to some wonderful people I would have never met without it. I consider my CDE and endocrinologist to be two of those people. This life with diabetes has given me an opportunity to become my own best advocate, and I am so thankful for the health insurance that I have that allows me to have a wonderful health care team behind me.
I frequently refer to myself as ‘the difficult child’ – not so much in my family setting, because there I am clearly the perfect daughter (just ask my sister!). But professionally, I am sometimes difficult because I have been known to ask a lot of questions, and to think outside of the square. I am a risk taker.
And I would also be termed difficult in other settings.

According to a recent article on the health-related news blog, wbur’s CommonHealth, by Dr. Anna Reisman, an associate professor at the Yale School of Medicine, many physicians would consider me to be a “difficult patient,” a term that I really struggle to understand.

In the article, Dr. Reisman shared a recent conversation she had with some of her medical students who seemed to long for past days, where the physician was seen as the decision-maker and the patient was simply expected to comply with orders without question or comment. Patient questions are time consuming, schedule bending, and sometimes even exhausting. The medical students in Dr. Reisman’s class expressed a longing for “easy patients” who would accept and trust their expertise and opinions, and not be “difficult” by asking questions.

Living with diabetes can be difficult. It doesn’t behave how we would like it to or how we expect it to. It makes us frustrated and angry and sad and annoyed. It makes us want to try different things as we hope to get better results and see in-range numbers. And sometimes – often – we are the ones searching for a solution to an ever-changing disease, Googling, reading, researching, asking others for advice, and desperately wanting more, better, and different treatments that can make living with diabetes one thing and one thing only – easier.

When I ask questions or walk into a healthcare provider’s (HCP) office asking to try something new, I am not being difficult or questioning their expertise. Quite the opposite. I am there to solicit their expertise, to have a discussion about how I can improve my health, and couple what I know about my life with diabetes with their knowledge of medicine to try to crack the combination that leads to success, longevity, and less fear of eventualities and unknowns.

The only reason I manage my diabetes the way I do is because I researched, asked questions, and told my HCP it was what I wanted to do. I wasn’t being difficult when I first raised the idea of ditching multiple daily injections (MDI) for an insulin pump. Nor was I being difficult when I asked about continuous glucose monitoring (CGM). Or when I wanted to change to a different type of insulin.

I was looking for ways to make my diabetes less difficult – because diabetes is a difficult monster! It is not the person being difficult. It is the condition. And this clarification is important.

Diabetes is a condition that persists every moment of every day of my life. I cannot hide from it, ignore it, stop it, or replace it. Diabetes and the routines required to manage it are always there, forcing me to question everything. If I had my choice, I would question nothing, and enjoy every minute of it. With diabetes, I have to constantly make a decision about what comes next. Do I eat more food? Do I exercise? Do I go to sleep? Do I care? Do I really have to do this?

I get it, and agree with these medical students and physicians. The questions are absolutely time consuming, schedule bending, and exhausting. But the relationship that they have with their patients is as necessary as the relationship that I have with my diabetes, and the questions are required for both to prosper.
A few years ago, my endocrinologist and I decided that seeing a certified diabetes educator (CDE) was the best move to help my diabetes management.

Unfortunately, my insurance company had a different view: The powers-that-be didn’t think diabetes education was necessary and denied my claim.

This certainly isn’t unique to CDE requests, or even diabetes care. It’s a systematic healthcare failing that irks many people – why is my insurer deciding what’s best for my health, and not listening to what my doctor and I have already decided is needed?

My doctor appealed and helped my insurer see the “medical necessity” of a CDE. However, when the bill arrived, I couldn’t help but be amazed that the CDE was charging me $65, which was twice as much as it cost me to see my endocrinologist who my insurance considered a “specialist.”

I ended up seeing this CDE once, and after that decided it wasn’t worth paying double the amount of a regular endocrinologist office visit. As someone living with type 1 diabetes (T1D) for roughly three decades at the time, it wasn’t critical enough for me to have that insight for what I was forced to pay.

Fast forward to 2016: I’m dealing with this exact same issue with a new health maintenance organization (HMO) insurance plan that is a bit picky on things like this.

The only choice I have for diabetes education and fine tuning my diabetes management is to consult someone from outside of my endocrinologist’s office. With my HMO insurance configuration, in order to work with a CDE elsewhere, it requires a referral from my insurance-mandated Primary Care Physician, and out-of-pocket costs for the larger “specialist” co-pay that is higher than what it costs to see my endocrinologist.

For now, I have to say, “No, thanks.”

It’s not worth the time and hassle for me to make this happen right now, despite the likelihood of a CDE helping me achieve better diabetes results. I do think I’m lucky that I don’t need a CDE as a key part of my D-management routine. For me, today, having a CDE is a “nice to have” more than a “need to have.” A combination of my own diabetes experience, access to good doctors, and peer-support from the diabetes online community (DOC) are all big parts of keeping me healthy.

However, one diabetes complication, one life-altering low blood sugar requiring emergency assistance, or one episode of diabetic ketoacidosis (DKA) from hyperglycemia, and that story changes. “Nice to have” then becomes “medical necessity,” and shifts the acute goals of my diabetes management from “preventative” to “responsive.”

Imagine those who are not living with decades of T1D experience, but are newly-diagnosed with any particular type of diabetes. They are scared, overwhelmed, and need support and basic education that goes beyond the typical few minutes with their clinician during an endocrinologist visit.

These folks are just starting the world of diabetes management, which is 24 hours a day, 7 days a week, 365 days a year, for the rest of their lives. It’s overwhelming. It’s overwhelming even if you have lived with diabetes for more than three decades like I have. Yet, we are asking them to take these new demands on life and all of this new information, with the expectation that they will simply figure it out.

I wonder about these people who need access to a CDE but can’t afford it. Or those who are told insurance won’t cover

By Michael W. Hoskins
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the visit, and they don't know the decision can be appealed. Where do they get advice from? What do they do? How do they figure it out?

We already know that people with diabetes don’t have good enough access to CDEs. The latest data from the American Association of Diabetes Educators (AADE) shows an amazingly small percentage of people with diabetes routinely see a diabetes educator.

You have to wonder why that is. Personally, I think that access and affordability are big barriers to diabetes education.

Reaching out to my current endocrinologist about this, he pointed out that “nothing with insurance companies surprises me any longer.” And my former endocrinologist in another state told me his office just started charging for diabetes education in March, because the time has to be justified to the payers.

I get it. Really, I do. Diabetes care is a business, and our providers need to get reimbursed and make a living just like everyone else. Still, the cost of CDE coverage by insurance doesn’t seem to make much sense – to me, there’s no reason why a CDE visit needs to cost more than the endocrinologist’s office visit co-pay.

When it comes to costs, this is baffling. We could prevent so many incidents of diabetes emergency response if we simply had better training and more information. This same argument applies to continuous glucose monitoring, and soon even closed-loop insulin pump systems. As it is with these technologies, time with a CDE seems like a small investment for such a grand payoff in cost savings of diabetes emergency care and diabetes complications.

The AADE and the American Diabetes Association continue to advocate for better access to diabetes educators. Data from a recent study published in Patient Education & Counseling shows that diabetes education, when added to usual diabetes care, lowers HbA1C and leads to better health outcomes, yet insurers don’t seem to be listening.

Whether we are patients, clinicians, or researchers, it’s easy to agree that more education about the best practices and strategies of managing diabetes of all types is preferable to ignoring actions that can lead to positive results. Now more than ever, research and reputable sources are confirming that diabetes education is beneficial to long term success with all types of diabetes.

If this education is so important, I shouldn’t be forced by my insurance company to pay more for a CDE visit than what it costs to see my endocrinologist. Maybe I could be a bit healthier and even cost my insurance company less money if they simply offered better coverage for quality diabetes education.

Maybe I could recommend diabetes education to my peers in the diabetes online community. Seeing an educator can be just as important, if not more, than many other parts of a person’s D-management. Maybe we could live longer, more productive, and healthier lives without diabetes complications and even cost less for insurers and the overall health system.

Maybe in the near future diabetes education will become the standard for all people with diabetes, instead of the exception.

Maybe sooner than later.

FURTHER READING

Will the Affordable Care Act Deliver?

An Interview with Marshall Kapp, JD, MPH
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Marshall Kapp is an authority when it comes to the intersection of medicine and law. Presently he is the Director of the Florida State University Center for Innovative Collaboration in Medicine and Law, where we had the opportunity to chat with him about how the Affordable Care Act (ACA) is impacting people living with diabetes.

There was a lot of excitement among people with diabetes (PWD) when the Affordable Care Act was enacted, especially considering the struggles that PWD have had over the years with trying to obtain and keep insurance coverage with a pre-existing condition. Six years in, where are we today with the ACA?

Enactment and implementation of the Affordable Care Act since 2010 has been accompanied by high hopes on the part of advocates for persons with diabetes. Specifically, proponents of this legislation and its accompanying plethora of implementing regulations have promised that the ACA will create or foster improvements in the quality, accessibility, and affordability of medical care for individuals with diabetes and that, in turn, improvements in those aspects of medical care will directly produce improved health status and quality of life for affected individuals. Clearly, such improvements are sorely needed by a burgeoning patient population burdened by a very high-cost chronic disease. Whether the positive diabetes-specific expectations associated with the ACA actually end up being achieved remains to be seen over the coming years. That said, there are structural components of the health reform law that create the potential for progress.

Many people with diabetes see the Affordable Care Act as their first opportunity to finally obtain health insurance after repeatedly being denied due to their pre-existing condition. What are the key takeaways on the provision of health insurance with the ACA?

Many of the key provisions in the ACA are aimed at changing the American health insurance system. Prior to the ACA, many people with diabetes lacked sufficient health insurance, if they had coverage at all. Uninsured individuals, including those with diabetes, report poorer access to medical services (for example, lacking a regular source of preventive or therapeutic care) than insured persons. It is presumed by ACA proponents that, as the ACA enhances coverage for this population, it will reduce the gap between care needed and care provided, and that the resulting enhancement of health care utilization will lower the incidence of diabetes complications and improve the health of people with diabetes. Expanded health insurance coverage for persons with diabetes may occur under several specific ACA provisions.

Are you referring to the expansion of private insurance?

Precisely. Under the ACA, many individuals with diabetes who are not covered by Medicare, Medicaid, or other public/governmental insurance plans will have expanded access to private insurance coverage. Many of those individuals will be covered under employer-provided plans, which large employers are required to provide for full-time (30 hours per week or more) employees or pay a financial penalty. However, smaller employers do not fall under this “Play-or-Pay” mandate. To further complicate the matter, employers who do fall under the mandate may elect to pay the penalty rather than incur the costs of insuring their respective workforces. People without public health insurance or private employer-provided insurance are mandated, with some exceptions such as illegal immigrant status or inability to purchase an insurance policy whose premium would cost less than 8% of household income, under the ACA Shared Responsibility Provision to purchase a private individual insurance policy or pay a tax on non-compliance with the law. These private policies are available for purchase on the health care exchanges/marketplaces that are run either by individual states or the federal government. For individuals with incomes between 100-400% of the federal poverty line, government tax credits or direct financial subsidies are available to assist the consumer and make the insurance premium more affordable.
The ACA forbids private insurers from utilizing their earlier underwriting practices by prohibiting exclusions or increased premiums based on a pre-existing condition. A requirement of “guaranteed issue” means, in effect, that insurers must accept all applicants who can pay. Policyholders may not be dropped from coverage for acquiring a new health status, an assurance that should reduce – and ideally eliminate – the phenomenon of “job lock” that previously prevented individuals with serious chronic diseases such as diabetes from changing their positions for fear of jeopardizing the continuity of insurance coverage.

Health plans must now cover, until age 26, the children of policyholders for whom the policyholder agrees to pay the premium. Before the ACA, many young adults were left uninsured between the time they left school and obtained a job that offered health insurance that would cover their pre-existing condition. This dilemma resulted in many young adults with diabetes being forced to neglect their diabetes management, else risk acquiring considerable financial debt from out-of-pocket costs.

Private insurance policies sold on the public exchanges/marketplaces must include a broad package of Essential Health Benefits (EHB), with no annual or lifetime dollar coverage amount caps for the essential benefits. The EHB list includes coverage for diabetes self-management education and medical nutritional therapy. Diabetes- pertinent preventive services enumerated in the required EHB package at no extra direct charge to the consumer include diabetes (type 2) screening for adults with hypertension, dyslipidemia screening for children at higher risk of lipid disorders, gestational diabetes screening for women 24-28 weeks pregnant and those at high risk of developing gestational diabetes, depression screening, annual wellness visits for Medicare patients, flu and pneumococcal vaccine inoculations, cholesterol screening, blood pressure screening, and assessment and counseling for obesity and healthy diet.

The opaqueness of the health insurance industry has long been a bane to health care consumers with chronic diseases. Under the ACA, each private insurance plan must provide a plain-language summary (Summary of Benefits and Coverage [SBC]) of its benefits. The SBC must include a coverage snapshot of how much the plan might pay for a sample patient with type 2 diabetes. In addition, all marketplaces must establish some form of an Enrollment Navigator and Assister program to help consumers understand their options and enroll.

What about the expansion of public insurance? How does the ACA impact or influence programs like Medicaid?

As interpreted by the United States Supreme Court in National Federation of Independent Businesses v. Sebelius, 132 S.Ct. 2566 (2012), the ACA offered the states a financial incentive (through increased federal dollars) to expand their individual Medicaid programs to cover individuals with income below 138% of the federal poverty level. Some states have expanded their Medicaid coverage populations accordingly, others have negotiated different variants of expansion with the federal Department of Health and Human Services (DHHS), and others (included several states with the highest prevalence of diabetes) have declined to take advantage of this opportunity. Early data seem to suggest a positive correlation between Medicaid program expansion and the number of newly diagnosed and treated persons with diabetes. This finding is not surprising, as people with diabetes are disproportionately covered by Medicaid.

Are there other ACA provisions relating to diabetes that haven’t gotten as much attention as some of those that you’ve already mentioned?

In addition to the insurance-related ACA reforms, the legislation contained several other provisions intended to improve the quality of health services available to individuals with diabetes. For example, the ACA authorized the creation of a National Diabetes Prevention Program at the Centers for Disease Control and Prevention (CDC) for the purpose of eliminating “the preventable burden of diabetes.” Moreover, the Catalyst to Better Diabetes Care Act was incorporated into the body of the ACA, which directs the DHHS and the CDC to enhance diabetes surveillance and quality standards across the country. Among other things, DHHS must prepare a publicly available national diabetes report card for each state every two years.

There has been a lot of argument and controversy over the provisions and implementation of the Affordable Care Act. Given the polarizing effect of the act, will the ACA be successful?

The ACA, in both theory and practice, remains controversial. Its future success in addressing quality, accessibility, and affordability challenges for both the general population and for persons with diabetes is far from guaranteed. Specific provisions continue to be open to actual or potential political change, compliance dates and enforcement mandates have been malleable to the point of unpredictability (if not outright ignored when politically convenient), administra-
Objective implementation remains problematic, and sufficient funding of implementation expenses is less than assured. Even with federal subsidies available to assist people to purchase insurance exchange products, the inevitable escalating costs of the private insurance policies offered on the exchanges, as well as substantial deductible and co-insurance liabilities, may impede the affordability of coverage for patients of moderate economic means with diabetes.

Ramifications of much higher individual and corporate taxes, both overt and hidden, to pay for promised ACA benefits may bring about negative results for the nation’s economic well-being (for example, weaker job creation) that are poorly anticipated or acknowledged today. Navigation of the staggering complexity enveloping the emerging health care system wrought, in large part, by the ACA necessitates much greater health literacy on the part of patients with diabetes, their families, and advisors. It is improbable that any of the ACA reforms will exert much noticeable impact on the availability of health care providers in primary care and endocrinology.

On September 9, 2009, President Barack Obama confidently told a Joint Session of the United States Congress, “I was not the first President to take up this cause [of health reform], but I am determined to be the last.” This expression of confidence has not been borne out by subsequent events. The challenge of translating recent legislative and regulatory health reform exercises into tangible accomplishments, let alone significantly improving on those exercises, means that advocates for the diabetes patient community and their governmental and private partners still have much work to do.

FURTHER READING


PERCEIVED BENEFITS AND BARRIERS TO THE DIABETES PREVENTION PROGRAM

ABSTRACT

Objective: Diabetes prevention interventions have a proven positive effect on health outcomes. The goal of this project is to understand the factors that motivate and deter people with prediabetes from utilizing evidence-based education programs, such as the Diabetes Prevention Program (DPP).

Research Design and Methods: Formative research was conducted among program facilitators, health providers who care for diabetes patients, and patients living with prediabetes to generate an in-depth understanding of perceptions of the program. The methodology included a mixed methods approach. A total of 97 interviews and 5 focus groups were conducted with health providers, program facilitators, and patients. An online survey was administered to 50 patients with prediabetes.

Results: All three populations agreed the DPP aided in implementing lifestyle changes and preventing the onset of type 2 diabetes, and the classes provided a positive experience for support, in-depth discussion, and opportunities for learning how to make lifestyle changes. However, while the overall benefits of the program were expressed, there were barriers noted by all populations that affect program utilization and physician referrals. General lack of knowledge, cost of the program, and the significant time commitment necessary to complete the program were barriers discussed.

Conclusions: The Diabetes Prevention Program is successful in helping individuals with prediabetes make positive lifestyle changes. The lack of knowledge about the program, however, is a deterrent for utilization. Creation of a social marketing campaign based on the findings from this research will aim to increase healthcare provider referrals to the DPP.

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INTRODUCTION

Prediabetes is indicated by elevated blood glucose levels that are below the clinical range for a diabetes diagnosis, but above 100mg/dl [1]. If left untreated, poorly managed, or undiagnosed, prediabetes can lead to serious health complications [1]. Close to 57 million adults in the U.S. and approximately one in four U.S. adults over 20 years old are categorized as pre-diabetic or at risk for developing type 2 diabetes [2].

Prediabetes and diabetes present a significant challenge for individuals, communities, and healthcare systems. Diabetes can result in debilitating complications like kidney disease, cardiovascular disease, blindness, and amputations [1]. As of 2012, the healthcare costs associated with diabetes are $176 billion annually and diabetes contributes to $69 billion in loss of productivity in the workplace [1]. With the rise of newly diagnosed diabetes cases and an increase of prediabetes, efforts focusing on the prevention of diabetes and diabetes complications have emerged in community-based settings across the nation.

The Diabetes Prevention Program (DPP) is an effort to combat the rising numbers of prediabetes. It began as a multisite research study funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) comparing a dietary and physical activity intervention with oral anti-diabetic medication as a means of preventing the onset of diagnosed diabetes among individuals at high risk for developing diabetes [3]. The results of the study indicated that those participants who experienced modest weight loss through lifestyle intervention lowered their diabetes risk more significantly than participants receiving oral medications (58% versus 31%) [4]. Additionally, the study found that lifestyle intervention was highly effective in all subgroups of age, gender, and ethnicity. This research became the model for the National Diabetes Prevention Program (NDPP) that includes education on diet, physical activity, and behavior modification. The behavioral goals of the program are to eat less fat and fewer calories and exercise for a total of 150 minutes a week in order to lose 7 percent of their body weight and maintain that loss. The year-long program targets individuals at high risk for developing type 2 diabetes. Eligibility for the program is determined using the following metrics: the Centers for Disease Control and Prevention (CDC) Prediabetes Screening Test, BMI measurement over 24, fasting glucose test indicating prediabetes, and over 18 years of age.

The implementation of the NDPP Recognition Program sets program delivery standards of Diabetes Prevention Programs to assure fidelity and quality in programs throughout the United States. Local organizations offering DPP programs can submit applications for recognition including proposed curriculum and available organizational resources. The applications are reviewed and offered “pending status” while initiating programs and collecting participant outcomes data. If programs are able to meet benchmarks, “full recognition status” is awarded. The review process is free of charge for organizations and usually takes 2-3 years. Local recognized programs benefit in reputation from the CDC seal of approval.

The CDC sponsors trainings for “lifestyle coaches.” Lifestyle coaches are encouraged to attend CDC sponsored trainings by the Diabetes Training and Technical Assistance Center (DTTAC) and partner organizations that deliver approved curriculum. Additionally, the standardized program provides technical assistance and support to assure fidelity, capacity, and sustainability.

The NDPP partners with non-profit organizations and private insurance companies to provide and expand offerings of the DPP across the United States. It has recognized several grantee organizations that provide the program through their memberships and local programs: American Association of Diabetes Educators, American Health Insurance Plans, Black Women’s Health Exchange, National Association of Chronic Disease Directors, Optum Healthcare Solutions/Diabetes Prevention and Control Alliance, and the YMCA of the USA. The American Medical Association (AMA) is collaborating with the NDPP in an attempt to prevent the progression of prediabetes by addressing risk factors and developing new approaches to reduce diabetes [5]. This aligns with the AMA’s goal of improving health outcomes in cardiovascular disease and type 2 diabetes due to the detrimental impact on patients nationally and the increased costs on the healthcare system. The YMCA of the USA has been an active partner in this effort by providing the program in YMCA locations. The ultimate goal of these partnerships is to increase the number of referrals of adults who have prediabetes to this evidence-based program.

Formative Research Objectives

Despite evidence that lifestyle intervention can reduce the incidence of diabetes, and despite evidence that this reduction is applicable to the diverse population of the U.S., participation in the DPP is less than desired. The
The goal of this formative research is to understand the factors that motivate and deter people with prediabetes from utilizing evidence-based education programs. The population of interest is isolated to the state of Florida, since the research was partially funded through a grant from the Florida Department of Health. Results from this research will be used to create a multi-faceted intervention to increase health provider referral to these programs and develop other materials needed to increase DPP program utilization.

RESEARCH DESIGN AND METHODS
A mixed methods approach was utilized combining qualitative and quantitative data collection and analysis. Specifically, an exploratory design was used, where findings from the qualitative analysis guided the survey design for the quantitative analysis.

Participant Recruitment
Participants were recruited for this research in multiple ways. Health Professional and Program Facilitator recruitment occurred through email and phone calls for interviews and focus groups. Researchers began with a database of professional contacts and used snowball sampling to increase recruitment efforts. Patient recruitment was the final phase of the research and research team members had already established relationships with the program facilitators to receive permission to recruit patient participants from active programs.

Qualitative Methodology
A semi-structured interview guide was developed to aid researchers in developing an understanding of how DPP programs are implemented and to explore the perceptions of program benefits and barriers. A total of 97 interviews and 5 focus groups were conducted. Sixty-nine interviews with healthcare professionals and program facilitators were conducted, and 28 patient interviews were conducted. Informed consent was signed or verbally agreed upon by the interviewees prior to each interview. Information about the minimal risks associated with their involvement with this research study was discussed as per the Institutional Review Board (IRB) guidelines. All study procedures were reviewed and approved by the University of South Florida IRB.

Participants
Program Facilitators are those that work within accredited and non-accredited diabetes prevention programs. These people include those that are administrators of programs and/or class facilitators.

Healthcare Professionals are those that are qualified to provide clinical care to patients. The professionals interviewed work in multiple discipline areas, from general practice, pharmacy, internal medicine, obstetrics, and nursing.

Patients are those who have participated in the DPP programs. Patient characteristics varied among all interviewed. Income level, age, race/ethnicity, and health insurance status were mixed between all patients interviewed.

Qualitative Data Analysis
As interviews were conducted, codes were generated based on project goals and themes that emerged from the interviews. The codebook was modified through the use of the Constant Comparative Method throughout the coding process to accurately reflect all ideas represented. Three researchers coded all of the transcripts and compared/revised codes until 100% inter-rater agreement was achieved. Interviews and focus groups continued until thematic saturation was achieved with each target audience.

Survey Participant Recruitment
Survey participants were recruited through the research team's professional contact database, as well as from panels purchased from Survey Monkey. The panels were specifically designed to match the research objectives for each group: Healthcare Providers and DPP Patients. DPP Patients were provided surveys by DPP Program Facilitators with whom the research team had received permission.

Quantitative Methodology
Survey data was gathered through the use of survey panels from Survey Monkey. Survey participants were all over the age of 18, could read English language, and were either people with diabetes in the state of Florida, or healthcare providers in the state of Florida. All survey participants had access to a computer and were able to respond to a Survey Monkey link. The surveys were created with language...
that was specific to each population: healthcare providers and patient groups. Healthcare professionals were queried about their perceptions of DPP utility, benefits and risks of referral to DPP, and the perceived benefit of DPP when considering patient outcomes and experiences. Patients were queried about their overall impression of DPP, as well as their specific experiences.

Participants

Healthcare Providers

In total, 251 healthcare providers (65% males) were surveyed on their experiences with diabetes prevention education programs. Of those healthcare providers, 46% were primary care physicians, 19% were in internal medicine, and the remainder held various job titles including endocrinologist, OB-GYN, registered nurse, dietician, pharmacist, psychologist, and physician’s assistant. Of these healthcare providers, 23% were certified diabetes educators, but all who participated treated patients with either diabetes or prediabetes. Forty-four percent of providers had been practicing for over 20 years, 31% between 11-20 years, 20% between 5-10 years, and 5% practicing less than five years.

DPP Patients

Patients (n=50) who participated in a Diabetes Prevention Program in Florida completed a survey describing the experiences in their program. Respondents’ ages ranged from 34-80 years with the mean age being 58.7 years (SD=11.30). Participants (35% males) had a racial background of 83% white and 6% African American. Regarding educational background, 56% had completed or at least attended some college, and 28% had completed or at least attended graduate school. All participants had some form of health insurance; 58% of respondents had health insurance through either their employer’s plan or their spouse’s employer’s plan. Other forms of health insurance included Medicare (38%), Medicaid (4%), the Health Insurance Marketplace Plan, military/veteran benefits, were self-insured, or were covered under their parent’s plan.

Quantitative Data Analysis

Survey responses were collected electronically from Survey Monkey and analyzed using Excel and SPSS (v. 22). In order to investigate possible sub-population characteristics in each target audience, several key demographic variables were examined for interactions with evaluation and opinion questions on the surveys using Pearson Chi-Squared Tests for Independence ($\chi^2$). Chi-square estimates the probability that the association between variables is a result of random chance or sampling error by comparing the actual distribution of responses with the expected distribution of responses [6]. When relevant, data were segmented and compared using Analysis of Variance techniques (ANOVA F-tests). This analytical technique aims to determine whether variables are related to each other by comparing the differences between three or more subgroups and the variance on the same variable within each of the subgroups [6].

Table 1

<table>
<thead>
<tr>
<th>Table 1</th>
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</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
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</tr>
<tr>
<td>Male</td>
<td>17</td>
<td>35%</td>
</tr>
<tr>
<td>Female</td>
<td>32</td>
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</tr>
<tr>
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<td>20%</td>
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<tr>
<td>Professional Certificate</td>
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<td>8%</td>
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<tr>
<td><strong>Total</strong></td>
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<tr>
<td><strong>Health Insurance</strong></td>
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<tr>
<td>Employer or Spouse’s Employer</td>
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<td>57%</td>
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<td>Military/Veteran Benefits</td>
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<td>1%</td>
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<td>Self-insured</td>
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<td>.5%</td>
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<td>Health Insurance Marketplace Plan</td>
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<td>.5%</td>
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<tr>
<td>Parent’s Plan</td>
<td>1</td>
<td>.5%</td>
</tr>
<tr>
<td>None</td>
<td>0</td>
<td>0%</td>
</tr>
</tbody>
</table>


INTERVIEW AND FOCUS GROUP RESULTS

Benefits of DPP: Program Facilitator Perspectives

According to program facilitators of DPP programs, the benefits for participants are tremendous. When the program is adopted into daily life, the DPP can significantly improve health, well-being, and prevent the onset of diabetes. Many program facilitators have witnessed the benefits the program can offer. For example, one program facilitator stated:

“It’s the most beautiful transformation to witness, and to be a part of; and to say that you contributed to someone regaining their mobility. You contributed to someone getting their blood pressure management reduced. You contributed to them giving up the unhealthy choices and substituting those for now-healthy choices… that has been such a gift I have witnessed and experienced in this program.”

Incremental Lifestyle Change

According to program facilitators, the evidence-based curriculum is a primary strength of the program. The goal of the program is systematic behavior change that is targeted incrementally. The incremental steps taken in the program were perceived as beneficial for participants who may be overwhelmed by major lifestyle changes happening quickly. Another program facilitator stated:

“From a lifestyle change, I think for a lot of these folks one at a time was plenty. ‘Let’s start here; let’s just look at what you’re eating. Start documenting, it doesn’t matter what you eat, just put it on a pad of paper. Then start looking at your fat grams. Now we’ve got two things.’ Then we slowly added more. It was so easy. It wasn’t too much for them.”

Peer Support

The community-based format allows for group education that results in powerful peer support. All of the facilitators in the study described how the dynamics of the group format created a sense of accountability and encouragement for participants. The development of peer support was made possible by the long-term format of the program.

Long-term Format

Meeting regularly for a year allowed for relationships to develop and for behavior change to be reinforced. For facilitators, this is a hallmark of the DPP. Ironically, the long-term format of the program was perceived by some new participants as a barrier, but once participants began the program they valued the extended time frame, even asking for the program to continue past the original year commitment.

Flexible Program

A final significant benefit is the flexibility of administering the program. The program requirements are flexible enough to allow for programs to operate in a variety of community settings including YMCA facilities, health department locations, community centers, libraries, churches, and workplaces. The use of trained lay facilitators was reported as a strength of the program and would allow for easier expansion of programs.

Benefits of DPP: Healthcare Professional Perspectives

Providers reported several benefits of DPP including communal support, ease of information, and the convenient location of the educational venue. Some providers acknowledged the healthy lifestyle component of the program to be a viable success and motivating component in reaching diabetes prevention goals. For example, a family medicine physician said, “What I like the most about the DPP is that they talk about nutrition but also have a holistic approach. It focuses on obesity and healthy weight with the help of a healthy diet.” Additionally, an internal medicine physician stated:

“I like the activity component…the idea of physical activity encouragement…I think a really important thing is knowing how activity affects your blood sugar levels, and how certain foods affect them, and how following the healthy diet and being active actually prevents long-term problems.”

Benefits of DPP: Patient Perspectives

Patients participating in DPP programs indicated communal support and an encouraging environment are beneficial and assist in their efforts toward diabetes prevention. A female participant provided the comment, “It’s a feeling of
everybody having something in common. I feel comfortable here talking, because I know everybody understands, probably, what I’m going through. I understand what you’re going through.”

The comfort and ease of the program was also highlighted as a benefit of the curriculum. For example, one participant said, “I like the simplicity of just dealing with one thing. If I worry about fat grams, and I worry about it good enough, I will come in and will have lost some weight. That works for me.”

Barriers to the DPP: Program Facilitator Perspectives

Cost
The implementation costs for organizations to offer DPP classes is an important consideration for future policy decisions. Program facilitators discussed cost barriers in two contexts. They described the investment costs necessary to run the program and the need for insurance coverage to relieve patient financial burden. For programs, there are several operational costs including staff salaries, data tracking software, cost of materials, incentives, and purchasing supplemental materials like nutrition books.

Program facilitators also reported that participant costs impede recruitment and success in the DPP. While some programs offer reduced rate or free access to the DPP due to grants or special coverage, these offers are not long-term solutions. Without insurance coverage many participants are unable to afford the program. One program facilitator said, “The biggest problem is seeing that population that has no insurance, or their insurance doesn’t cover for them to come to class.”

Content
The content of the DPP curriculum is described as outdated. For example, a program facilitator stated, “Because you can’t change the curriculum, one of the barriers we see from our coordinators is that the curriculum is not up to date. They haven’t changed it since whenever they wrote it in the ‘90s.” There is also a reported lack of cultural competency. For example, the curriculum is offered in English and Spanish, but there were no ethnic dishes used as examples in the curriculum. This can make it challenging to engage diverse groups.

Time
Program facilitators perceived the length of the program, scheduling conflicts, and the time commitment required in the program as barriers when attempting to recruit new participants. Potential participants are dissuaded by the long-term format of the program and report having difficulty fitting classes into their schedule. However, facilitators report that once participants become engaged in the sessions, many appreciate the long-term support and education afforded by the DPP. The time commitment becomes an asset.

Barriers to DPP: Healthcare Professional Perspectives

Lack of Knowledge
Many of the providers indicated the lack of knowledge about the existence of the program was a barrier to referring to the program.

Credibility
The credibility of the program was noted by a few providers questioning if group facilitators may not be as informed as medical professionals about issues with pre-diabetic patients. Physicians explained that if they did not know what was taught or felt it was a credible program they would not make referrals to DPP programs. For example, an internal medicine physician stated:

*It's so complex...Because a lot of people, especially with the non-compliant people, they have a lot of other issues, life issues, financial issues that really prevent them from getting control of their diabetes and their health. Probably adding on some sort of mental health counseling.*

Cost
Insurance coverage or cost issues and time commitment restraints were also noted as barriers. Another internal medicine physician stated:

*Expense is probably the number one thing, if their insurance doesn't pay for it. As a whole, patients don't really like to pay for anything. Number two is the time commitment that they have to put into the comprehensive programs. Those are probably the major barriers.*
Barriers to DPP: Patient Perspectives

Time
There are numerous barriers for participating in the DPP programs. Some patients vocalized how the time commitment or limited time for the program was a hindrance to participation at times. Transportation and timing of classes were barriers for existing participants. For example, a male participant provided the following comment:

*I mean the education classes, it’s not that you don’t know where they are. You know where they are. It’s the motivation to go and the desire, the interest, and the environment. And available on weekends, or evenings, or something around a work schedule and not in the middle of the day.*

Content
Patients felt that the program curriculum was a bit “too basic” at times and more techniques or education were needed.

Cost
Additionally, the cost of the program and insurance coverage could possibly cause patients to reconsider participating in the program. For example, a female participant said, “This sounds fantastic, but is it going to cost me because my insurance is not going to cover it?”

SURVEY DATA RESULTS

Healthcare Provider Perceptions of DPP Programs
A key finding from the survey data is that only 51% (128/250) reported referring patients with prediabetes to DPP programs. A little over half of the respondents (55%; 138/250) felt that DPP programs are helpful to their patients with 53% (132/249) stating that they were “very satisfied” or “satisfied” with DPP programs.

When asked to rank what aspects of the DPP they like best, HCPs reported the highest ranking factor as “dietary education” (30%; 78/257), followed by “peer support” (25%; 64/257), “group setting” (18%; 46/257), and “lifestyle coach/non-professional leader” (15%; 39/257).

Table 2

<table>
<thead>
<tr>
<th></th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietary education</td>
<td>78</td>
<td>30%</td>
</tr>
<tr>
<td>Peer support</td>
<td>64</td>
<td>25%</td>
</tr>
<tr>
<td>Group setting</td>
<td>46</td>
<td>18%</td>
</tr>
<tr>
<td>Lifestyle coach / Non-professional leader</td>
<td>39</td>
<td>15%</td>
</tr>
</tbody>
</table>

Two barriers were equally reported as being primary barriers to referring prediabetes patients to DPP programs, “patients’ lack of interest” and “cost for patients due to lack of insurance coverage” (28%; 68/244 for each).

Table 3

<table>
<thead>
<tr>
<th></th>
<th>Count</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Motivation to attend</td>
<td>99</td>
<td>41%</td>
</tr>
<tr>
<td>Time / Schedule of classes</td>
<td>60</td>
<td>25%</td>
</tr>
<tr>
<td>Cost to patient</td>
<td>52</td>
<td>21%</td>
</tr>
<tr>
<td>Transportation</td>
<td>19</td>
<td>8%</td>
</tr>
<tr>
<td>Child care needs</td>
<td>13</td>
<td>5%</td>
</tr>
</tbody>
</table>

When reporting barriers for patients to attend DPP, healthcare providers reported “motivation to attend” (41%; 99/243), time/schedule of classes (25%; 60/250), followed by cost to patient (21%; 52/243), transportation (8%; 19/250), and child care needs (5%; 13/243).

While 53% (132/248) believed that the information taught in DPP was “about right,” a proportion of healthcare providers (29%; 72/248) were unaware of what is taught in DPP. Suggestions for changing DPP programs were dominated by the “referral process” (38%; 94/246), “location of classes” (21%; 51/246), “content of classes” (15%; 38/246), “time of classes” (14%; 34/246), and “quality of instructors” (15%; 38/246).

For HCPs who stated that they were or were not certified diabetes educators, and for those who were identified as male or female, the data were segregated and compared via Analysis of Variance techniques (ANOVA F-tests) to see what significant results, if any, ensued. Those who are certified HCPs are more likely to be “very satisfied” with the DPP programs, while also suggesting that changes should be made to DPP “content.” Those who are not certified are significantly more likely to say that they are “not sure where to refer my patient” and also more likely to say they are “not sure what is taught in the DPP programs.” Those who are not certified are also significantly more likely to mention “time” as something that needs to be changed with DPP.
Patient Perceptions of DPP Programs

Data received by participants in the Diabetes Prevention Program reports that the program was well received. Respondents (n = 50) generally reported a positive impression of the DPP, with the majority (90%; 45/50) either “very satisfied” (74%; 37/50) or “satisfied” (16%; 8/50) with their experience in the program. Most participants also felt the “length of the program” (92%; 45/50) and “content” presented (86%; 42/50) were appropriate for meeting their expectations. Only 30% (15/50) of participants reported difficulty attending the classes, citing “inconvenient times/schedules” and “lack of motivation” as the greatest challenges. It should be noted that several participants were able to attend classes offered at their workplace, making attendance easier and more convenient.

Patients responded to what would help make their lives with prediabetes easier. The responses are consistent with the DPP program design, further supporting the patient satisfaction findings.

Audience Segmentation: DPP Patient Interactions

Several of the key demographic variables were examined for interactions with evaluation and opinion questions on the survey using Independent Samples t-test and Pearson Correlation Coefficients. None of the demographic variables (gender, age, race/ethnicity, level of education, type of health insurance coverage) were found to have a statistically significant relationship with any of the evaluation or opinion questions. These findings suggest there are no relations between demographic variables and patient responses for this sample. An explanation for the lack of interaction may be inherent homogeneity in the DPP sample.

DISCUSSION

This research study examined the factors that motivate and deter people at risk for developing type 2 diabetes from utilizing the evidence-based Diabetes Prevention Program. Physician referrals are viewed as powerful encouragements for patient behavior change; therefore, understanding physician perceptions is critical to addressing their concerns about the program. Results from the survey data demonstrate that only about half of healthcare providers refer patients to the DPP, which may be in part due to the lack of awareness and knowledge about the program. Additionally, providers reported during interviews that they question the credibility of the program since classes are not led by medical professionals, and 29% of survey respondents reported being unaware of what is actually taught in the DPP classes.

Program length, scheduling conflicts, and time commitment were repeatedly noted as barriers to participation by HCPs, program facilitators, and participants during interviews and focus groups. This sentiment was also relayed through survey data by many participants who desired classes at their workplace (e.g. during lunch) to make scheduling, transportation, and arranging childcare less difficult. Likewise, cost to participate in the program was stated as a deterrent for engaging in the DPP. Program facilitators, HCPs, and patients all conveyed that the out-of-pocket costs to participate in the program may be too expensive for those without insurance, or whose insurance will not cover the costs of the program; this was reflected in both the qualitative and quantitative data.

Interestingly, length of the program was regarded as both a barrier and a benefit by program facilitators and DPP participants. The year-long format was initially perceived as a barrier due to the extensive time commitment, but once participants engaged in the program they valued the extended time frame as it provided the opportunity to develop supportive relationships and reinforce behavior change. This hesitance for patients to participate in the DPP was also reflected in the survey data by providers and patients who both reported...
lack of “motivation to attend” as the greatest barrier for engagement. Participants, program facilitators, and HCPs all expressed during interviews the benefits of the long-term format in that it allows for incremental lifestyle change. The nutritional and physical components praised by HCPs are presented in a slow, progressive format that allows for ease of information comprehension which is appreciated by participants who fear being overwhelmed. Additionally, the extended length of the program allows participants to build relationships and provide communal, peer support. Participants disclosed during interviews their joy of being able to openly share their feelings and the struggles they experience making lifestyle changes with others who truly understand. Program facilitators also reflected on the power of peer support for fostering accountability and encouragement among participants.

Finally, the flexibility built into the DPP was recognized by program facilitators, HCPs, and participants as one of the program’s strengths. The program enables classes to be taught in a variety of community settings, allowing for the creation of convenient times and locations.

Given the benefits of the program, 90% of survey respondents reported an overall positive impression of their experience participating in the DPP. Unfortunately, the lack of knowledge about the DPP is a barrier that must be overcome to increase utilization of this evidence-based program.

CONCLUSION

Findings in this formative research study provide evidence that the Diabetes Prevention Program is successful in helping individuals with prediabetes make positive lifestyle changes and attain better health management. Healthcare providers, program facilitators, and patients/participants all believe the DPP provides individuals with support and the opportunity to learn essential skills for healthy living. However, while the overall benefits of the program were expressed, there were barriers to program utilization noted by all populations. Cost of the program and the significant time commitment necessary to complete the programs were two barriers that were discussed on numerous occasions. While those barriers are at a macro-level, the large barrier present, the lack of knowledge about the programs, is something that can be addressed and would create significant impact.

LIMITATIONS

This study is limited by use of convenience sampling and a limited time frame.

FUTURE DIRECTIONS

Results of this study highlight two significant findings. First, there is a general lack of awareness of the Diabetes Prevention Program among patients and healthcare providers. Those who heard of the program had limited knowledge of what the DPP entails and how to find a local program. Second, participation in the DPP aids in better health management, lifestyle change, and diabetes prevention. These findings emphasize the need to increase knowledge and awareness of the programs offered in local communities.

ACKNOWLEDGEMENTS

This research was funded by the Florida Department of Health and thus focused within the state of Florida.

CONFLICT OF INTEREST DISCLOSURES

The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. The authors report no potential conflict of interests relevant to this article.

REFERENCES


We welcome diabetes research articles in a number of topic areas:

- Communication
- Pregnancy and family planning
- Education
- Insurance, healthcare policies, and cost of care
- Technology and innovation
- Mental health
- Measures of success
THE FAKEBETES CHALLENGE:
A Pilot Study of the Patient as Educator in Diabetes Care

Michelle Litchman, PhD, FNP-BC
University of Utah

DOI:
http://dx.doi.org/10.17125/plaid.2016.64

ABSTRACT

Objective: Healthcare providers do not typically fully understand what it is like to live with a chronic condition. One strategy to help healthcare providers better understand the day-to-day challenges of living with diabetes is to practice being a patient. The purpose of this study was to understand the experiences of healthcare providers and patient educators who participated in the Fakebetes Challenge, a high-fidelity simulation of living with diabetes that utilized patients who were living with diabetes as teachers.

Research Design and Methods: In this descriptive qualitative pilot study, blogs written by participants following their participation in the Fakebetes Challenge were examined using content analysis.

Results: The Fakebetes Challenge was beneficial to both healthcare provider learners and patient experts who served as educators. Three themes were identified: 1) enjoyment from the teaching-learning process of having Fakebetes; 2) healthcare providers’ ability to relate, understand, and empathize; and 3) Fakebetes Challenge concerns and frustrations expressed by Fakebetes Teaching Associates.

Conclusion: The Fakebetes Challenge as a pedagogical approach is promising in educating healthcare providers about the day-to-day challenges of living with diabetes and should be replicated with a larger sample. Patients with personal experience and expertise in diabetes can supplement healthcare provider education and support patient-centered care.
INTRODUCTION

Over twenty million Americans have diabetes, and the incidence continues to rise [1]. Individuals who have adequate knowledge and skills to manage their diabetes have better glycemic control [2, 3]; therefore, healthcare providers have a responsibility to adequately educate their patients with diabetes in an effort to support patient care and optimal outcomes. Despite extensive training, healthcare providers do not always fully understand the day-to-day challenges experienced by individuals with diabetes.

One strategy that may help healthcare providers better understand the challenges of living with diabetes is to practice being a patient using high-fidelity simulation. High-fidelity simulation is an environment where healthcare providers can experience living with diabetes by practicing the management of day-to-day diabetes care. The purpose of this study was to understand the experiences of healthcare providers and patient educators who participated in a high-fidelity simulation of living with diabetes called the Fakebetes Challenge. In this study, individuals living with diabetes were placed in the role of a Fakebetes Teaching Associate, and healthcare providers were placed in the role of a patient with diabetes. The Fakebetes Teaching Associates were paired with the healthcare providers in an effort to provide the healthcare providers with realistic examples of day-to-day glucose variation and an enhanced assessment of the physiologic and psychosocial aspects of living with diabetes.

Simulation has been used for teaching purposes for decades. There have been a variety of approaches to simulation to provide education on diabetes management; however, few simulated experiences allow the learner to fully understand the day-to-day challenges of living with diabetes. Pharmacy students have participated in a 1-week simulation experience as if they had diabetes, checking glucose levels, taking saline injections, and logging diet and exercise [4, 5]. In another simulation, pharmacy students engaged in a 6-week patient/provider interaction simulation. While results of diabetes simulations are positive with regards to improving empathy [6, 7], self-efficacy [6], confidence in teaching diabetes self-management skills [4, 5], and diabetes attitudes [5], none incorporated advanced critical thinking skills related to day-to-day challenges (unexpected hypo- or hyperglycemia, changes in glucose related to illness, stress, or exercise, etc.). Utilizing the expertise of real patients may benefit healthcare providers with regards to attaining complex skills and knowledge [8], improving communication [9], and supporting patient-centered learning [10]. While there are anecdotal reports of healthcare providers learning from patients, little is known about organized learning in which patients are the educators and healthcare providers are the learners.

Theoretical Framework

This study was guided by the Transformative Learning Theory [11]. The Transformative Learning Theory posits that individuals can change their points of view through critical reflection. Transformation and reflection can take place when an individual is able to do the following:

1. elaborate on the current point of view
2. establish new points of view
3. transform the point of view
4. transform their habits through a deeper understanding of their own biases [12]

Healthcare providers are expected to be autonomous and responsible thinkers, and oftentimes have inherent assumptions about individuals with diabetes and management strategies. Specifically, healthcare providers do not typically understand the day-to-day challenges experienced by those living with diabetes. The Fakebetes Challenge provided healthcare providers an opportunity to self-reflect on the day-to-day challenges of diabetes management, further developing the foundational knowledge of what it must be like to live with diabetes. For example, this self-reflection supported mastery of task-oriented and critical thinking activities related to daily diabetes care, as well as understanding how living with diabetes may impact psychosocial health. Furthermore, self-reflection allowed healthcare providers to critically evaluate their point of view of successful diabetes management from the patient and provider levels, supporting the ability to adapt and collaboratively problem solve with patients.
Research Design and Method

Participants

This qualitative descriptive study was conducted by examining healthcare providers and Fakebetes Teaching Associates blogs following their participation in the Fakebetes Challenge. A convenience sample of nurses and dietitians were recruited from Salt Lake City, UT. Healthcare provider participants were eligible for the study if they were 18 years or older, could read/write English, and were currently providing care for individuals with diabetes. Recruitment advertisements for Fakebetes Teaching Associates were posted to diabetes social media sites. Fakebetes Teaching Associate participants were eligible for the study if they were 18 years or older, could read/write English, and had lived with insulin-dependent diabetes for at least 5 years, and were living in the United States. All participants volunteered to participate in the Fakebetes Challenge knowing there would be no additional compensation.

Procedure

Healthcare provider participants were supplied with a glucometer, syringes or insulin pump supplies, and randomly matched with a Fakebetes Teaching Associate. Working in pairs, healthcare provider participants and the Fakebetes Teaching Associates communicated diabetes-related information via text throughout the Fakebetes Challenge. Since patients do not get to choose their diabetes diagnosis date, Fakebetes Teaching Associates notified the healthcare provider when they were diagnosed with Fakebetes, thus initiating the Fakebetes Challenge.

Throughout the Fakebetes Challenge, healthcare provider participants were expected to 1) test his/her blood sugar using a glucometer at least four times per day and when additional testing was needed as determined by glucose levels or symptoms provided by the Fakebetes Teaching Associate; 2) count and log carbohydrate intake, calculate and log insulin doses, and administer the appropriate dose of fake insulin (saline) using a syringe or insulin pump; 3) notify the Fakebetes Teaching Associate of glucose levels, planned activity levels, carbohydrate intake, and other factors that may affect glucose levels; and 4) respond to the Fakebetes Teaching Associate when provided with glucose levels or symptoms that should prompt glucose testing or ingestion of rapid glucose.

Fakebetes Teaching Associates were expected to provide healthcare provider participants with glucose levels or symptoms throughout the day based on likely scenarios (e.g., hypoglycemia following increased activity levels, or hyperglycemia following an insulin pump site occlusion). Given that diabetes can be unpredictable, there was no restriction on the frequency or time of day when the Fakebetes Teaching Associate could communicate a glucose level or symptom to the healthcare provider. Finally, Fakebetes Teaching Associates were expected to provide advice about what they may have done to manage Fakebetes in various scenarios (e.g., adjust insulin for “sneaky” carbohydrates found in sushi or avoid certain foods altogether due to the effect it may have on blood sugar).

Data Analysis

Following the Fakebetes Challenge, participants were asked to write a reflection about their experience and post it to an online blog. These blogs were qualitatively examined using content analysis [13]. The data was analyzed line by line using an open-code approach in order to develop a codebook consisting of categories and subcategories. The categories and subcategories were then systematically organized to develop a taxonomy that informed the themes [14]. Member checking was employed to validate results [15].

Results

Participants included nurses (n=3, one male and two females), dietitians (n=2, both female), and Fakebetes Teaching Associates (n=5, all female). Sex was identified by the use of pronouns in the blogs. At the time of this study, the participating healthcare providers were providing diabetes specialty care to patients as certified diabetes educators (n=3), or worked in an outpatient facility that provided diabetes care but did not specialize in diabetes care (n=2). The common criteria for the Fakebetes Teaching Associates included living with type 1 diabetes for over 15 years and using an insulin pump to manage their diabetes. Since this study examined blogs, demographic information was not collected. Blogs averaged 708 words (range 432-1165 words) and included an average of 2 pictures, most of which were screen shots of text message communication between the healthcare provider and Fakebetes Teaching Associate participants.
The results of the study provided insight about the experiences of healthcare providers and Fakebetes Teaching Associates following their participation in the Fakebetes Challenge. The analysis revealed the following themes, which are discussed in further detail in the subsequent paragraphs:

1. **Enjoyment from the Teaching-Learning Process of Having Fakebetes**

2. **Ability to Relate, Understand, and Empathize**

3. **Fakebetes Challenge Concerns and Frustrations**

1. **Enjoyment from the Teaching-Learning Process of Having Fakebetes**

Healthcare providers found the Fakebetes Challenge to be beneficial with regards to learning about the day-to-day challenges of living with diabetes. Healthcare providers decided to participate in the Fakebetes Challenge because they wanted to understand diabetes on a deeper level in order to better help the patients they treat. Participants were open to learning from Fakebetes Teaching Associates and appreciated the opportunity to gain tacit knowledge related to diabetes management.

Fakebetes Teaching Associates decided to participate because they were intrigued with the concept of supporting healthcare provider education with regards to day-to-day diabetes management and found their participation to be worthwhile and fun. Some Fakebetes Teaching Associates would throw “curve balls” or learning opportunities which required healthcare providers to make decisions to treat a glucose in real-time, but also consider trends throughout a day or two to determine if changes were necessary. One example included having a healthcare provider experience a hypoglycemia episode after several meals in a row, and over time, the healthcare provider realized an adjustment to the insulin to carbohydrate ratio was necessary. Other Fakebetes Teaching Associates were happy to share tips, tricks, and “life hacks” that they hoped the healthcare provider would be able to use to educate patients in the future. Overall, Fakebetes Teaching Associates enjoyed the process. One participant stated, “It was a really interesting and obviously rewarding experience helping [healthcare providers] learn more about the nitty-gritty of diabetes management and how it’s not always so easy to remember to do everything and do it right.”

The “diagnosis” of Fakebetes provided healthcare providers with opportunities to critically think about how to manage fluctuating blood sugars while meeting the demands of their everyday life. Healthcare providers had to trouble-shoot each scenario in real-time, identifying the factors that could not be changed, those that could be changed, then deciding how they wanted to respond, and how that decision would affect them later in the day. Textbook knowledge without the lived experience left some healthcare providers feeling vulnerable for the first few days, however, by the end of the challenge healthcare providers were becoming more comfortable with the critical thinking necessary to manage diabetes. Healthcare providers gained new perspectives from this learning experience. One healthcare provider stated, “Those of us who do not have diabetes, but work with people with diabetes, take for granted just what is involved in the day to day care of diabetes if we don’t try to immerse ourselves in it.”

Two healthcare providers related their experience to being a new mother, needing to plan ahead in order to be prepared for a variety of scenarios. Comparing the Fakebetes Challenge to motherhood, one healthcare provider stated, “One could read a parenting book, but it’s not the same as experiencing it firsthand. Other parents just get it, because they have lived it.” Having the hands-on diabetes learning experience provided an educational opportunity that had not been available elsewhere.

2. **Ability to Relate, Understand, and Empathize**

Healthcare providers did not anticipate the amount of time, preparation, and planning that went into the management of diabetes. There were several factors that had not been fully considered, including making sure there was enough battery/charge in the technology devices that supported diabetes management, being patient when waiting for blood sugar to respond after manipulating insulin or ingesting glucose, and being consistent and accurate with carbohydrate counting. Healthcare providers also noted that they did not always follow the advice they would give to their own patients. For example, some healthcare providers altered behaviors to avoid injections, or they completely forgot to check pre-meal blood sugars or “insulin” doses for a snack on the go.

The psychosocial components of having Fakebetes hit home for the healthcare providers. Participants realized firsthand what it would be like to check a glucose level or
take “insulin” while in public; how to make the best of social situations, such as attending a pool party while wearing an insulin pump that wasn’t waterproof; the challenges that being outside of your normal routine (e.g., vacation) can bring; or how hypoglycemia can wake you in the middle of the night or make you late for a meeting. One healthcare provider internalized what could have happened if her Fakebetes had actually been diabetes.

I had a low of 61 occur around the same time I would have left to pick my son up from preschool. Then it dropped to 48. In the world of Fakebetes, I “treated” it on my way, but in real life, I may not have made it there in 30 minutes, or ever…as a single mom, that is not cool.

Healthcare providers gained perspective and a new understanding of the day-to-day challenges faced by individuals with diabetes. By viewing diabetes through the lens of a patient, healthcare providers felt compelled to be more engaged with their own patients who have diabetes in an empathetic way. One participant stated, “Having done this challenge, I will be much more in tune with my patient’s needs.” Findings relate to Transformative Learning Theory (Table 1).

3. Fakebetes Challenge Concerns and Frustrations

Fakebetes Teaching Associates noted a sense of surprise with regards to how much they thought about their own diabetes during the Fakebetes Challenge. Several reflected on how they can sometimes be hard on themselves in moments of dysglycemia, but also mentioned that they were proud of their diabetes management overall. Even though participants enjoyed their experience with the Fakebetes Challenge, the constant communication between the healthcare provider and Fakebetes Teaching Associate was overwhelming at times as they were managing their own diabetes. One participant noted:

Within 4 hours of starting the challenge, I texted my mom saying how exhausted I was with narrating all the stuff I do regarding diabetes every day. There are so many things that I do subconsciously that are just part of my “normal life” until I stop and think about it.

While there was much to be gained from the Fakebetes Challenge, Fakebetes Teaching Associates noted there were areas in which the Fakebetes Challenge could not simulate. These areas included: 1) feelings of guilt or even fear over fluctuating glucose levels; 2) the stress over having to go in for fasting labs; 3) the financial distress as a result of costly prescriptions or technology devices; 4) frustration with pharmacies over not having refills ready or with insurance companies when prior authorizations were necessary; and 5) the physical symptoms of hypo- or hyperglycemia.

Despite some of the limitations of the Fakebetes Challenge, Fakebetes Teaching Associates appreciated being able to participate and function in an educator capacity, respected the healthcare provider participants for wanting to gain a deeper understanding of what it is like to live with diabetes, and acknowledged the Fakebetes Challenge being as the closest simulation of living with diabetes that currently existed.

<table>
<thead>
<tr>
<th>Transformative Learning Theory Components</th>
<th>Fakebetes Challenge Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability to elaborate on the current point of view</td>
<td>Healthcare providers participated in diabetes maintenance tasks (e.g. counting carbohydrates and testing blood glucose levels) and critical thinking through the case scenarios developed by the Fakebetes Teaching Associates.</td>
</tr>
<tr>
<td>Establish new points of view</td>
<td>Healthcare providers realized how living with diabetes would impact their own lives.</td>
</tr>
<tr>
<td>Transform the point of view</td>
<td>Healthcare providers appreciated the difficulties in managing diabetes, and in some instances, could not follow the advice they gave patients.</td>
</tr>
<tr>
<td>Transform our own habits through a deeper understanding of our own biases</td>
<td>Healthcare providers could relate to patients, had a deeper understanding of what it would be like to live with diabetes, and developed empathy towards their own patients.</td>
</tr>
</tbody>
</table>
CONCLUSIONS

This study explored the experiences of healthcare providers and patient educators who participated in the Fakebetes Challenge. The results indicate that the Fakebetes Challenge was a novel, well-accepted, and beneficial pedagogical approach to educating healthcare providers about diabetes management while at the same time improving empathy. This innovative approach contributes to our understanding of utilizing patients as educators in a high-fidelity simulation.

Empathy can be taught. In the context of patient care, Hojat and colleagues [16] define empathy as a cognitive attribute that involves understanding, and being able to communicate their understanding, of patient concerns and perspectives with intention to help by alleviating pain and suffering. Learning about diabetes from the lens of the patient allowed healthcare providers to feel vulnerable. This vulnerability provided healthcare providers an opportunity to relate, become more understanding, and ultimately achieve empathy towards their patients with diabetes. Research indicates healthcare providers who have empathy for their patients with diabetes build stronger relationships with their patients [17], and have better clinical outcomes [18, 19]. In this study, healthcare provider participants planned to be more engaged with their patients who have diabetes. The Fakebetes Challenge should be considered for healthcare providers and healthcare provider students who plan to care for individuals with diabetes to better understand and empathize with the day-to-day challenges that can be experienced by those with diabetes. Participation in a pedagogical activity such as the Fakebetes Challenge has the potential to improve patient outcomes and satisfaction.

Expert patients are valuable resources that should be utilized to educate healthcare providers and promote patient-centered care. In this study, healthcare providers were not threatened by receiving education from expert patients. In fact, healthcare providers enjoyed the process of being able to gain insight from the patient. While there has been a recent push to engage patients in the research process [20] and quality improvement [21, 22], patient participation in health sciences education is limited. This study included a novel approach to educating healthcare providers by harnessing the expertise of patients with diabetes. In this role reversal, patients were the educators and healthcare providers were the learners in understanding the day-to-day challenges of diabetes. Collaborating with patients in the education of healthcare providers, such as the patient-led Fakebetes Challenge curriculum, should be taken into consideration as a pedagogic approach to supplement continuing education in diabetes management.

Curriculum additions to the Fakebetes Challenge should be considered. In this study, Fakebetes Teaching Associates noted that the Fakebetes Challenge was not able to replicate some of the day-to-day challenges experienced by those with diabetes. For example, the Fakebetes Challenge could not simulate the physical symptoms or fully address the emotional concerns (e.g., fear, guilt, everyday ups and downs) associated with crisis management, or the financial strain [23] of not being able to afford lifesaving medications and equipment. Further, experiencing diabetes can involve uncertainty, isolation, stigma, and identity questions [24] which would be difficult, and ethically impossible, to simulate. However, there are areas in which the Fakebetes Challenge could be augmented to improve and more accurately reflect the experiences of someone living with diabetes, such as incorporating a visit to a Fakebetes pharmacy, a call from a Fakebetes insurance company about coverage, or to a Fakebetes healthcare provider about a prescription refill or concern about blood glucose levels. Further, given that individuals with diabetes often times live with multiple chronic conditions, incorporating additional diagnoses (e.g., hypothyroidism, hypertension, hyperlipidemia) should be considered to provide a more well-rounded simulation of living with diabetes. Finally, careful thought and consideration should be given to the Fakebetes Teaching Associates as to not overwhelm them as an educator given their necessary efforts to manage their own diabetes.

LIMITATIONS

There was a small sample of healthcare providers and Fakebetes Teaching Associates in this pilot study. While findings were positive, the study should be replicated with a larger and more diverse sample (both healthcare providers and Fakebetes Teaching Associate participants) to enhance reach and impact. Fakebetes Teaching Associates all had type 1 diabetes, the means to manage their diabetes with an insulin pump, and enough health literacy to be engaged in the diabetes online community. A Fakebetes Teaching Associate with type 2 diabetes, health disparities, disability, complications, low health literacy, or difficulty accessing tools to perform self-care behaviors may have resulted in different learning opportunities for the healthcare providers. Further, since participants volunteered to participate, results may have selection bias through interest in the project.
Blogs analyzed in this study were relatively short; therefore, focus groups or one-on-one interviews may elicit a richer understanding of the participants’ experience. While it is impossible to fully simulate the experience of living with diabetes, the Fakebetes Challenge and results from this pilot study provides healthcare providers a deeper understanding of the social and economic inequality of those living with diabetes. It is difficult to ascertain the impact of the Fakebetes Challenge in this study. Future research should include pre and post Fakebetes Challenge measures to determine how participation in the Fakebetes Challenge impacts healthcare provider practice, and longitudinal analysis to examine how the intervention may affect patient outcomes.

CONFLICT OF INTEREST DISCLOSURES

The author has completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Dr. Litchman reports other from Dexcom, Inc. during her time as a clinical site PI for an RCT between August-December 2015. No other disclosures were reported.

REFERENCES


TRANSITIONING FROM PEDIATRIC TO ADULT DIABETES CARE

ABSTRACT

Objective: The clinical transition from pediatric to adult diabetes care is often challenging for both young adults with type 1 diabetes (T1D) and the health care providers (HCPs) who care for this population. This study presents insights into the perceptions and needs of both patients with diabetes and HCPs during the clinical transition.

Research Design and Method: Two separate surveys were administered with questions specifically tailored to each audience. Perceptions of the transition phase for both patients with T1D and HCPs were analyzed for general trends and then compared to investigate similarities and differences between patient and provider needs.

Results: Both patients and HCPs expressed concerns regarding poor patient-provider communication during transition and the barriers to independently managing diabetes self-care responsibilities (e.g., navigating insurance, ordering supplies, arranging healthcare appointments). Although 45% of HCPs reported screening transition age patients for mental health issues related to diabetes, only 9% of patients stated their provider offered this opportunity. Furthermore, patients reported facing a variety of challenges not discussed with their HCP including; sexual issues (28%), depression or anxiety (17%), and eating disorders (11%).

Conclusions: Training in the assessment of young adult T1D needs and effective communication techniques may assist HCPs in working more effectively with young adults. Offering mental health screenings for transition age patients may open the conversation to discuss diabetes concerns such as depression, sexual challenges, and eating disorders not currently being addressed. Both patients and providers desired improved communication with more emphasis on independently managing diabetes responsibilities and adjusting to new life situations.
BACKGROUND AND RATIONALE

Gaining independence as a young adult is a challenging experience for anyone. The presence of a chronic condition such as type 1 diabetes (T1D) can exacerbate the complexities of this period of emerging adulthood by placing additional responsibilities on young adults as they adjust to a new environment and cope with new life situations [1]. Additionally, health care providers (HCPs) may face challenges assisting older adolescents and young adults transitioning from pediatric to adult clinical care due to gaps in patient healthcare utilization among emerging adults with diabetes.

Young adults transitioning to independence may face challenges in maintaining diabetes care plans, experience diabetes burnout and the stresses of taking on new life experiences in college or the workplace, while at the same time receiving less direct support from parents. Previous studies report several barriers that hinder optimal diabetes management during emerging adulthood, including difficulty finding health professionals with T1D expertise, diminished social networks and support, irregular schedules, the increased presence of drugs and alcohol, and financial struggles [1, 2]. These challenges often lead to a wane in diabetes management and self-care during the transition years of emerging adulthood.

In a qualitative study of young adults living with T1D, 71% reported that diabetes was more difficult to manage in college than in high school [1]. A similar study of urban youth with T1D conducted by Gee and colleagues found that challenges in establishing independence as a young adult were similar to those without a chronic condition, but coping with the management of diabetes magnified the difficulties of emerging adulthood and generally resulted in poor diabetes management [3].

Not only is young adulthood a period of personal transition from dependence to independence, it is also a clinical transition from pediatric to adult diabetes care. Unfortunately, studies report significant gaps in follow-up care and a decrease in physician visits after transferring from pediatric to adult care [4]. For instance, one study found 34% of patients reported a gap > 6 months between pediatric and adult diabetes care, resulting in greater risk for loss to follow-up care [5]. Other studies confirm a notable decrease in physician visits after transitioning to adult care and also report that fewer physician visits were associated with poor glycemic control [6, 7]. Research conducted by Nakhla and colleagues revealed patients with sporadic follow-up care had poorer glycemic control and higher rates of hospitalization compared to those with regular follow-up care [8].

It is important to note that a singular model for transitioning patients with diabetes from pediatric to adult care is not currently in place. Varying systems include transfer to an adult clinic or different hospital, transition to a combination of pediatric and adult care providers, and transfer to a young adult clinic within the same pediatric hospital [4]. Likewise, there is a wide-degree of variation in preparing patients for transitioning from pediatric to adult care with some patients receiving no information, some receiving specific adult provider or clinic recommendations, some having a specific visit to discuss transition, and others being prepared for adult diabetes care by having a pediatric diabetes visit without a parent/guardian in the room and discussing independent diabetes self-management with the pediatric provider [5]. In 2011, the American Diabetes Association (ADA) released recommendations for transition from pediatric to adult diabetes care systems, including preparing adolescents through a gradual shift to self-management (e.g. scheduling appointments and monitoring supplies); screening for complications, disordered eating behaviors and mental health issues; and having open discussion of the interplay between lifestyle behaviors (e.g. sex, alcohol, cigarettes, and drugs) and daily living with diabetes. The level of implementation has yet to be standardized in practice across the United States. Hence, the literature demonstrates that general recommendations for approaches to the diabetes clinical transition do exist, but as studies show, there is great variability in the quality of care young adults receive and the level of diabetes management they maintain.

This study presents insights into the perceptions and needs of both patients with diabetes and HCPs caring for this population. Research questions include: 1) How do patients perceive the quality of their diabetes care during the pediatric to adult transition? 2) What challenges are most problematic for young adults during transition? 3) What procedures do health professionals have in place to aid with adolescent transition? and 4) How do patient and health professional perceptions of diabetes care transition needs compare?
RESEARCH DESIGN AND METHOD

Survey data was collected from adults with T1D ages 18-50 and HCPs caring for adolescents and young adults with diabetes. The questions were based upon findings of a literature review and themes revealed from exploratory interviews conducted by the authors with 41 young adults with T1D ages 18-30. The result was two independent surveys with specific questions tailored to a young adult patient audience and a health care provider audience. For example, HCPs responded to questions such as: “Do you screen transition age patients for mental health issues related to diabetes?” and “From your experience, what are the most important needs during the diabetes transition?” Adults with T1D responded to: “What is/was the most dominant challenge for you in transition?” and “What could your provider do to help you more with your diabetes?”

Participants

Participants were recruited both online and in person at diabetes events. Study flyers were disseminated through online advertisements on social media websites such as Facebook and emailed to the membership lists of Bringing Science Home, American Association of Diabetes Educators, Juvenile Diabetes Research Foundation, and the American Diabetes Association. Participants recruited online were directed to a Survey Monkey site to complete the questionnaire, while participants recruited in person completed a paper version of the survey.

Participants self-selected to complete the anonymous survey. Eligibility requirements included being an adult living with T1D, at least 18 years of age, or a HCP caring for people with diabetes. Eligibility also included proficiency in English and access to a computer with an internet connection for those who chose to complete the online survey. A total of 224 participants met the eligibility requirements (adult T1Ds = 170, HCPs = 54) with a subset of willing participants (n = 30) excluded due to missing (n = 12) or incomplete data (n = 18). For the purposes of this study, missing data pertained to individuals who accessed the survey, but failed to complete the survey items, whereas incomplete data referred to participants who only partially answered each question item (e.g. filled-in only part of the ranked answer-items).

Research procedures were approved by the University of South Florida Institutional Review Board. Informed consent was obtained from participants. No incentives were provided.

Data Analysis

Perceptions of the transition phase for both adults with T1D and HCPs were analyzed for general trends using descriptive statistics. Results from independent analysis of the two data sets were then compared to investigate trends in differences of perception and reported needs between patients and HCPs. All statistical analyses were performed using SPSS (IBM Corp., v. 22).

RESULTS

Health care professionals offered their perceptions on the diabetes clinical transition by responding to a variety of questions. HCPs (n = 54) who participated in the study were predominantly female (87%). The HCPs who responded to the survey included: MDs (13%), nurses (48%), and registered dieticians (17%). Nearly half of participants were also certified diabetes educators (CDE) (48%).

Participants with diabetes (n = 170) were predominantly female (85%) with a mean age of 28.9 (SD = 11.42). The mean age of participants at diagnosis was 10.8 (SD = 5.55). The majority of participants (56%) had a college degree or higher and were currently covered for healthcare through an employer sponsored plan (43%) or parent’s insurance (34%). Similar to providers, patients with diabetes shared their perceptions of the clinical transition by responding to questions about their experience.

Provider Approaches to Aid with Transition

The majority of HCPs determined a patient’s readiness for transition largely based on maturity (43%), followed by interest level in transitioning (28%), and age (26%). Providers felt the most difficult challenges as a HCP during transition were: communicating effectively with youth (34%), evaluating family dynamics (28%), assessing the needs of youth quickly (22%), and anticipating the developmental needs of youth (18%). Interestingly, less than half of providers (45%) screened transition age patients for mental health issues related to diabetes, and only 6% offered shared office visits between pediatric and adult care providers during transition.

Concern for patient well-being during the clinical transition was reported by every health care provider who participated in the sample. As one provider stated, “[My biggest fear for patients is] that the transition will be a set-back rather than a positive transition.” HCPs noted patient difficulty in
following diabetes management plans on their own (33%), maintaining motivation (27%), gaining independence from parents (20%), understanding insurance and diabetes policy (16%), and timeliness making diabetes appointments and ordering diabetes supplies (8%). Patient success during the diabetes transition is believed by providers to be based upon individual skills with diabetes management responsibilities (e.g. navigating insurance, ordering supplies, and arranging healthcare appointments) (53%), and exerting independence as a young adult (32%).

**Patient Perspectives**

Most young adult T1D patients described the clinical transition as “Fair,” if not “Poor,” with the greatest challenges being the learning of diabetes management responsibilities (65%), followed by independently managing diabetes (55%), social issues (e.g. relationships or living with diabetes in public) (44%), and knowing how to communicate about diabetes with others (40%). Many reported that connecting with a social diabetes group in their local area would be the most beneficial resource during the transition years, along with education on how to manage insurance policies.

During analysis, the patient sample was divided into three separate age brackets to account for possible differences in clinical practice that may have occurred over time regarding transition age patients: 18-28 year-olds (n = 113), 29-38 year-olds (n = 23), and 39-50 year-olds (n = 34). Interestingly, respondents in the younger age brackets reported a more negative transition experience, with 60% of each group describing the experience as either poor or fair, while only 36% of those aged 39-50 described the clinical transition as such. Similarly, those aged 18-28 and 29-38 felt the most beneficial resource during the transition years would be a social group (40% / 41%) followed by an insurance/diabetes policy resource (28% / 29%). Patients aged 39-50 felt an insurance/diabetes policy resource would have been more beneficial (46%), followed by inclusion in a social diabetes group (29%). All three age groups overwhelming reported lifestyle management help (e.g. information about real life situations and diabetes) as the greatest need from diabetes care visits during the young adult years. Likewise, independently managing diabetes was reported by all three

### Table 1. Health care provider experiences with patients during the diabetes clinical transition: ranked questions

<table>
<thead>
<tr>
<th>Ranked 1 N(%)</th>
<th>Ranked 2 N(%)</th>
<th>Ranked 3 N(%)</th>
<th>Ranked 4 N(%)</th>
<th>Ranked 5 N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>From your experience, what are the most important factors during the diabetes transition? (Rank 1 to 5. One is the most important factor. Five is the least important factor.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-care behavior (insurance, ordering supplies, etc.)</td>
<td>26 (53.1)</td>
<td>9 (18.4)</td>
<td>5 (10.2)</td>
<td>7 (14.3)</td>
</tr>
<tr>
<td>Independence</td>
<td>16 (32.0)</td>
<td>15 (30.0)</td>
<td>11 (22.0)</td>
<td>7 (14.0)</td>
</tr>
<tr>
<td>General diabetes knowledge</td>
<td>5 (10.2)</td>
<td>19 (38.8)</td>
<td>15 (30.6)</td>
<td>6 (12.2)</td>
</tr>
<tr>
<td>Social knowledge</td>
<td>3 (6.1)</td>
<td>1 (2.0)</td>
<td>15 (30.6)</td>
<td>22 (44.9)</td>
</tr>
<tr>
<td>Triage care</td>
<td>2 (4.1)</td>
<td>4 (8.2)</td>
<td>2 (4.1)</td>
<td>8 (16.3)</td>
</tr>
<tr>
<td>From your experience, what are the biggest challenges for PATIENTS during the transition process?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Following diabetes management plans on their own</td>
<td>16 (32.7)</td>
<td>17 (34.7)</td>
<td>7 (14.3)</td>
<td>5 (10.2)</td>
</tr>
<tr>
<td>Maintaining motivation</td>
<td>13 (26.5)</td>
<td>11 (22.4)</td>
<td>10 (20.4)</td>
<td>4 (8.2)</td>
</tr>
<tr>
<td>Gaining independence from parents</td>
<td>10 (20.4)</td>
<td>10 (20.4)</td>
<td>10 (20.4)</td>
<td>11 (22.4)</td>
</tr>
<tr>
<td>Understanding insurance and diabetes policy</td>
<td>8 (16.3)</td>
<td>8 (16.3)</td>
<td>10 (20.4)</td>
<td>9 (18.4)</td>
</tr>
<tr>
<td>Making diabetes appointments and ordering supplies (timeliness)</td>
<td>4 (8.2)</td>
<td>4 (8.2)</td>
<td>11 (22.4)</td>
<td>19 (38.8)</td>
</tr>
<tr>
<td>From your experience, what are the biggest challenges for HEALTH PROFESSIONALS during the transition process?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicating effectively with youth</td>
<td>17 (34.0)</td>
<td>13 (26.0)</td>
<td>11 (22.0)</td>
<td>9 (18.0)</td>
</tr>
<tr>
<td>Evaluating family dynamics</td>
<td>17 (34.0)</td>
<td>10 (20.0)</td>
<td>10 (20.0)</td>
<td>13 (26.0)</td>
</tr>
<tr>
<td>Assessing the needs of youth quickly</td>
<td>11 (22.0)</td>
<td>16 (32.0)</td>
<td>18 (36.0)</td>
<td>5 (10.0)</td>
</tr>
<tr>
<td>Anticipating the next developmental needs of the youth</td>
<td>9 (18.0)</td>
<td>11 (22.0)</td>
<td>9 (18.0)</td>
<td>21 (42.0)</td>
</tr>
</tbody>
</table>
groups as one of the greatest challenges during transition. Those aged 18-28 and 39-50 also expressed challenges with learning the business of diabetes (e.g. ordering supplies, insurance, etc.), while those aged 29-38 expressed greater concern with knowing how to communicate about diabetes with others during the transition stage.

As a whole, only 9% of patients believed their provider offered the opportunity to participate in mental health screenings, but many reported experiencing mental health and social challenges around diabetes not discussed with their HCP. For instance, patients reported experiencing depression or anxiety (32%), workplace challenges (14%), eating disorders (12%), sexual issues (12%), academic challenges (12%), and expressed other concerns about diabetes not discussed with their HCP (12%).

In addition to reporting on the diabetes challenges as a young adult, patients provided information on what they felt would improve the transition experience. Better insurance coverage (35%), more technology (31%), help with emotional challenges of diabetes (21%), social connection with other people with diabetes (8%), and a better medical care team (8%) were ranked in order of easing life with diabetes. Patients shared ways providers could do more to help with their diabetes, such as offering ways to be involved in diabetes research (42%), keeping the patient up to date regarding diabetes drugs and technologies (41%), being unafraid to recommend trying something new in medical care (e.g. modifying insulin ratios or prescribing new medications) (37%), and connecting patients to others living with diabetes in their local community (32%).

### Differences of Patient and Health Care Provider Needs and Perspectives

Both patients and HCPs expressed concerns regarding poor patient-provider communication during transition and the barriers to diabetes management responsibilities. Furthermore, every provider expressed loss to follow-up as their greatest fear for patients, and 45% of patients desired greater access to their HCP and better communication.

While 45% of HCPs reported screening transition age patients for mental health issues related to diabetes, only 9% of patients stated their provider offered the opportunity to participate in mental health screenings. Although the patient and provider samples are not linked, this finding suggests that a disconnect may account for the number of diabetes concerns patients did not discuss with their provider such as depression and eating disorders.

### Table 2. Patient perspectives and experiences of the diabetes clinical transition: ranked questions

<table>
<thead>
<tr>
<th>(N = 170) N(%)</th>
<th>Ranked 1</th>
<th>Ranked 2</th>
<th>Ranked 3</th>
<th>Ranked 4</th>
<th>Ranked 5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What was/is the biggest challenge for you in transition? (Rank 1 to 4. One is the most important factor. Four is the least important factor.)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learning the business of diabetes (ordering supplies, insurance, etc.)</td>
<td>41 (37.6)</td>
<td>29 (26.6)</td>
<td>20 (18.3)</td>
<td>19 (17.4)</td>
<td></td>
</tr>
<tr>
<td>Independently managing my diabetes</td>
<td>39 (35.8)</td>
<td>21 (19.3)</td>
<td>22 (20.2)</td>
<td>27 (24.8)</td>
<td></td>
</tr>
<tr>
<td>Knowing how to communicate about my diabetes with others</td>
<td>15 (13.9)</td>
<td>28 (25.9)</td>
<td>28 (25.9)</td>
<td>37 (34.3)</td>
<td></td>
</tr>
<tr>
<td>Social issues (e.g. relationships, living with diabetes in public)</td>
<td>14 (13.0)</td>
<td>33 (30.6)</td>
<td>39 (36.1)</td>
<td>22 (20.4)</td>
<td></td>
</tr>
<tr>
<td><strong>What would you like more of in your diabetes care visits during the young adult years?</strong></td>
<td></td>
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</tr>
<tr>
<td>Lifestyle management help; information about your real life situations and diabetes</td>
<td>59 (46.8)</td>
<td>31 (24.6)</td>
<td>25 (19.8)</td>
<td>11 (8.7)</td>
<td></td>
</tr>
<tr>
<td>Open communication and easier/more accessibility to my health care provider</td>
<td>32 (25.4)</td>
<td>25 (19.8)</td>
<td>41 (32.5)</td>
<td>28 (22.2)</td>
<td></td>
</tr>
<tr>
<td>Opportunities to connect with others living with diabetes</td>
<td>23 (18.3)</td>
<td>33 (26.2)</td>
<td>22 (17.5)</td>
<td>48 (38.1)</td>
<td></td>
</tr>
<tr>
<td>General diabetes guidance /information</td>
<td>14 (11.1)</td>
<td>38 (30.2)</td>
<td>37 (29.4)</td>
<td>37 (29.4)</td>
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</table>
HCPs and patients both indicated that transitioning from pediatric to adult diabetes care was an enormous struggle, with the majority of patients describing their experience as “Fair,” if not “Poor.” Providers struggle with preparing their patients for independence and determining how to best communicate with patients who are moving through developmental stages. Patients struggle with taking on management behaviors and feeling they are being heard by their providers. Providers reported a patient’s level of maturity as the primary basis for transition and felt mastery of self-care behaviors was the most significant factor during the diabetes transition. This inclination is supported by Garvey and colleagues [5] who found individual patients’ self-care proficiency more relevant to health outcomes than chronological age at the time of transition [5]. In our study, providers and patients agreed that learning how to manage insurance policies and the financial costs of diabetes in order to independently maintain self-care were the greatest challenges. This notion reinforces research conducted by Rasmussen and colleagues [2] who found that for young adults with T1D, moving away from home and separating from parental support caused concerns related to finding health professionals with diabetes expertise, diminished social support, and access to diabetes supplies. However, as young adults gained knowledge and skills, their self-perception improved and enhanced their confidence in managing their diabetes [2]. Therefore, practical skill-building activities such as interacting with the medical team without parents present, monitoring supplies, refilling prescriptions, and making medical appointments are important for moving from basic diabetes self-care to independent self-management [9].

In addition to skill-building, both sides of the patient-provider relationship want improved communication. Patients have a desire for increased access to providers and more lifestyle management support (information about real life situations and diabetes). Previous research demonstrates that young adults and HCPs face barriers and struggle to communicate effectively. One study found that participants felt the care they received was not relevant to young adult lifestyles and that the practitioners’ consultation style needed to shift with age [10]. However, research also indicates that acknowledging the unique challenges faced during the transition period and preparing ahead of the transition can improve health outcomes [9, 11]. Given the uncertainty associated with taking on a new independent role, patients desired more “real-life” lifestyle management help that reflect their less structured lifestyles as students and employees, and open communication with their HCP to discuss challenging topics. Participants in the current study also wanted providers to inform them of ways to become involved in research, updates on diabetes drugs and technologies, recommendations for new treatments in medical care, and social connection to others with diabetes. These expressed needs correlate with findings from previous research [2].

Findings from this study highlight the need for implementing and evaluating standardized care for the clinical transition from pediatric to adult diabetes care. As the ADA suggests, greater emphasis needs to be made developing skills for independently managing diabetes, providing lifestyle management help (e.g. information about real life situations and diabetes), and screening for mental health issues.

**Strengths and Limitations**

This study should be considered in context of certain limitations. While the survey allowed for geographic diversity, participants may not be representative of the overall population of young adults living with diabetes nor the providers who care for them. The sample size for both patients and providers were small, limiting the generalizability to the larger populations. The majority of HCP respondents were nurses or CDEs, with only 13% of respondents being MDs. Understanding the perspectives of nurses and CDEs who care for young adults with diabetes is valuable, but future studies should consider gathering responses from MDs whose experiences and perspectives of the diabetes clinical transition may differ from those of nurses and CDEs.

Similarly, the significant variation in patients’ age, 18-50, may impact data analysis as clinical transition practices have certainly changed over time.

Additionally, the patient and provider samples in this study were not linked; the patient respondents were not those seen by the HCP respondents. While this does not threaten the validity of the study, it does limit the ability to make definitive interpretation of some findings. As with all surveyed responses, there is the possibility of socially desirable responding, though data were collected anonymously to address this issue. Similarly, patient perceptions of the transition experience may be subject to recall bias. Tailoring the surveys to the two audiences allowed for a more thorough examination of the needs and perspectives of each population, but limited comparisons of survey responses to general themes.
Future studies should examine communication barriers between patients and providers during the diabetes transition using a larger, more representative sample. Longitudinal and evaluation studies may help to determine effective methods for improving care of young adults living with diabetes.

CONCLUSION

Given the uncertainty associated with taking on a new independent role, young adult patients desire more lifestyle management help, open communication with their HCP, and opportunities to connect with peers who also have diabetes. Providers are quick to acknowledge difficulty communicating effectively with youth, which may account for the number of diabetes concerns patients did not discuss with their provider, such as depression and eating disorders. Overall, independently managing diabetes and adjusting to new life situations that arise throughout young adulthood are areas where patients need guidance. Providing greater emphasis on lifestyle management help may improve patient-provider communication, and in-turn, diabetes management and health outcomes.

Future Directions

Results of this study highlight two significant findings. First, there is need for improvement in communication between providers and young adult patients with diabetes throughout the clinical transition. Patients noted several areas of concern that they do not address with their provider, while health care providers expressed difficulty in quickly assessing the needs of young adults and communicating with this population effectively. With this in mind, providing training in these areas may assist HCPs in improving these communication skills and working more effectively with young adult patients. Second, mental health screening tools appear to be underutilized during such a critical phase of life when changes in support, finances, and environment are all occurring at once. Offering mental health screenings for transition age patients may open the conversation to discuss diabetes concerns such as depression, sexual challenges, and eating disorders.

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CONFLICT OF INTEREST DISCLOSURES

The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. The authors report no potential conflict of interests relevant to this article.

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ABSTRACT

As the prevalence of diabetes continues to increase in the United States, a higher proportion of elective surgical candidates will require specific preoperative education and guidelines to maximize patient outcomes and reduce the costs of care. The purpose of this article is to review the current literature to determine how preoperative glycemic control affects the lengths of hospital stays, postoperative complications, and mortality in people living with type 1 and 2 diabetes. Additional recommendations are provided for preoperative hypo- and hyperglycemia, the use of insulin pumps or continuous glucose monitors, and day-of-surgery management of insulin and oral hypoglycemic agents. Gaps in medical evidence are acknowledged and future directions in research are proposed to provide high-quality guidelines for the preoperative care of adult patients with diabetes.
INTRODUCTION

As the prevalence of diabetes increases in the United States, practicing physicians must be able to educate and manage these patients in the preoperative setting. With 29.1 million (9.3% of the U.S. population) Americans living with diabetes today, nearly 1 in 10 surgical candidates may have diabetes and require special recommendations before surgery [1].

While the 2011 Joint British Diabetes Societies Inpatient Care Group (JBDS) created guidelines for the preoperative management of patients with diabetes undergoing elective surgery, many physicians in the U.S. may not know these guidelines exist [2]. In a 2014 study on preoperative hemoglobin A1C (A1C) and its effect on clinical outcomes for patients undergoing surgery, the authors say “there are no standards of care for optimal A1C levels before surgery” [3]. A letter to the editor in response to this article stated that there are, indeed, standards for optimal A1C from the 2011 JBDS. The original authors responded to the letter with, “We were not aware of these guidelines and believe that most surgeons and anesthesiologists in the U.S. are not aware of them either” [3-5]. Despite the available evidence, there is a need for a practical set of guidelines that physicians can use to manage surgical candidates with diabetes safely and effectively in the preoperative setting to improve patient outcomes and reduce the costs of care.

This article seeks to review the current literature for preoperative glycemic control in adult patients with type 1 and 2 diabetes undergoing elective surgery. We will review the specific needs of patients with diabetes in the preoperative setting, such as A1C monitoring, pharmacologic alterations in oral and injectable glycemic agents, managing morning-of-surgery hypo- or hyperglycemia, and the costs associated with glycemic control.

PREOPERATIVE GLYCEMIC CONTROL

Hemoglobin A1C (A1C)

The A1C is a measure of the average blood glucose over a two to three month period, and has been used by surgeons as a risk assessment tool in the preoperative assessment of patients with diabetes who require elective surgery. The American Diabetes Association (ADA) has not provided recommendations for the optimal A1C in patients undergoing elective surgery, but generally recommends an A1C less than 7% to avoid the long-term complications of type 1 and 2 diabetes [6-10]. Several studies have shown associations between the preoperative A1C and increased morbidity of surgery, which raises questions regarding the ideal A1C range patients and surgeons should strive to achieve before agreeing on elective surgery.

Hospital length of stay after surgery is a reliable indicator of both patient morbidity and cost of care, as each additional day in the hospital costs more than two thousand dollars [11]. A 2014 study from Brigham and Women’s Hospital looked at nearly 450 individuals with diabetes from the National Surgical Quality Improvement Program (NSQIP) database to determine the relationship between preoperative A1C and the length of hospital stay [3]. The authors showed an A1C greater than 8% was associated with a significantly longer length of hospital stay and greater costs of medical care, but an A1C between 6.5% and 8% was comparable to individuals without diabetes. Another study showed longer hospital stays and increased healthcare costs in spine surgery patients with previously undiagnosed diabetes and an elevated A1C [12].

Beyond the increased length of hospital stay and cost of care, other studies have looked at how preoperative A1C affects complication and death rates after surgery in patients with diabetes. One study of nearly five hundred patients showed an A1C less than 7% was significantly associated with lower infections after non-cardiac surgery, which included pneumonia, wound infections, urinary infections, or systemic infections [13]. A similar A1C cutoff was observed in patients with diabetes undergoing bypass surgery, as an A1C greater than or equal to 7% was associated with a reduced five-year survival [14] and increased unfavorable events, including renal failure, stroke, and surgical wound infection [15].

While current research indicates that lowering a patient’s A1C prior to elective surgery may lead to shorter hospital stays, reduced costs, and improved clinical outcomes, no research compares patients who reduce their A1C before surgery to those who do not. Current evidence points toward a recommended preoperative A1C somewhere between 7% and 8.5% [2], the benefits of which should be discussed with patients in the preoperative setting despite a lack of official guidelines.
Hyperglycemia

Despite the lack of A1C recommendations in the perioperative setting, the ADA recommends perioperative glycemic control between 80 to 180 mg/dL [16], and advises against intensive insulin therapy due to the lack of benefit and potential for increased hypoglycemic episodes [17]. While hyperglycemia can be dangerous and patients may be tempted to aim for higher blood glucose during fasting, hyperglycemia in the perioperative setting has been described as a risk factor for poor surgical outcomes. A recent, large review showed diabetes is an independent risk factor for surgical site infection (SSI), and further showed hyperglycemia in the preoperative setting doubles the SSI risk [18]. In addition to the increased risk for SSI, perioperative hyperglycemia has been shown to increase the length of hospital stay and associated healthcare costs [19]. This highlights the importance of maintaining the ADA's recommended perioperative glycemic recommendations and properly educating patients before surgery.

There are no official guidelines for cancelling elective surgeries based on preoperative hyperglycemia. Some have proposed, however, that a preoperative blood glucose between 300 to 500 mg/dL is an indication to cancel surgery [20]. More definitive recommendations to cancel surgery include severe dehydration, diabetic ketoacidosis (DKA), and hyperosmolar hyperglycemic nonketotic syndrome (HHNS) [21]. One U.S. hospital (Boston Medical Center) uses a preoperative blood glucose of 300 mg/dL as a cutoff for when to screen patients for potential DKA and HHNS, but there is no evidence to support this screening method [20]. There is a need for high-quality prospective studies to determine the ideal glycemic cutoff to undergo elective surgery, as operating room time is costly at $62 per minute and surgical outcomes are concerns for both patients and physicians [22].

Hypoglycemia

A dearth of evidence exists for the management of preoperative hypoglycemia the day of elective surgery, but certain patient-centered recommendations will help ease this potential burden on fasting diabetes patients. NPO status (withholding of oral food and fluids) in preoperative setting is concerning given the results from a patient survey presented at a national conference that showed a knowledge gap in key principals to avoid hypoglycemia in type 2 diabetes patients [23]. While NPO status after midnight is important to prevent the risk of aspiration during surgery and subsequent pneumonia [24], it may increase the risk of hypoglycemia in patients with diabetes. For this reason, patients with diabetes should be scheduled as the first case to reduce the NPO time and missed meals [2]. Contrary to what most patients are told for preoperative planning, the 2011 American Society of Anesthesiologists practice guidelines for preoperative fasting allow for clear fluids, which include sugary drinks and fruit juices without pulp, up to 2 hours before a surgical procedure [24]. This is an important and often overlooked aspect of preoperative education for patients with diabetes who may fear low blood glucose the morning of surgery.

To monitor for hypoglycemia, the ADA recommends finger sticks every 4 to 6 hours while NPO [16]. This is especially important in patients with hypoglycemic unawareness, a loss of the signs of hypoglycemia, due to long-standing diabetes [25]. Alternatively, patients achieving the 80-180 mg/dL perioperative standard may experience hypoglycemic symptoms if they generally have uncontrolled diabetes, and thus, should closely monitor their blood glucose [25]. One study looked at fasting diabetes patients who had hypoglycemic symptoms while driving to have routine labs drawn, and found a 68% reduction in risk when patients were properly educated on fasting precautions [26]. While surgical patients are typically accompanied by another individual to drive them to the hospital, similar guidelines should become standard to prevent hypoglycemia in the preoperative setting.

A growing trend in glycemic monitoring for people living with type 1 diabetes is the use of continuous glucose monitors (CGMs), which can alert patients to decreasing glucose trends in the absence of hypoglycemic symptoms [27]. While CGMs are not yet meant to drive glucose decision-making, and should be supplemented with self-monitoring of blood glucose, clinical trials are currently underway to answer this question [10]. It should be noted, however, that CGM use in conjunction with acetaminophen may lead to falsely elevated glucose readings that could be significant for the NPO diabetes patient [28]. This effect is most pronounced up to eight hours after acetaminophen ingestion, and is likely due to interactions of acetaminophen at the CGM sensing electrode [28]. This further highlights the ADA's recommendations to monitor blood glucose in the preoperative setting, and not to rely solely on CGM measurements [10, 16].
Insulin and Oral Hypoglycemic Agents

The ADA has limited guidelines for managing insulin and oral hypoglycemic agents in the preoperative setting, but does recommend stopping oral hypoglycemic agents the morning of surgery and taking half the intermediate insulin dose or the full long-acting insulin dose [16]. A consensus statement from the Society for Ambulatory Anesthesiology and the JBDS guidelines recommend stopping short-acting insulin the day of surgery due to NPO status [2, 21]. While seemingly simple, there are other considerations patients with diabetes may wish to know before the day of surgery, such as the use of insulin pumps during surgery and specific medication guidelines.

Several studies have demonstrated that insulin pumps in the surgical setting are reasonable alternatives to standard insulin injections, but pumps must be well-documented to ensure the hospital staff is aware of their use [29]. One study found insulin pump use in the perioperative setting had no increased medical expenditures and had similar patient outcomes as standard insulin injections [30]. Some protocols recommend reducing the basal insulin by 20% at midnight before surgery when using an insulin pump, but no consensus has been agreed upon [20]. The current authors believe another reasonable option is to maintain the patient's basal insulin without bolusing starting at 10:00 PM the evening before surgery. Other considerations for insulin pump use should surround the placement of the pump away from the surgical site, but no guidelines are available to further clarify preoperative pump site placement.

Additional considerations for managing oral medications relates to metformin and the use of intravenous (IV) contrast in the surgical setting. IV contrast was previously thought to increase the likelihood of dreaded metformin complications resulting from kidney damage and accumulation of lactic acid in the blood [31]. New guidelines have since emerged that allow for more liberal use of metformin in the setting of IV contrast, and do not require stopping metformin with type I-III chronic kidney disease. Metformin should, however, still be stopped prior to undergoing elective surgery, and may be restarted after surgery as long as patients with acute kidney injury or severe chronic kidney disease did not receive IV contrast [32].

TRANSLATION TO CLINICAL PRACTICE

Despite the preoperative glycemic guidelines created by the JBDS, many physicians are unaware of their existence and studies have shown various barriers to adopt guidelines into clinical practice. One qualitative study identified various barriers that prevent the adoption of clinical guidelines, noting a lack of incentive to incorporate guidelines into physician practices as a major barrier [33]. Such incentives to adopt guidelines that improve patient outcomes while reducing costs are emerging through negative incentives for provider preventable conditions (as defined by the Centers of Medicare and Medicaid Services), including manifestations of poor glycemic control [34, 35]. The researchers also highlighted the importance of recognizing the interactions between patients, physicians, and systems that allow the integration of guidelines into practice, and found a lack of education and a preference for clinical experience were reasons to forgo practice guidelines [33].

Integrated care pathways facilitate the translation of practice guidelines into local protocols that overcome barriers to utilize evidence-based care as the standard of care [36]. Such an approach was utilized by researchers at Boston University and Yale University hospitals in the creation of a perioperative glycemic control program [20]. By implementing local protocols based on the evidence available for perioperative glycemic control, researchers were able to install system-wide practices to better manage diabetes surgical candidates with evidence-based medicine. Similarly, researchers at the Mayo Clinic developed a protocol to improve documentation of insulin pump use in patients with diabetes undergoing elective surgery to increase medical team awareness of pump use [37]. Figure 1 demonstrates an algorithm that incorporates the available evidence in the literature to make surgical decisions based on preoperative glycemic control in patients with diabetes undergoing elective procedures.
Preoperative recommendations for glycemic control in patients with diabetes undergoing elective surgical procedures based on current evidence and previous protocols [20, 29]. A1C, hemoglobin A1C; DKA, diabetic ketoacidosis; HHNS, hyperosmolar hyperglycemic nonketotic syndrome; OR, operating room.

**Figure 1. Algorithm for preoperative glycemic control**
CONCLUSIONS AND OUTLOOK

This review illustrates the current evidence available for preoperative glycemic control in adult patients with diabetes undergoing elective surgical procedures. While evidence is available for using the A1C and preoperative blood glucose to assess a patient’s risk of surgical complications and mortality, no consensus has determined how these variables should alter a patient’s surgical care. A multidisciplinary collaborative approach between the medical personnel involved in the preoperative care of patients with diabetes should consider implementing more patient-centered recommendations to address specific needs surrounding glycemic control. Notably, expanding awareness of anesthesia guidelines that allow patients to drink clear, sugary drinks without pulp (e.g., apple juice) up to two hours before surgery would ease patient concerns of hypoglycemia while NPO. Recommendations regarding insulin pumps and continuous glucose monitors in the preoperative setting further enhance the patient-centered education that should take place to improve patient care and surgical outcomes.

This information serves as a basis to educate patients with diabetes before surgery and identify gaps in the literature that should be filled with high-quality clinical trials. The cost implications associated with glycemic control in the preoperative setting are clearly illustrated by hospital length of stay, complications, and the surgical cancellations that may result from inadequate glycemic management. It remains unclear how patient outcomes and medical costs are affected by delaying surgery to improve glycemic control, but this is a topic of interest for future research.

CONFLICT OF INTEREST DISCLOSURES

All authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Mr. Weir has no disclosures to report. Dr. Deeb reports grants and personal fees from Novo Nordisk, outside the submitted work.

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ABSTRACT

Diabetes self-care is integrally and holistically connected with everyday life, but research prior to 2008 primarily used surveys and interviews to understand the psychosocial aspects of the illness experience. Narrative research methods, in contrast, can give greater attention to connection and context. The aim of this paper is:

1. to review empirical studies using narrative methods to understand the insights narrative inquiry can offer into diabetes psychosocial experiences and concerns; and
2. to provide methodological recommendations for researchers interested in using narrative inquiry.

Twelve published empirical articles using narrative inquiry in diabetes research were reviewed, and themes were identified using content analysis. Findings from the analysis of these 12 studies suggested narrative inquiry can offer insight into psychosocial experiences and concerns by:

1. illuminating how those with diabetes think about and make meaning of this chronic disease;
2. articulating the social contexts of their experiences; and
3. making visible the self-care and treatment challenges they face.

Insights from narrative inquiry could enhance diabetes self-management education and support such as encouraging patients to express their experiences as stories to make their challenges visible.
INTRODUCTION

Diabetes is a major public health burden and growing national epidemic. Nearly 10% of the United States’ population lives with this chronic health condition [1]. It is a demanding self-care disease that requires ongoing attention and complicated treatment. The “cluster of daily behaviors” [2] necessary to manage diabetes includes regular blood glucose monitoring, medication adherence, physical activity, and a healthy diet. People with diabetes may lack the information, education, or problem-solving skills necessary to balance these self-care behaviors and integrate them with daily life [3, 4]. The daily struggles and unpredictable outcomes of self-care, moreover, may impact psychosocial adjustment in these individuals [5, 6, 7]. Understanding how people with diabetes comprehend and make sense of their experiences may inform interventions and suggest changes in the types and nature of psychological, social, and self-management support provided to them.

Evidence suggests that psychosocial factors influence health outcomes. Self-efficacy, social support, and diabetes distress are common in literature on the experiences of people with diabetes. Self-efficacy has been positively associated with glycemic control, medication adherence, and self-care [8, 9, 10, 11]; social support has been positively related to self-care [8, 9]; and distress has been associated with suboptimal self-care across multiple countries [4, 12]. Psychosocial support for people with diabetes remains inadequate [4, 13] despite evidence that psychosocial factors influence health outcomes and appear modifiable through intervention [5, 14, 15]. A greater understanding of how people with diabetes comprehend and make sense of their psychosocial experiences and concerns could result in improved outcomes and self-care.

One way to better understand the psychosocial experiences of human beings is through narrative inquiry [16, 17]. Narratives articulate how experiences are understood rather than how they actually happened. Narrative inquiry is a qualitative methodology that studies stories or storied text [18]. Telling stories is an attempt to organize experiences and make sense of events and experiences. The stories people tell include what they choose to share with the listener and how they connect the multiple components of experience; plots, characters, scenes, and motives are connected into comprehensive representations of experience. Narrative research attempts to analyze whole experiences rather than fragmenting accounts into discursive units or thematic categories. This holistic focus makes narrative inquiry well-suited to study the complicated intersection of psychosocial experience with daily life.

The two-fold aim of this paper is to review empirical studies using narrative methods to understand the diabetes experience in order to identify insights these methods can offer, and to provide recommendations for researchers interested in using narrative inquiry. To accomplish these aims, the authors present three intersecting themes that represent the insights narrative inquiry can offer into the psychological and social aspects of living with diabetes. The themes overlap but are presented separately to highlight the distinct contributions narrative can make to diabetes research. Excerpts of participants’ stories from the findings of published narrative studies help illustrate the themes. Narrative research on diabetes can offer insight into psychosocial experiences and concerns by: 1) illuminating how those with diabetes think about and make meaning of this chronic disease; 2) articulating the social contexts of their diabetes experiences; and 3) making visible the self-care and treatment challenges they face.

METHODS

Empirical articles that used narrative methods to investigate diabetes were identified for review. The studies in this review: 1) represented original research; 2) were published in a peer-reviewed academic journal; 3) had diabetes as a primary subject; and 4) incorporated narrative inquiry in data collection and/or analysis. Four academic databases (PubMed, PsycINFO, Scopus, and Web of Science) were searched over seven months (February through August, 2014) for diabetes studies employing narrative research methods (data collection, analysis, or both). Search terms included pairing “diabetes” with “narrative methodology,” “narrative study,” “narrative method,” “narrative research,” “narration,” “personal narratives,” and “narrative inquiry.” Additional studies were identified in bibliographies of key studies and journal indexes and through consultation with a health sciences librarian. Consultation with researchers experienced in narrative methodologies also guided data collection.

Twelve articles were identified and subsequently examined for concepts and themes using qualitative content analysis. [19]. Each article was read multiple times by the first author. Reflective notes were recorded in a research journal that commented on narrative characteristics, connections to literature, and tentative patterns. Research findings
and data from the 12 articles were examined for recurring concepts. QSR NVivo 10 software facilitated an emergent coding process. Final codes represented aspects of diabetes psychosocial experiences and concerns. Codes were combined into preliminary themes that were shared with colleagues through informal academic presentations, and feedback was incorporated into the final representations.

RESULTS

The twelve previously mentioned articles reported results from eleven unique studies (Table 1). With one exception, all were published in the last seven years (2008-2014). The studies sampled people with either type 1 (T1D; n = 5) or type 2 diabetes (T2D; n = 6). One study included patients with either T2D or chronic pain. Ten of the eleven studies sampled adults over age 18; the one exception sampled adolescents age 13-18. Two studies recruited young (age 21-30) or emerging (age 19-25) adults. Among all the studies, the average age of participants ranged from 16.5 to 62.7. Five studies originated in Europe (England = 2, Italy = 2, Germany = 1); five were conducted in the United States (Los Angeles, Boston, Pennsylvania, Arkansas delta, rural Appalachia); and one took place in Canada. Nearly all the studies explored aspects of diabetes self-care. Four studies considered the meaning-making and healing consequences of storytelling, and two of these four incorporated narrative self-writing or autobiography.

Findings from the analysis of these studies showed how narrative research methods can offer insight into diabetes psychosocial experiences and concerns by: 1) illuminating how those with diabetes think about and make meaning of this chronic disease, 2) articulating the social contexts of their diabetes experiences, and 3) making visible the self-care and treatment challenges they face. Altogether, these themes demonstrate how narrative inquiry offers a holistic understanding of diabetes psychosocial experiences and concerns.

Illuminating How People Think About and Make Meaning of Diabetes

Narrative research can illuminate how people think about and make meaning of their illness. Gomersall, Madill, and Summers [20], for example, used a biographic-narrative method to explore the inner dialogues of women with poorly controlled type 2 diabetes. Eight women were interviewed and prompted to narrate their life stories and experiences since diagnosis. Key moments, defined as emotionally-laden stories, were analyzed using a dialogical narrative approach. One woman described her thoughts about self-care: “So you’re telling me ‘Rachel you’ve got diabetes. Now you’ve got to learn to control this sugar. You need to cut down. You need to cut these things out.’ And I think, ‘Who are you to tell me what to do?’” The excerpt from this woman’s life story demonstrates her inner struggle to accept diabetes and the self-care it requires.

Stuckey and Tisdell [21] found similar conflict in the thoughts of people with diabetes. In this narrative interview study of how adults make meaning of type 1 diabetes, participants described their experiences living with and managing diabetes. Interview transcripts were summarized in story form and then analyzed thematically. Women in this study narrated negative and positive thoughts and feelings about their illness. One woman described frustration over low blood glucose: “At 2:00 am, who am I going to get mad at? . . . it’s a constant reminder . . . It’s part of me, and it’s easy to be stubborn and angry and say, ‘I’m not going to take care of it anymore,’ but that would be more hurtful than helping” [21]. Positive thoughts also emerged about diabetes as some participants considered negative aspects optimistically. One woman thought “a key to being whole with diabetes was to be positive [21]. Endurance sustained the women in this study through difficult times. Findings from these narrative interview studies demonstrate inner struggles and conflicting thoughts about diabetes and provide evidence that narrative inquiry can illuminate how people think about diabetes.

In addition to narrative interviews, narrative self-writing can be used as an approach to understand the thoughts of people with diabetes. This method includes autobiographical writing in journals and diaries. Piana et al. [22] conducted a qualitative feasibility study to test an autobiographical narrative approach in adolescents with diabetes. Thirty adolescents (age 15-18) with type 1 diabetes completed daily self-writing proposals during a nine-day summer camp, and semi-structured questionnaires were administered to elicit their views of the writing process. The researchers found that narrative self-writing provided a way to make meaning of diabetes, and it facilitated changes in the adolescents’ relationships with diabetes. One adolescent expressed this transition in writing: “Before, I felt a certain anger and negativity in facing up to it, this has now been removed” [22]. Another adolescent commented, “I started to come to terms with it and stop thinking, why just me? Well, since it happened to me and so many others, we must learn to
<table>
<thead>
<tr>
<th>Source</th>
<th>Location</th>
<th>Purpose</th>
<th>Sample</th>
<th>Diabetes Type</th>
<th>Collection</th>
<th>Analysis</th>
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<tbody>
<tr>
<td>1. Barton [27]</td>
<td>Canada</td>
<td>Expand understanding of diabetes within a specific cultural context</td>
<td>Persons of Nuxalk ancestry (N = 4)</td>
<td>Type 2</td>
<td>Life narratives</td>
<td>Analyzed stories at universal &amp; local levels over a number of years</td>
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<tr>
<td>2. Bhattacharya [38]</td>
<td>USA</td>
<td>Understand spiritual issues that may hinder or promote self-management</td>
<td>African American men &amp; women (N = 31)</td>
<td>Type 2</td>
<td>Semi-structured interviews</td>
<td>Grounded theory</td>
</tr>
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<td>4. Graffigna et al. [23]</td>
<td>Italy</td>
<td>Explore reasons for disengagement</td>
<td>Men &amp; women</td>
<td>Type 2</td>
<td>Narrative diaries &amp; in-depth semi-structured interviews</td>
<td>Interpretive content analysis</td>
</tr>
<tr>
<td>5. Lucius-Hoene, Thiele, Breuning, &amp; Haug [45]</td>
<td>Germany</td>
<td>Understand patients’ experiences concerning their doctors</td>
<td>Men &amp; women with either diabetes (N = 26) or chronic pain (N = 30)</td>
<td>Type 2</td>
<td>In-depth interviews</td>
<td>Positioning &amp; narrative analyses</td>
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<td>6. Manoogian et al. [28]</td>
<td>USA</td>
<td>Explore family experience of type 2 diabetes</td>
<td>Men &amp; women with diabetes &amp; family support members, 40 Family dyads (N = 80)</td>
<td>Type 2</td>
<td>Focus groups, individual interviews &amp; family interviews</td>
<td>Constant comparative analysis</td>
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<tr>
<td>7. Piana, et al. [22]</td>
<td>Italy</td>
<td>Observe effects of narrative-autobiographical approach on adolescents’ self-awareness, concern for self-care, and well-being</td>
<td>Adolescents age 13-18 attending a 9-day summer camp (N = 94)</td>
<td>Type 1</td>
<td>Daily self-writing proposals and semi-structured questionnaires</td>
<td>Content analysis</td>
</tr>
<tr>
<td>8. Pyatak, et al. [30]</td>
<td>USA</td>
<td>Explore motivations underlying nonadherent treatment decisions made by young adults with type 1</td>
<td>Emerging adults age 19-25 years (N = 8)</td>
<td>Type 1</td>
<td>Semi-structured interviews</td>
<td>Narrative thematic analysis</td>
</tr>
<tr>
<td>9. Ritholz &amp; Jacobson [31]</td>
<td>USA</td>
<td>Increase understanding of the everyday experiences of those with type 1</td>
<td>Men &amp; women age 21-30 (N = 20)</td>
<td>Type 1</td>
<td>Semi-structured interviews</td>
<td>Standard qualitative methods</td>
</tr>
<tr>
<td>10. Snow et al. [34]a</td>
<td>UK</td>
<td>Explore impact of patient education on their lives</td>
<td>Men &amp; women age 20s to 60s (N = 21)</td>
<td>Type 1</td>
<td>Longitudinal semi-structured interviews &amp; observations</td>
<td>Narrative thematic &amp; structural analyses</td>
</tr>
<tr>
<td>11. Snow, Sandall, &amp; Humphrey [46]a</td>
<td>UK</td>
<td>Explore the impact of education and target-setting on life stories</td>
<td>Men &amp; women age 20s to 60s (N = 21)</td>
<td>Type 1</td>
<td>Longitudinal semi-structured interviews &amp; observations</td>
<td>Narrative thematic &amp; structural analyses</td>
</tr>
<tr>
<td>12. Stuckey &amp; Tisdell [21]</td>
<td>USA</td>
<td>Explore meaning that patients ascribe to having diabetes</td>
<td>27-57 (N = 8)</td>
<td>Type 1</td>
<td>Interviews</td>
<td>Narrative &amp; content analyses</td>
</tr>
</tbody>
</table>

*a Snow et al. [34] and Snow et al. [46] report unique findings from the same study.*
accept it and to live with it” [22]. In this study, narrative self-writing illuminated adolescents’ evolving thoughts about diabetes and increased their coping capacities.

Graffigna and colleagues [23] took a similar approach in their study on patient engagement and diabetes self-care. Adults with uncontrolled type 2 diabetes (defined as A1C > 8) each kept a diary for one week. They wrote stories about their experiences with self-care at diagnosis and in daily life. The stories illuminated how the participants gave meaning to diabetes, its management, and its connections to daily life. These findings were interpreted to identify and explain factors hindering engagement in diabetes self-care.

Articulating Social Contexts of Diabetes

As discussed previously, diabetes narrative studies have been used to illuminate how people think about and make meaning of diabetes. There is, however, a need to go “further outward into the social” when considering illness experiences [6]. Family and friends have been found to play a significant role in diabetes self-management [24]. The second theme demonstrates how narrative research can be used to describe diabetes experiences within these social contexts.

Family involvement in diabetes self-care has been well-documented [25, 26]. Findings from narrative studies can articulate the relationships between family and diabetes self-care. A life narrative study by Barton [27], for example, considered the cultural contexts of diabetes. The participants included four adults of Nuxalk ancestry living in Canada, and multiple stories were collected from each adult. Findings from this study described the role of family elders in diabetes experiences; participants looked to elders for knowledge and advice about diabetes. Other narrative studies have also described family roles and influences on perceptions and behaviors [28, 21]. Manoogian et al. [28] investigated diabetes experiences in rural Appalachia through a multi-phase narrative study of people with type 2 diabetes and their families. Data were collected through focus groups, individual interviews, and family interviews. Participants from this study described how family storytelling shaped diabetes beliefs and behaviors. Family elders both shared and silenced stories about diabetes within their families; stories were shared to encourage positive self-care behaviors and silenced to protect younger family members from distressing storylines.

Family involvement in an individual’s diabetes self-care may not always be supportive [29]. Results from a narrative study by Stuckey and Tisdell [21] described family strain in which women with type 1 diabetes were prompted to narrate their diabetes experiences during interviews. One woman described an incident in which she added jelly to a sandwich and was caught by her father. Her father told her mother, and she felt guilty because she did not adhere to her diet. While family strain is not new to the diabetes literature, narrative methodologies offer a deeper understanding by organizing such experiences as stories. These stories combine family members, plots, and motives into holistic representations that can more clearly illustrate how experiences are understood.

Narrative inquiry can also provide insight into the role of friends [30, 31]. A narrative study investigating emerging adults’ (age 19-25) perspectives on nonadherence to diabetes self-care discovered social support problems [30]. They were adversely influenced by friends. Perceived peer pressure challenged self-care behaviors among young adults in this study. For example, one participant described: “We’ll be out to dinner and I’ll check [my blood sugar] under the table, and you can tell the conversation has stopped because everyone is staring. And I’m like, ‘What are you doing? This is weird’” [30]. Ritholz and Jacobson [31] identified another social challenge in their narrative study of diabetes hypoglycemic experiences. Through semi-structured interviews, the researchers elicited stories of hypoglycemic episodes from adults with type 1 diabetes, and interpersonal conflict was a salient theme. One woman described conflict with her boyfriend:

My boyfriend has had to deal with several [hypoglycemic episodes] recently. . . . I’d be upset that he recognized that I was low and I didn’t, and that he was in control. And all sorts of issues that are tenuous in our relationship would start to come up. And I’d be very mean to him and shun him and tell him to just go away. Let me deal with this on my own. He’d feel incredibly hurt. And then I’d reject treatment from him, and he’d feel like I was calling our whole relationship off. [31]

This story excerpt is an example of how women in this study at times had difficulty accepting help during a hypoglycemic episode.

Explaining Self-Care and Treatment Challenges

Psychosocial barriers to diabetes self-care include inadequate self-efficacy [32]; uncertainty about self-care regimens and disease identities [3, 33]; and inadequate family support
Two narrative studies explored disengagement in diabetes self-care and treatment [23, 30]. Participants from these studies reported uncertainty, psychosocial adjustment, and weariness. The stories of adults with uncontrolled type 2 diabetes (HbA1c > 8) described uncertainty about doctors’ instructions [23]. They noted that the doctor instructions were too abstract, and information was ineffective and incomplete. The participants articulated a need for specific examples of self-care requirements. For example, “The doctor told me that I have to do some physical activity, but he didn’t advise on the kind of exercises I should do” [23]. Shifting blood glucose targets were a source of uncertainty among young adults (ages 19-25) with type 1 diabetes enrolled in higher education [30]. The standards for blood glucose control shift as children transition from youth to adulthood and encounter more intensive therapies. One young adult’s story described her frustration: “When I was diagnosed at age 14, I was in pretty good control by whatever standards they were using at the time . . . but more and more they have better standards” [30]. Fluctuating treatment standards appeared to overwhelm young adults in this study.

Findings from the narrative studies identified psychosocial adjustment as another reason for disengagement from self-care. A narrative study using diaries to collect stories about diabetes management found that self-care practices were a constant reminder of their illness. Adults with uncontrolled type 2 diabetes in this study were reluctant to accept a disease identity and thus avoided health behaviors [23]. Adjustment issues for young adults related to social pressures [30]. Anxiety and embarrassment explained their non-adherent treatment decisions around friends. Weariness was an additional challenge to engagement with self-care. A female with type 2 diabetes described feelings of tiredness:

*I feel tired and without motivation. When I am in control, I achieve better results. In that case, I feel extremely happy and I feel like I can succeed in managing the disease. I think motivation is key. It is hard, but I have to find motivation.* [23].

In addition to concerns related to uncertainty, adjustment, and weariness, a longitudinal narrative interview study found that tension with healthcare professionals complicated diabetes self-care [34]. Participants were adults with type 1 diabetes completing a patient education course in the United Kingdom. Narrative interviews were used to collect stories about the impact of the course on self-care in daily life. Open-ended questions prompted descriptions of interactions with family, friends, and healthcare professionals following the course. Many participants reported having more knowledge than their primary care providers, and health care professionals were uncomfortable with their new education. One participant was denied additional testing strips, for example, because a health professional deemed them unnecessary. A lack of provider trust was an obstacle to self-care.

Findings from this third category of narrative studies illustrate the daily challenges people face related to self-care and treatment. Uncertainty, psychosocial adjustment, weariness, and tension with healthcare professionals were identified and explained through narrative representations of experience.

**DISCUSSION**

This paper reviewed the empirical literature that uses narrative method to understand what insights narrative inquiry can offer into diabetes psychosocial experiences and concerns. The results from this analysis suggest that narrative can offer insight into diabetes psychosocial experiences and concerns by illuminating thinking processes, social contexts, and self-care challenges.

Diabetes research has primarily used quantitative surveys [35], focus groups [28, 36], and interviews [37] to understand the psychosocial aspects of illness experience and self-care. Surveys provide useful information about variables and concepts but lack connections and context from the patient’s point of view. Focus groups and interviews elicit contextual data, but transcripts have commonly been analyzed using content analysis, a method that fragments experiences into codes and categories. Diabetes self-care is integrally and holistically connected with everyday life, and narrative research methods attend to interconnectedness and context. The stories people share include how they connect the multiple aspects of their experiences. These factors can be represented as whole, rather than fragmented, accounts.

Current diabetes narrative research, however, does not always take this approach. Some studies analyzed narrative material using content analysis [23] and grounded theory [38], approaches that continue to fragment experiences into codes and categories. Two studies described holistic approaches...
that could offer deeper understanding and provide models for future research. Snow and colleagues [34] coded whole stories by theme and created a summary document for each story to enable comparison across participants. Similarly, Stuckey and Tisdell [21] summarized interview transcripts in story form. In both cases, whole stories were preserved rather than fragmented into categories and codes.

Narrative analysis can look at themes and structure. Themes describe single narrative accounts and structure considers how a story is arranged and told. Narratives can be collected in natural conversations or solicited in interviews and writing. Narrative interviews focus on plots, characters, scenes, and motives and the connections between these components. A narrative interview may begin with “tell me about a time . . .” and follow up with “what happened next?” or “who was there?” Narrative writing includes journals, letters, and autobiography.

Limitations to the use of narrative research methods relate to study design. Interviews were a primary data collection tool in the studies reviewed here, but the ability of participants to narrate stories could have limited the narrative approach. Not everyone is a natural storyteller, and the stories people share in interviews may lack chronology and coherency. Storytelling is, however, considered a common human behavior [39], and people may provide more information through storytelling than through traditional interview formats. A second limitation was the cross-sectional study design of narrative studies. Because psychosocial experiences are temporal and shifting, analysis of people’s experiences at one point in time limits our understanding of psychosocial concerns. Longitudinal designs, however, are possible in narrative inquiry. For example, one study utilized a series of six interviews to examine adherence and decision-making in the everyday lives of emerging adults with type 1 diabetes [30]. A third limitation relates to generalizability. Narrative data present specific themes and concepts and are not meant to generalize to a population. Narration does, however, provide unique contextual information about diabetes psychosocial experiences.

Implications for Practice

Psychosocial support for people with diabetes remains inadequate [4, 13]. Narrative inquiry is well positioned to illuminate the emotions, contexts, and challenges of diabetes. These insights could inform interventions and enhance diabetes self-management education (DSME) and support. The national standards for DSME recommend tailored curriculum to meet individual needs. The curriculum includes personal strategies to address psychosocial issues and concerns [40]. Narrative methods can provide insight into these issues because people choose to narrate what is important to them. Thus, stories can illuminate the salient concerns of people with diabetes. Educators and instructors could use this knowledge to create tailored curricula to meet the individualized needs of people with diabetes leading to improved health and quality of life.

Narrative approaches to diabetes research could also suggest changes in the types and nature of psychological, social, and self-management support and thus increase the options for patient-centered care. DSME, for example, could incorporate storytelling or autobiographical self-writing to facilitate meaning making. Patients could be taught to organize and express their experiences as stories, making visible the self-care and treatment challenges they face. Piana et al. [22], for instance, observed the effect of a narrative-autobiographical approach on adolescents’ self-awareness, concern for self-care, and well-being. The integration of biography allowed adolescents in this study to improve self-efficacy and responsibility for self-care. Narrative reports may also facilitate conversation in clinic appointments; patients may describe signs and symptoms in story form. A person with diabetes, for example, may describe what happened before and after a mild hypoglycemic episode, who was present, and what actions were taken. These stories may open conversation about disease self-management and provide enhanced support without additional resources. Patients could also share stories with family members and friends to communicate their needs and foster supportive relationships. These examples illustrate the potential of storytelling and self-writing to support psychosocial needs in patient-centered care.

In addition to sharing stories to facilitate meaning making in patient-centered care, DSME could incorporate patient success stories to motivate others. This is particularly important since patient perception influences diabetes self-management [14, 41]. Identification with characters in a story may affect individuals’ health attitudes and beliefs [42]. For example, an educational intervention using African American patients’ success stories about hypertension demonstrated the feasibility of creating stories that meet scientific goals and resonate with patients [43]. As another example, cancer survivors shared stories about their experiences with other women in a community- and church-based program promoting self-efficacy and screening behaviors. Screening behaviors among these women increased from pre-to post-exposure [44].
In conclusion, narrative inquiry offers a holistic understanding of diabetes psychosocial experiences and concerns. Findings from empirical studies which use narrative methods could inform interventions and suggest changes in the types and nature of support provided to people with diabetes.

CONFLICT OF INTEREST DISCLOSURES

The authors have completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. The authors report no potential conflict of interests relevant to this article.

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Nine years ago I was dying of kidney cancer, I survived, and now I’m pre-diabetic, so I know from experience that healthcare is different in a crisis or chronic condition. What I had to do for each was completely different except for one thing: in both cases I did everything in my power to understand my situation, learn, and take empowered, effective action.
It turns out that in each case what I did was called being an engaged, empowered patient – an e-patient. The term was coined by “Doc Tom” Ferguson MD, who died ten years ago. He was a visionary who saw that technology was opening a new world in which “empowered, engaged, equipped, enabled” e-patients would start sharing the balance of power, authority, and capability with their medical professionals. The Society for Participatory Medicine was formed in 2009 by his followers.

The culture of medicine changes slowly; most clinicians and scientists have never heard of e-patients. (Try asking one.) But whether or not anyone knows it’s happening, the change is underway. Medical authority is starting to view patients as active contributors, not passive recipients.

What a remarkable and diverse set of places to see such recognition of patients not just as sick people who need help, but as actual partners.

But hardly anyone has heard of it. Ironically, in medicine word travels slower than usual. One famous paper documented that on average it takes 17 years for half of physicians to adopt new knowledge [2].

Reality is what it is, whether we know it or not.

One thing I learned during cancer is that it’s not useful to wish a situation does not exist, and it’s not useful to pretend it doesn’t. To the contrary, the better informed you are about reality, the more able you are to produce results that matter to you.

Here’s where patient power is a game-changer: if my health is about what’s important to me, instead of what I’m told I have to do, it takes on a whole new feeling. It’s up to me to take action or not; sometimes I ignore a stomachache, sometimes I ignore a stomachache, sometimes I ignore a stomachache, sometimes I ignore a stomachache, sometimes I go to the doctor. After all, who’s the person with the problem in the first place?

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Consider This:

- In 2012 the Institute of Medicine (IOM) published a 382 page report [1] that said medicine needs to be “anchored on patient needs and perspectives.” That’s pretty much the opposite of telling patients to comply with doctor’s orders!

- The same report called for “patient/clinician partnerships” with “engaged, empowered patients.”

- That same year the National Library of Medicine began capturing some patient blogs in its History of Medicine Division, saying “blogs authored by doctors and patients illuminate health care thought and practice in the 21st century.”

- In 2014 the editors of the BMJ (formerly called the British Medical Journal) announced its Patient Partnership (http://www.bmj.com/campaign/patient-partnership), inviting patients to become peer reviewers of articles about their disease – yes, to review articles written by scientists – and encouraging patient voices in the design of the research!

- The BMJ also named a patient editor, Rosamund Snow – a person with type 1 diabetes.

- In 2015 the Mayo Clinic invited a patient to be Visiting Professor in Internal Medicine, calling for “a union of forces between providers and the patients who entrust us with their care,” since, “patient engagement and empowerment is a natural extension of Dr. Will Mayo’s vision of a medicine as a cooperative science.”
IT ALL LOOKS DIFFERENT WHEN YOU’RE THE ONE WITH THE PROBLEM

An activated, empowered patient comes to the doctor looking for a “summit,” in a sense – a gathering of stakeholders. If that’s not how the visit comes across, the patient – the ultimate stakeholder, the one with the most at stake – can end up feeling not trusted. As in any relationship, that can lead to the patient no longer trusting the provider: a downward spiral of distrust, truth-hiding, nodding when you don’t mean it, which all too often ends in labels such as “non-compliant,” and sometimes the patient being “fired” – or vice versa.

The sad thing is that no provider got trained with that in mind, nor does any patient want that. So where’s the breakdown?

One answer is available from other industries, where for decades it’s been understood that the ultimate definition of quality always ends up coming from the person with the need – the customer (in this case the patient). In healthcare, that idea makes some people crazy. For example, I’ve heard comments along the lines of, “Medicine is really hard to learn – do you have any idea what I had to go through to get this license?” or “How can someone with no medical training at all know anything worth knowing?” Can you see the quandary? Having been saved from certain death by great clinicians, I have the deepest respect for that training. However, leading thinkers are emphasizing patient/clinician partnership and recognizing the value of understanding patient needs and perspectives.

That’s why patient autonomy and empowerment are really challenging, until both partners figure out the new “dance steps.” Consider IT (information technology): highly trained security professionals know the best measures to minimize viruses and data breaches would be tight, because network and software restrictions would limit our ability to interact with other systems. But that expert protection would not work well in the “patient’s” life; it would dramatically limit the way we share and use data, which is why we have the computer in the first place.

So today we have technologies that make interacting with information easier, from saved passwords and shared bookmarks, to social networks, to targeted advertisements based on our likes and preferences. The expert advice is folded into methods that work in the “patient’s” life. This happens to be exactly the approach used by the great endocrinologist Dr. Victor Montori at the Mayo Clinic, who espouses “minimally disruptive medicine” (https://minimallydisruptivemedicine.org/), which is essentially “health care that fits” in your life through the use of “effective care programs designed and implemented in a manner that respects the capacity of patients and caregivers and minimizes the burden of treatment the care imposes on their lives.”
The DOC is exactly where the IOM (which was renamed in 2015 to “National Academy of Medicine”) wants patients to be, as an anchor to healthcare, and an empowered part of the healthcare team focused on successful patient outcomes.

Our healthcare systems have every ability to help patients get to the goals that they want. They need simply ask. And ask. And ask again, until the outcomes meet the expectations of the entire healthcare team, with the patient at its center.

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IT’S ABOUT PARTNERSHIP, NOT DOMINANCE

None of this diminishes the value of the trained clinician’s mind and experience. To the contrary, any shift in the balance comes entirely from elevating the patient’s potential. It’s the opposite of the old-fashioned cultural assumption that only highly trained people can know anything useful, which can lead well-trained critical thinkers to disregard the perspective of the person who has the problem. It can also lead patients to put an unrealistic burden on clinicians, if they expect every doctor to know everything important. (Did you know thousands of new medical articles are published every day? Who can keep up?)

Patients can help us raise our levels of consciousness about complex health problems. They can help us understand living with these problems better, and realize what can be done to solve them. The answer doesn’t have to always come from the clinic. Sometimes, it may come from the community.

IT’S ABOUT PARTNERSHIP, NOT DOMINANCE

IT’S ABOUT PARTNERSHIP, NOT DOMINANCE

IT’S ABOUT PARTNERSHIP, NOT DOMINANCE

NOBODY’S MORE “E-PATIENT” THAN A HEALTHY PWD

Since I first heard of e-patients it’s been clear to me that the archetypical engaged patient is the person with diabetes. If they are not actively involved, they can’t possibly do well with the disease. And the diabetes online community (DOC) is a great example of an engaged patient community.
Illness experience has become an increasingly important cornerstone of understanding health and well-being for people living with chronic conditions [1, 2]. Even if you’ve never heard the term “illness experience” before, you probably understand what it means on a more intuitive level. Think about the health journeys you and your loved ones have taken in your own lives. What decisions did you make about how to manage your health? What did you come to understand about your condition that you didn’t know at first? What emotions did you experience when you were diagnosed and as you continued to seek care? How were your social relationships affected by changes in your health? Did you encounter challenges in your professional life as you learned to live with your condition? What did you learn from each of these experiences? And how did you change along the way? Illness experience is a complex constellation of elements, all related to how a person moves through life with one or more specific health conditions [3].
Getting insight into the illness experiences of people with highly prevalent chronic conditions like diabetes is positively critical for all of us in the health world, whether we’re more on the clinical care side or more on the research side or experiencing things from the patient or family perspective. Illness experience has become a key emphasis in research and outreach for several reasons. These reasons are nuanced and complex, but fall generally into two basic groups: quality of services and affirmation of self. First, the ability to envision what the experience of diabetes is like for people living with it and their loved ones can transform others’ ability to provide effective clinical care [4, 5] and social support [6, 7]. Second, sharing these experiences can be incredibly nurturing and healing for people with diabetes [8, 9] and those who share their lives [10]. Examples of these benefits are as diverse and complex as all the people in our communities whose lives are touched by diabetes.

One major area of impact is food access and preparation. By sharing stories and ideas, people with diabetes have helped to transform nutritional options in homes and public spaces alike. For instance, the voices and advocacy efforts of people with diabetes in the African Methodist Episcopal (AME) church led not only to changes in food offerings at AME community picnics across the United States, but also to the development of evidence-based resources for home cooks [11]. The American Diabetes Association partnered with AME churches to develop cookbooks and supportive tools, all focused on the preparation of nutritionally balanced versions of traditional soul food dishes appropriate for the macronutrient needs of people with diabetes. Prevention of insulin resistance in people at risk for Type II diabetes was also a major emphasis in this effort [12]. The partnership between AME churches and the ADA represented a major step forward in person-centered, culturally affirming community approaches to diabetes care [13].

Other examples include but are certainly not limited to:

- Peer mentorship opportunities for people newly diagnosed with diabetes
- Development and continuous improvement of insulin pumps
- Greater understanding of intersectionality between diabetes and social determinants of health
- Educational tools for patients and families with different learning needs
- Development and use of metformin therapy for insulin resistance
- Better and more diverse tools for self-monitoring
- Increased and more varied funding for diabetes research and outreach
- Reduced stigma surrounding diabetes diagnosis and management
- Social activities for patients and their loved ones
- Attention to how diabetes affects others in a person’s life
- Widespread awareness of diabetes and potential associated patient needs

These domains of benefit and many others are often intertwined [14]. To illuminate these complex interplays between clinical and community elements of living well with diabetes and other chronic conditions, we need narratives and critical analysis of all aspects of illness experience. We need stories of crisis points that bring about transformational change in people’s understanding of their health and the care they receive [15]. We need stories of routine clinical care and what health professionals can do to achieve positive impact in partnership with patients and their loved ones [16]. We need stories of the everyday ups and downs of living with a disease that never goes away [17]. And we need stories told from the perspective of clinical care professionals [18] and family caregivers [19] as well as patients themselves. Narrative medicine [20] is a powerful tool for health promotion within and far outside of clinical settings.

To promote sharing of these narratives—both from people with diabetes and from a diverse array of others living with chronic physical and mental health conditions as well as experiences within and between marginalized communities—we started the Write Where It Hurts project. You can find us on the Web at www.writewhereithurts.net, and also on Facebook and Twitter. WWIH is a narrative-based blog and social media outreach hub focused on disclosure and critical analysis of experiences in health and the social world that are challenging and/or traumatic in nature. We expect that many PLAID readers and contributors will have diverse experiences in these areas and many more. The project grew out of our own realization, as scholars and activists, that the insights we ourselves have gained from our own adverse experiences have fundamentally transformed our ability to make an impact for others.
Our team consists of three people who live with chronic conditions. All three of us have a deep passion for championing the unique voices and contributions of people with diabetes and other chronic conditions. Perhaps as a result, we understand firsthand that the best person to share your story and make an impact with lessons learned from your own experiences is you! Whether you’re a researcher, a clinician, a caregiver, a patient, a supporter, an advocate, or any combination thereof, we welcome your contributions at Write Where It Hurts. Indeed, we enthusiastically encourage you to get in touch with us and contribute a guest post to our blog! We also realize that some experiences may lend themselves to better comfort if shared in an anonymous post, so we always offer that option for writers who feel apprehensive about attaching their name to a piece. Our primary focus is on working with you to offer a positive and affirming outlet for your story, and for the unique lessons it has instilled in you about living well with diabetes and helping others to do the same.

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