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The Association of Health Insurance and Quality of Life in Type One Diabetics

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ABSTRACT

The main purpose of this study was to investigate the correlation between health insurance and the quality of life of type 1 diabetic adults in Connecticut. Type 1 diabetics over the age of 26 living in Connecticut were invited to participate in a mixed methods case study. Quality of life data was collected from a questionnaire with questions drawn from the 12-Item Short Form Health Survey and the Appraisal of Diabetes Scale. Each participant was assigned a quality of life score after taking the questionnaire. After taking the survey, a semi-structured interview was conducted with each participant with questions assessing their health insurance plan, access to care, and self-perception of quality of life. The quality of life scores from the survey were cross-referenced with how each participant responded in the interview, then analyzed The average quality of life score was 37, revealing a below average quality of life for type 1 diabetic adults in Connecticut. Patients reported in the interviews that health insurance helps maintain quality of life, but can restrict individuals from improving. The interviews also revealed higher levels of concern for the financial burden of diabetes and the effectiveness of insurance. The study concluded that type 1 diabetics face quality of life disparities. Health insurance effectively maintains a level of quality of life, but often restricts individuals from elevating themselves.

Literature Review

Diabetes mellitus is a class of diseases that affects the human body's breakdown of glucose, an energy producing molecule. When food is consumed, the body digests and circulates nutrients throughout the bloodstream to fuel cells. This increases the amount of sugar in the blood. In a normal biological process, the pancreas secretes the hormone insulin into the bloodstream when blood sugar levels are too high. The insulin signals the cells to absorb the sugar. All classes of diabetes mellitus affect the body's response and production of insulin; this leads to hyperglycemia, or sugar buildup in the bloodstream. Left untreated, hyperglycemia can cause death and long term complications such as cardiovascular disease, nerve damage, obesity, and more (Mayoclinic, 2020).

While there are several different types of diabetes, type 1 diabetes was selected for analysis because it is associated with more complications and comorbidities than gestational or type 2 diabetes. Although type 1 diabetics are a minority—consisting of about 5.2% of the diabetic population—their increased complications have a greater individual impact (CDC, 2020). Additionally, type 1 diabetics have a higher dependence on insulin medications. In contrast to type 2, where cells build resistance to the action of insulin, a type 1 individual's immune system attacks insulin producing cells in the pancreas, which permanently damages the organ and requires regular insulin injections to manage blood glucose levels (Mayoclinic, 2020). Today, an estimated 1.4 million Americans aged 20 and over have type 1 diabetes, with about 40,000 more people being diagnosed each year (CDC, 2020).

As a biological molecule essential to the functioning of a human body, insulin is an essential medication for those who cannot naturally produce it. To maintain glycemic control, type 1 diabetics must inject insulin several times a day. The United States is notorious for its high prices, with the average annual per capita cost of insulin nearing about $6,000 — and this price is steadily rising (Hayes, 2020). In a 2019 analysis on the 49 top-selling drugs conducted by doctors at the Scripps Research Translational Institute, insulin was one of the 16 drugs that more than doubled its insurer and out-of-pocket cost from 2012 to 2019 (Pradhan, 2020). These prices are over eight times higher in the United States when compared to 32 of the world's highest income nations (Lagasse, 2020).

The cost of illness for type 1 diabetics is disproportionately higher than the cost of illness for any other form of diabetes. A 2018 analysis study published by the American Health and Drug Benefits forum entitled "Estimating the Real-World Cost of Diabetes Mellitus in the United States Using 2 Cost Methodologies" attributed the annual cost of a type 1 diabetic diagnosed at age 14 to about $25,855. This took into account the additional expenses besides insulin, such as medications treating comorbidities, hospitalizations, physical check-ups, or outpatient services (Bouchard, 2018). Since insulin injections were not discovered until the 1930s, the health complications affecting diabetics were not made apparent until their life expectancies increased (Rosenfeld, 2002). In addition to glycemic control, type 1 diabetics must manage these comorbidities, which subsequently affects daily functioning and quality of life in addition to extra costs.

Generally, disease-specific quality of life studies assess the impact of the disease and its management on the wellbeing of the patient. Pre-existing studies on type 1 diabetes have concluded that patients and immediate family have a diminished quality of life compared to the nondiabetic population, and that diabetes is a disease that requires great sacrifice to maintain an individual's health (Laffel et. al, 2003). Multiple other studies have documented the combined estimated lifetime burden of type 1 diabetics to be $813 billion more than the national average, predicting an eventual unsustainable financial impact. However, very few studies analyze the effects of health insurance on alleviating these diabetic disparities.

Health insurance is insurance that provides compensation for any medical expenses. These programs serve to assist individuals in paying for losses from any health-related costs by working with health providers to give the best care. Therefore, it is a variable that encapsulates an individual's access to care and effectiveness of treatment. One study on health insurance and diabetics entitled "The Association between Health Insurance Coverage and Diabetes Care" concluded that uninsured individuals in 2000 received significantly poorer healthcare than those with insurance (Nelson et. al, 2005). Another study conducted in 2009 by doctors affiliated with the University of Chicago health departments entitled "Insurance Status and Quality of Diabetes Care in Community Health Centers" compared the health and quality of diabetes care by insurance type among participants at public health centers in various states, finding that different health insurance coverages did not reach the same levels of quality of care (Zhang et. al, 2009). Both of these studies focused on diabetes mellitus as a whole, and were limited as they did not address comorbidities among the different types of diabetes that could potentially affect participants. They also suggested that further research was necessary to examine how the affordability of treatment after health insurance could potentially impact a patient's overall health, and that future studies should try to identify differences in the quality of care offered by healthcare providers. A critical review of this literature reveals a gap in health insurance studies on type 1 diabetics and quality of life.

The purpose of this study is to fill the gap in the literature by investigating the correlation between health insurance and financial quality of life among type 1 diabetic adults in Connecticut. This research presents implications for the recently proposed 2020 Connecticut Senate Bill no. 1, an act to expand health insurance coverage for prescription drugs, equipment, and diabetic supplies, require pharmacy benefit managers and pharmacists to distribute supplies without prescriptions in certain situations, and make changes to statutes concerning high deductible health plans. While the public was generally supportive of the bill, various testimonies criticized its action against insurance companies and drug distributors. Therefore, this research will present implications for potential changes to this bill by revealing the effects of health insurance on type 1 diabetics' quality of life.

Design

A study yielding both quantitative and qualitative data was chosen as the design for this research to enable an in-depth exploration of the role of health insurance in quality of life for type 1 diabetics. As previously mentioned, the studies researching this topic (Zhang et. al (2009) and Nelson et. al (2005)) only analyzed data from large databases of patients under specific healthcare systems. Therefore, including an in depth case study interview design in addition to surveying participants was necessary to fill the gap in the literature and add a qualitative component. The case study methodology also made sense given the limited number of type 1 diabetics and the resources of the researcher. These two methods yielded comprehensive data from which patterns could be drawn. Whereas the survey extracted data on quality of life, interviews were conducted to gather more in depth information about the individual experience and perspective. Although the quantitative data gathered from this study would be statistically insignificant under a smaller number of participants, the survey data was cross-referenced with the interview to explain specific differences between each participant's responses to questions, based on their quality of life. The two parts of this study were as follows

a) A quality of life survey. This part of the study formed the quantitative results.
b) A semi structured interview. This part of the study involved open-ended questions on health insurance to form qualitative results.

Approval to conduct this study was obtained from the Internal Review Board at a rural high school in Connecticut. All participants gave written and informed consent prior to participating.

Participants

According to the 2016 Connecticut Diabetes Statistics report, an estimated 8.9% of Connecticut adults have diagnosed diabetes. Type 1 diabetics make up 5% of these reported cases (Connecticut DPH, 2016). Under this limited population, the case study design allowed a sample size of 5-12 participants, as the smaller number of participants allowed a more in-depth exploration of each case.

Participant qualifications were as follows: participants must have type 1 diabetes, be over the age of 26, and live in Connecticut at the time of the study. Under the Affordable Care Act, an individual can remain under a parent/guardian's health insurance plan until they reach 26 years of age; therefore, this age constraint was necessary to ensure all participants were aware of their insurance status. The state of Connecticut was chosen for analysis, as the researcher lives within this state. Several participants were gathered via the Facebook group for the Connecticut branch of T1 International, a nonprofit organization dedicated to supporting people impacted by type 1 diabetes. Other participants joined via word of mouth, as information about the study was spread around. Participants indicated interest by filling out a form and then signing their consent to participate.

Quality of Life Survey

Each participant was sent a digital survey to score their overall quality of life. Prior to assessing quality of life, basic questions about the age and gender of participants were asked. Questions regarding participant's health insurance plan or lack thereof then followed. Participants were asked to classify their health insurance plan under a type and to explain the details of their plan. This survey drew questions from the 12-Item Short Form Health Survey (SF-12) and the Appraisal of Diabetes Scale (ADS) to assess their quality of life as diabetics. The study "Outcome Tools for Diabetes-Specific Quality of Life" conducted by Canadian physicians Rajesh Nair and Paul Kachan (2017) recommends usage of these two outcome tools based on their meta-analysis. Short form-36 (SF-36) was also considered for this study, as it is one of the most widely used general assessment tools for quality of life. However, SF-12 is considered to be the better scale, because SF-36 has a greater completion time and number of questions. SF-12 has also been verified to be reliable in assessing adults with chronic diseases (Hayes et. al, 2017). Compared to other diabetes-specific quality of life outcome tools, the ADS is generally valid, short, and reliable. Nair & Kachan (2017) and Polonsky (2000, p. 36) have found a significant link between the ADS and glycemic control, cementing its reliability as an outcome tool. As the researcher chose to assess psychological quality of life in the interview, any questions assessing emotional well-being were not included in this survey.

Qualitative Interviews

15-20 minute semi-structured interviews were conducted over Google Meets with each participant to gather qualitative data. These interviews were recorded, transcribed, and analyzed. These interviews sought to obtain a deeper understanding of whether or not health insurance was useful in ensuring participants could receive necessary medications or therapies. They included seven questions centered around a participant's health insurance, access to healthcare, and self-perception of personal wellbeing (Table 1). When necessary, patients were asked to elaborate or clarify some statements.

Table 1

Questions included in the semi-structured interview

Question 1	Does your health insurance plan effectively alleviate the costs of managing diabetes? If so, how?
Question 2	Are you able to obtain the necessary healthcare to treat pre-existing and developing conditions?
Question 3	How does the coverage of your health insurance influence your healthcare decisions?
Question 4	Have you ever had to prioritize the treatment of one condition over another?
Question 5	Do you feel that you have an adequate quality of life as a result of your health insurance plan?
Question 6	Does the level of healthcare you can affordably access give you the resources and treatments to manage your diabetes?
Question 7	What are the major grievances you have with life as a type one diabetic?

Data Analysis

Data analysis on the quality of life survey was performed by assigning each participant a quality of life score based off of their answers to the survey. Each question was scored on a 5 point scale, with answer choices indicative of a poorer quality of life having lower point values than choices indicative of a higher quality of life. The SF-12 and ADS instruments are scored in this manner, and include grade ranges for their scores. Quality of life grades are as follows:

- Score of 56-70 — excellent quality of life
- Score of 42-55 — satisfactory quality of life
- Score of 28-41 — below standard quality of life
- Score of 14-27 — poor quality of life
- Score of 14 or less — skipped questions

Although the survey itself was anonymous, the quality of life results were matched to each participant and analyzed to find potential correlations between interview responses.

Qualitative data gathered from the interviews was analyzed using thematic analysis, a methodology that focuses on obtaining themes and patterns in qualitative data. These interviews were transcribed, coded, and combined in an inductive manner, so that the themes were built off of the most common patterns in each interview.

Results

Question 1: All participants had private insurance plans. When asked how effective their health insurance plan was for alleviating diabetes-related costs, participants gave responses like the following.

No. Most of the other stuff is covered pretty much right away, but the insulin itself is always astronomically expensive [patient code female, score of 36]

The cost of being a diabetic through my health insurance is expensive [male, score of 39]

Yes, but I still do pay fairly large portions of it out of pocket [female, score of 42]

There's still a significant cost out of pocket [male, score of 61]

It covers part of mine, but I still pay a lot [female, score of 51]

Most of the extremely high medication costs fall on me [female, score of 33]

Question 2: Three of the participants in the study reported comorbidities. Some of their replies were the following.

Yes, they do a really nice job [male, score of 61]

There's some medications that need prior authorization, so you need to pay attention [female, score of 42]

Question 3: Regarding coverage, two participants stated that their insurance plans were not tailored for their specific needs.

Some months you go without buying things so you can afford insulin [female, score of 42]

I don't have the assumption that they would cover everything [male, score of 39]

Question 4: Three participants in the study recalled at least one occasion where they had to prioritize a certain condition over another.

There are months we don't do certain things due to medical expenses [female, score of 36]

I have some other minor issues so I prioritize by how much I can take on [male, score of 39]

At my previous plan it was really expensive, Dexcoms and CGMs weren't covered [female, score of 40]

Question 5: All participants believed that they were able to have an adequate quality of life as a result of their health insurance plans, but some believed they were restricted from having a better quality of life because of their plans.

I've yet to find an insurance plan by a company that is willing to cover costs upfront from the very beginning [female, score of 36]

It's a lot of responsibility on me as the patient to self navigate [male, score of 39]

No matter what insurance we have, we're always going to have those costs associated [female, score of 40]

Sometimes, I have to let my health go downhill a little bit while stretching insulin due to costs [female, score of 33]

Without a plan, I would do the same things, but it would be harder on expenses [male, score of 61]

It doesn't set me back at all [female, score of 51]

Question 6: All participants were satisfied with their doctor visits, but some expressed dissatisfaction with medications. One felt that the healthcare system lacked educational resources on diabetes.

I've had to self-teach myself most things [male, score of 39]

Question 7: All participants had at least one major grievance with life as a type 1 diabetic. Most of these were related to the cost of medications or imposed responsibility.

There's a lot of barriers when it comes to the system and you have to pay attention constantly [female, score of 40]

It doesn't feel good to me that I have to rely on what the insurance has decided is best for me rather than the doctor [male, score of 39]

It's worrying how dependent everyone is on their health insurance [female, score of 33]

There's all these tricks you have to learn from a young age to afford your life saving medications [female, score of 36]

If I didn't have a high income, this would be painful [male, score of 61]

I pay 6,000 dollars a year out of my own pocket for things I need to keep myself alive [female, score of 51]

Most Prevalent Themes

Nearly all participants could recall a time that a different insurance plan was not suitable for their needs, or a plan that was more effective than their current plan. One participant expressed anxiety about switching his plan within the year.

*He (*the participant's father) *had the highest possible premium you could pay for insurance, and that's the only way everything was covered—honestly, [employer] has one of the better health insurance plans I've been on, which is kind of sad [female, score of 36]*

At my previous job, it was really expensive [female, score of 40]

I am actually concerned about what changing my plan is going to do for my expenses and what's covered; it will likely involve more of my own pocket [male, score of 61]

Once upon a time I used to get everything covered for free [female, score of 51]

Participants also expressed that they were only in good health because of their luck.

*I feel pretty lucky about it (*the participant's insurance plan) *but no matter what insurance I have, those costs will never go away [female, score of 40]*

I've been fortunate, I've been in a high paying job. That may not be typical for every diabetic [male, score of 61]

My parents have helped since I got my own plan, but if they weren't supporting me I would have much worse health [female, score of 33]

It's fortunate I can afford it, but it's still a lot of money out of my pocket for things I need to live [female, score of 51]

Finally, participants discussed frustrations with transparency issues around health insurance and the responsibility imposed on diabetics.

I feel that there could be a more frontier and transparent and resourceful way of figuring out why I can or cannot get some things [male, score of 39]

My plan switched out the brand of insulin they covered to one that I was allergic to; I had to write letters and get authorizations for them to accommodate me [female, score of 40]

Discussion

The results of the present study suggest that adults with type 1 diabetes face quality of life disparities compared to a non diseased population. This can be concluded from the scores of the quality of life survey. Out of the six participants that took the survey, four had below standard quality of life scores. The average score out of all participants was also 37, which is below standard. The guidelines of the two outcome tools used in this study suggested that scores of 42 and above have a satisfactory quality of life. The interviews also yielded relevant information on the role of insurance for individuals with chronic illnesses like type 1 diabetes, and highlighted concerns around health insurance about coverage, medications, and financial burden. Additionally, the results of the SF-12 and the ADS showed correlations to the interview question responses; the participants with lower scores on the survey expressed stronger dissatisfaction in the interview.

Health insurance was shown to be effective in improving quality of life for type 1 diabetics, but it was still limited under different circumstances. Income level was shown to influence the level of health insurance one could afford, or the extent of financial burden. Although none of the participants stated their income level in the interviews, those who stated that they had higher paying jobs recorded better quality of life scores. This finding makes sense, as having a higher income decreases the burden of medication expenses and allows individuals to afford higher premium insurances. The management of disease was also reported to be slightly offset by health insurance plans. Many participants disclosed at least one occasion in which prior authorizations by their doctor and letter writing was required for them to get medications covered. Others recounted situations where regulatory devices like glucose monitors or blood ketone meters were not covered. Even if a participant could afford an out of pocket expense, the participant was less likely to purchase devices when they were not subsidized by health insurance.

Other participant characteristics may offer explanations for the results. Generally, the younger participants had lower quality of life scores, and reported lower satisfaction in the interview. This could be because younger participants closer to 26 years of age would have entered their own plan more recently, causing them to struggle to adapt and balance expenses. A younger type 1 diabetic would also be healthier than an older one, so there would be a less aggressive pursuit of care and a lower perceived value of constant check-ups. As such, individuals on high deductible plans would have more trouble reaching their deductibles and getting items covered.

Implications

Similar to previous studies, the results show that not all types of health insurance are equal. Nelson et. al (2005) identified that diabetic individuals with higher income and higher premium insurances were more likely to have better access to services like hemoglobin tests and management classes. Zhang et. al (2009) revealed how quality of care is affected by presence and quality of health insurance for diabetics. Both of these studies analyzed large-scale patient databases to reach these conclusions. Finally, Alvarado-Martel et. al (2015), a mixed-methods study assessing diabetes treatment satisfaction, identified that type 1 diabetics are primarily concerned by glycemic control, eating, and chronic complications. This study adds to the literature by linking the qualitative study approach to the variables of health insurance and quality of life, establishing how health insurance is generally beneficial. The differing methodology as well as the focus on specifically type 1 diabetics also effectively addresses the limitations of these three studies.

These findings have important implications for the effectiveness of current policies and the proposal of new ones. Since most of the concerns raised by participants were about the affordability of medications and regulatory devices, the aforementioned 2020 Connecticut SB 1's provision of expanding coverage of diabetic supplies would be a reasonable solution to the issues raised in this study. However, it should be noted that the results of this study are not representative of the entire United States, since all participants resided in Connecticut.

Limitations

This study had several limitations. The interviews were audio-recorded and transcribed at a later date. Since these interviews were conducted over a video call, the transcriptions are subject to human error and some statements could have missed nuance. Furthermore, there was a very limited number of participants. Although case studies typically do not collect data from a large number of participants, the time constraints of the study and the researcher's resources were only able to collect data from six different individuals. Having a larger number of participants would mean a greater amount of data from which more reliable claims and patterns could be drawn. It would also make the data gathered from the quality of life survey more statistically significant, which would allow the quantitative data to be examined on its own. Paired with correlated interview responses, this quantitative data would be seen as a greater representation of Connecticut's type 1 diabetic population and would have stronger reliability.

Additionally, selection bias could have affected the results of this study. Because participation was completely voluntary and drawn from social media, those who volunteered to participate could have possessed an unknown characteristic that differs them from those who did not participate. One variable that may have been affected by this could be the type of health insurance plan. All participants in this study were on private insurance plans. Because of this lack of variance, the results of this study can only be applied to type 1 diabetics with private insurance plans living in Connecticut. Future research should address these limitations by drawing data from a larger number of participants. More research should also be conducted on the effectiveness of different types of health insurance plans on diabetic quality of life and the differences in quality of care among these plans. Identifying these factors may help policymakers and healthcare providers reform policy provisions in order to improve overall wellbeing for type 1 diabetics.

Overall, health insurance benefits the quality of life for type 1 diabetic adults in Connecticut, but also restricts individuals from improving their quality of life. The findings of this study suggest that enforcing policy to make health insurance companies increase coverage on diabetic supplies and/or reducing high deductibles will benefit the quality of life for type 1 diabetics in Connecticut.

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