


Subjective Experience of Illness Among Adolescents and Young Adults With Diabetes: A Qualitative Research Study

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Abstract

Diabetes mellitus type 1 is a chronic illness that has its onset in childhood or adolescence. It is determined by the insufficient production of insulin. The main therapies consist of replacement of the lacking insulin, diet, exercise, and glycemic control. If treatment is managed by parents in childhood, adherence seems to be a difficult issue during adolescence. In order to understand the subjective experience of the illness and treatment, the present study aims to investigate the patients' subjective perspective by addressing a group of adolescents and young adults in pediatric care. A qualitative research design was adopted with semi-structured interviews, and later software thematic analysis was performed. Six core issues were deepened: family and health-care professional's mediation support for self-management, adherence to treatments as a boring responsibility, disclosure problems in peer relationships, difficulty in becoming autonomous in a period of socioeconomic crisis, illness as concern for the future, and seeking a normal life in daily activities. The knowledge can be useful for designing more appropriate interventions that favor the active engagement of patients.

Keywords

adherence, chronic illness, diabetes, qualitative analysis, youth, adolescence, patients perspectives/narratives

Introduction

Chronic diseases are increasingly common, also among youth. In particular, the prevalence of diabetes in adolescents is increasing (1). Diabetes mellitus type 1 (T1DM) is a chronic medical condition that has its onset in childhood and adolescence. It is determined by the insufficient production of insulin, the hormone needed for glucose utilization by the β cells of the pancreas. The primary therapies consist of the replacement of insulin through multiple daily injections (using syringes or "pens") or via a portable, battery-powered infusion pump, which delivers insulin subcutaneously. The therapy also includes diet planning, exercise, and glycemic control.

Although parents are generally responsible for care and supervision when the patient is a child, in adolescence and early adulthood patients have to learn to self-manage the treatments. As noted by Hilliard et al, the transition from adolescence to young adulthood, often referred to as "emerging adulthood", is a vulnerable period marked by changes in physical, emotional, and social domains (2). It is a newly recognized developmental period of life from the late teens through the 20s (1,3,4), in which patients explore their identity and experience many new transitions,

desires, expectations, and roles (2). Some researchers indicate, however, a difficult adherence to treatments during this age transition (2, 5). It is an important phenomenon, little studied by researchers (6), also because emerging adults at an increased risk of declining health status during this age transition can increase the future complication linked to T1DM (2).

Recent psychosocial literature has addressed the issue of adherence according to patient difficult engagement as a crucial aspect of medical care (7–9). As noted by Martinez and colleagues, "Diabetes management in the adolescent age group presents a more complex set of challenges given the range of physiological, social, and emotional changes which occur between childhood and adulthood, including puberty, peer pressure, a desire to be 'normal,' identity formation and, often, testing of boundaries set by health care professionals,

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parents, and caregivers” (5, pp. 1-2). Young patients have to contend with contradictory aspects (i.e. dependence vs autonomy) that affect their ability to actively participate in care (10–13). The medical prescription is therefore grounded in the everyday life of the young people, balancing different desires.

Furthermore, as indicated by Balfe (6), routines play an important role in diabetes self-care, but management practices of them can be very difficult in some social context as school or work, for the fear of stigma or isolation. Healthcare routines, therefore, should be first internalized as something of good for the self and then they can be transformed in good practices.

So adherence to therapy in adolescence and early adulthood must be understood in the light of the values, images, and meanings. As pointed out by several authors, subjective “experiential truth” influences in fact the decision-making processes and daily practices (14, 15).

From this perspective, we designed a qualitative research project that involved interviews with teenagers and young adults with diabetes. This research is part of a larger ongoing research project that explores adjustment to transitions in different chronic diseases (16, 17).

Aims and Methods

The present research project aims to clarify the subjective experience of illness in a group of teenagers and young adults with diabetes in care at the pediatric division of an Italian Hospital.

Since our interest is to explore the representation of living with diabetes as it emerges in this particular period of transition to adulthood, we used in-depth interviews. In-depth interviews create a format for narrative power to convey emotions, thoughts, beliefs, which is why both psychology and medical research consider this medium to be a rich qualitative research tool (17–19).

This explorative study, in fact, highlighting the core psychological issues, intend to explore the richness of participants’ illness representation, revealing the depth of their idiographic subjective experience. The interest of this research is to understand how each issue is developed and valued by our participants.

Sample

Adolescents and young “emerging” adults aged from 11 to 25 years with T1DM were first contacted by the pediatric physician from the university hospital department where they were in care as outpatients. The physician described the study, encouraging their participation explaining and acting as a mediator for the survey. Interested patients received a letter explaining the research aims and methodology in detail. They also received a sociodemographic questionnaire that included sex, type of therapy, and age.

Fifteen of the 25 contacted patients agreed to participate. Each participant was given a voucher for the purchase of books or music products as a way to thank them for their participation.

Age of the sample was mostly equally distributed according to sex (7 males and 8 females). All practiced home treatment. Six of the participants used the pump at the time of the interview, while 9 others used a syringe or pen.

Data Collection

The face-to-face, semi-structured interviews, each lasting about 60 minutes, took place in a private office in the pediatrics department and were conducted by one of the authors of this article. Researchers had obtained informed consent from all participants and from parents of minors, together with their permission for the anonymized transcripts. Parents were not present during the interviews.

An interview grid was prepared ad hoc. The areas that we wanted to explore were: self-image, relationships, first awareness of having diabetes, coping strategies growing up with diabetes, adherence with treatment regimens, perceived social support, and aspirations for the future.

Participants were encouraged to talk about their personal experience of illness, and their own perspective was elicited with nondirective prompts and open-ended questions.

All the interviews were audio-recorded and anonymously transcribed verbatim. The university’s ethics committee approved the research project.

Study Design and Data Analysis

In analyzing the interviews, a bottom-up approach was preferred, deepening through the patients perspective the most common key themes (19, 20). To do this, a software for text analysis was used (T-Lab; 21), so that the starting point was not the researcher’s categorization of interviews’ contents, but the observation of respondents’ lexical choices and of particular patterns of words identified across all the narratives.

The resulting themes that summarize all the data production can be considered latent themes, as they can be influenced by the topics solicited by the interviewer, but do not correspond to them. A particular association of concepts/words, in fact, may appear in response to different matters, so what emerges as a main theme will be the topic expressed through such association. Specifically, T-Lab was used to perform cluster and factorial analyses on the interviews.

From an operational point of view, interview transcripts were merged into a single text file, omitting the researchers’ questions. The software identified the co-occurrence of keywords within the text and their combination in groups of words to form clusters, that is, themes expressed by the participants. For each cluster, the list of keywords was provided, together with examples of the sentences in which they co-occur. Clusters are more or less inclusive of patients’ perspective, depending on the percentage of phrases

Table 1. Extracts of the Typical Phrases for Each Clusters.

Cluster 1: "Social support as a facilitator for self-management of care"	<p>"My mother said me: 'Just call your doctor because I do not know if I can give you [a tattoo]'. I said 'I'll call the doctor T., and she told me not to worry, everyone has one, including people with diabetes.'";</p> <p>"If they [friends] do not understand when I explain the first time, I can explain a second time, and show it, I have no problem. Since childhood my parents have got me used to knowing that this is my life, like it or not, it's my life, and I'm perfectly used to it and it is normal."; "Family members are very important. It is all the strength that you are given, they are the first to welcome you and make you understand that nothing has changed, that the relationship with you is always the same, and make you accept sickness!"</p>
Cluster 2: "Diabetes as an organic disease and care routines as a mechanical duty"	<p>"It's happened only once [to forget it], but it was an oversight . . . I still don't understand how it happened, I didn't do the insulin and test . . . it was the morning after, and at the lunchtime test I had blood sugar of almost 600, because I had played sports but I had not taken insulin, and my blood sugar went up again"</p> <p>"Even if I forget that she [the physician] advised me, then I notice it when I go to do take the glycemic test".</p> <p>"I realize that I arrive at dinner and my blood sugar is up to 200, and then I say: ah, yes, it is true, she told me to check."</p>
Cluster 3: "Commitment in disclosure and coping activities"	<p>"It was a new environment, with different classmates. My problem when I returned to school was that I had to bring out the syringes . . ."</p> <p>"In elementary school there was a lot of collaboration, both with the teacher and with my classmates, they helped me, there was no derision or mockery . . . from the teacher either."</p> <p>" My friends don't even know that I have diabetes, because I'm pretty good at masking it, and I do everything that others do. Well, if they see me while I take the insulin I have to tell them, because otherwise they might think . . . this is not right!"</p>
Cluster 4: "Ambiguity toward autonomy"	<p>"Right now I'd like to find a job, even start to do something to be a bit more independent, now that they are also quite a bit older, but still . . . it is difficult."</p> <p>"If I'm accepted [at university], I'll be happy. Otherwise I'll go to a totally different university, and I think I'll do that anyway, I don't think I'll work. Because, anyway, partly due to the period, you know, because our country is in [economic] crisis."</p> <p>"University is not in my mind, but you never know. I would like it very much"</p>
Cluster 5: "Loss, disruption and fear for the future"	<p>"[. . .] there might be some company managers who want perfectly healthy people, because I have a crisis, and I day I can't go, for him it's a loss . . . but no I think because diabetes has become quite common and so you should not make great discrimination."</p> <p>"[. . .] but come on, I think it can happen, for a twenty year old, even when I was younger I was always losing everything all the time, other than that . . . ah but I am like that by nature, I'm careless."</p> <p>"If by chance I lose a grandparent, because usually when I'm sad I have mood swings fast . . . diabetics suffer a lot."</p>
Cluster 6: "A desire for normality and a daily life like any teenager"	<p>"Up to now my job has been to study, so I put that first. Then if I have time I do other things, but since I can't, because I go to school at one-thirty, I get home at three o'clock, the time to study, because there are a lot of subjects, the teachers expect a lot."</p> <p>"In my spare time . . . I'm a little listless, in the sense that . . . maybe I try to exercise, to do sport, because anyway with diabetes it makes me feel quite well, and to stay in motion, so the gym, swimming."</p> <p>"Instead of staying at home to study, I went out with friends . . . entertainment, that is the fun."</p>

comprising them compared to the total number. After analyzing and interpreting the output, the researchers assigned a label to each cluster.

The software also identified factors (generally 2 or 3) that can be considered the basic categorization systems for the analyzed topic. Each factor is divided into 2 polarities (negative and positive) which indicate 2 opposite poles of sense-making processes. These dimensions are formed by different words. After analyzing the words that make up the positive and negative polarities of each factor, the researchers assigned a label to each pole of the factors. Graphically, the factor axes form a factorial space, that is a broader map of meanings inside of which lie the clusters, that is the themes, positioned near the polarities of the factors by

which they are best represented. The positioning of the clusters on the factorial space helped also the authors to interpret the themes (note 1).

The software analysis was carried out by a trained researcher (one of the authors). The coding process of the statistical output was iterative and involved all authors.

Findings

The analysis highlights 6 relevant themes, ranked according to their importance (weight), established by the number of sentences divided by the total number of phrases. In Table 1, some examples of the typical phrases are indicated, while below the main themes are shown.

Clusters

1. *Social support as a facilitator for self-management of care.*

This theme is made up of 367 utterances within the 1029 total utterances, and it saturates 35.67% of the variability of the text, so this theme is the most common among the adolescents and young adults surveyed. Participants showed a high degree of acceptance of the illness and were learning to live with diabetes with the help of key figures such as parents and hospital staff considered friendly and helpful. In particular, the importance of the pediatric department is evoked.

Reassurance is considered important, together with the need for understanding the disease, talking about and listening to explanations (some main keywords of this cluster are explain, talk, understand, teach, learn, accept, fear, manage).

Social support is viewed as protective and a facilitator for self-management of care. These aspects seem to favor the positive process of acceptance, elaboration of emotions, and sense-making for patients. However, the process of the integration of the illness in the self and autonomous everyday life still seems to offer challenges. Young patients must develop the ability to manage their care by themselves, overcoming forgetfulness, laziness, fear, and shame (keywords mentioned by the respondents, also implied by reference to the bathroom as an ideal place to self-inject in secret).

2. *Diabetes as an organic disease and care routines as a mechanical duty.* The second theme occupies 18.95% of the total variability of the text (it is formed by 195 utterances). In this theme, illness seems to be experienced as an organic disease and therefore as an error to be corrected.

Diabetes therapy actions are described as almost mechanical (most common words are check, value, measure, monitor, correct), and the person is represented like a device that works better or worse, depending on whether the patient forgets or remembers to take his insulin regularly.

The control—referred to the amount of insulin to be injected, to food, and levels of glucose in the blood—and the regulation of treatment appear rigid.

Moreover, this representation is linked to some objects such as pens, needles, insulin pumps, syringes, whose use must become daily. Instead of being integrated into identity and routine, the objects seem to recall a duty that must be performed for the respondents. This theme does not evoke any particular key figure or emotions.

3. *Commitment in disclosure and coping activities.* This theme is composed of 179 utterances, accounting for 17.40% of the total. This topic refers to the disclosure of being person with diabetes (PWD) to peers and other adults. The illness is associated with a sense of diversity, the fear of stigma by peers, and the feeling of being unfortunate or disadvantaged. This theme refers to all school levels, relationships with classmates and teachers, normal activities of adolescence (such as listening to music, sports, surfing the Internet),

where certain character traits are useful for a good social life (like being cheerful). Adolescents and young adults may have to deal with their illness and inform their peers, even arguing with them.

Participants were very involved in disclosure and coping activities and are touchy about teasing or comments. Moving into different classes seems also to pose a problem, settling in a new environment and meeting new people to whom, at each step of the school system, they have to explain their condition. This issue also regards receiving help in times of need or explaining reasons for their unusual behavior, such as leaving the classroom, eating during lessons, or not eating a cheesecake in a party.

4. *Ambiguity toward autonomy.* The fourth theme is composed of 110 of a total of 1029 utterances analyzed by the software, accounting for 10.69% of the total. The process of achieving autonomy is depicted at the same time as challenging and enjoyable. A great difficulty is read into the economic crisis and the historical period we are living in, which makes adolescence and young adulthood in general problematic life phases but still full of hope and plans for the future.

In particular, young people ask themselves what place they will find in society. Education and work are considered a strong part of personal realization, which is however hampered by the sociopolitical context, where the difficulty of finding work is compensated by affection from friends and family.

In this theme, being PWD does not seem to be a problem or a status with which adolescents identify, but is considered a condition in relationship to broader personal and professional projects.

5. *Loss, disruption, and fear for the future.* This cluster consists of 92 utterances and covers 8.94% of the total variance. As opposed to the previous theme, this theme focuses on the broken dreams and concerns for the future, particularly distressing emotional dimensions such as the sense of death and loss. The illness emerges with words such as device, use, needle, pocket, calculate, biscuit, weigh, pen. Specifically, needles are associated with “dope” (indicating drugs). Diabetes is envisaged as a hindrance to pursuing goals and dreams in the future.

Dreams of having a child, buying an apartment, are shattered because of illness. This theme evokes not only loss of health but also loss of the tools necessary for self-care, which can be forgotten, or loss of the control that is constantly required.

6. *A desire for normality and a daily life like any teenager.* Finally, the last cluster, the smallest, is made up of 8.36% of the utterances, totaling 86 utterances of 1029. In this theme appear daily activities, life in a small town, peaceful afternoons with friends, games, study commitments, hobbies in their leisure time.

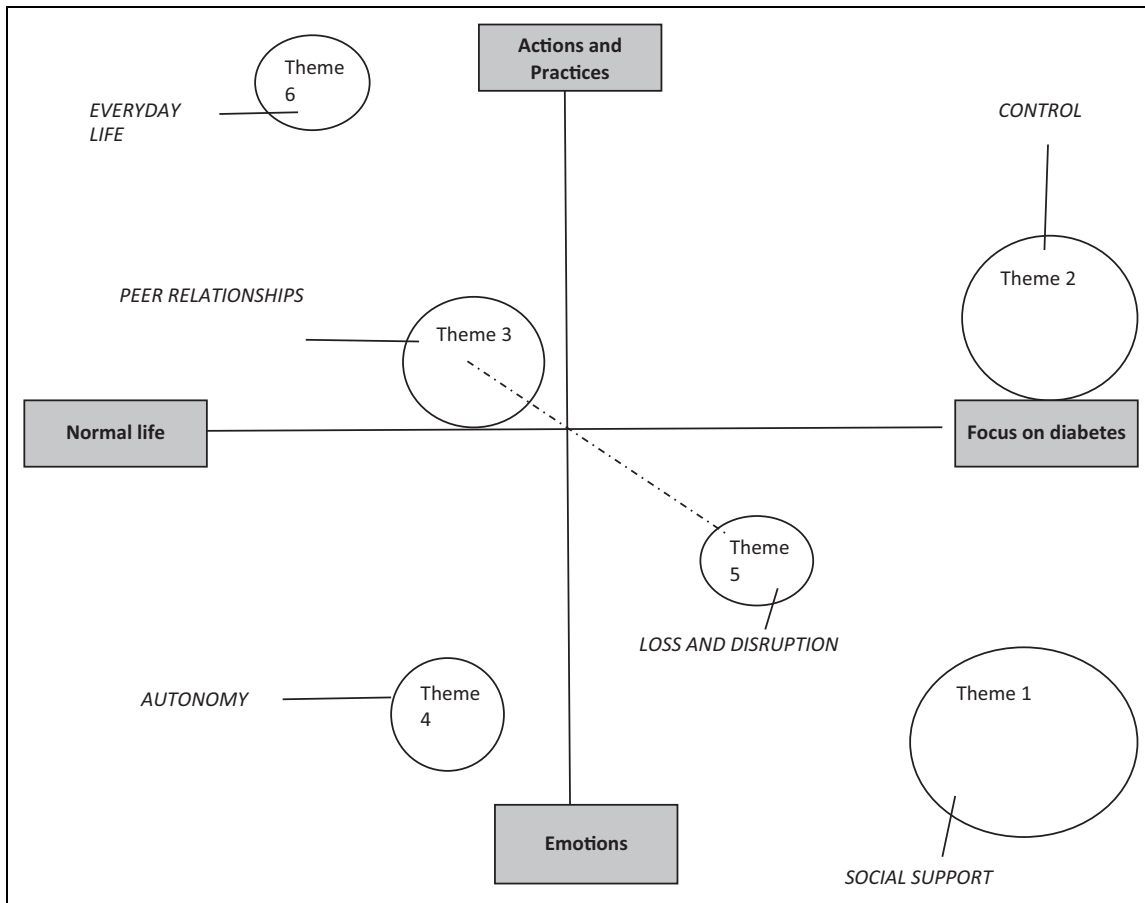


Figure 1. Factorial space and themes.

Among activities appear the gym, swimming, basketball, soccer, and sport in general, as well as music and travel. Along with daily life, periods of rest are also mentioned, such as weekends and summer. In these situations, the emotions reported are stress and tension, for fear of making a bad impression.

The words and the sentences that are grouped in this cluster don't seem to address any specific issue concerning diabetes, that is mentioned only with references to its consequences such as weakness and feeling like a fool. Indeed respondents talk about themselves describing ordinary activities and emotions of every adolescent.

Factorial Space

The analysis identified also 3 factors that describe the main oppositions in the sense-making process (Figure 1). The horizontal axis shows a process organized around a shift between a normal life typical of adolescents or young adults, on one hand, and a life focused mainly on diabetes, on the other. The vertical axis shows a contrast between 2 other opposite dimensions: on the lower polarity we found a reflexive process and an elaboration of emotions toward the acceptance of illness, while on the upper polarity we found a focus on actions and strategies based mainly on medical

interventions. Finally, the third factor (perpendicular to the page) shows a contrast between the conception of diabetes as loss and disruption and an experience of diabetes as linked to significant relationships.

As we can see from the figure, the control (cluster n. 2) is placed in the quadrant defined by actions and a focus on diabetes, while the autonomy process (cluster n. 4) is located in the zone of the factorial space defined by emotions and life marked by sustainable routine. Social support (cluster n. 1) is placed in the quadrant defined by the focus on diabetes and on emotions, while the theme of everyday life (cluster n. 6) is in the quadrant defined by practices and normal activities. More oriented on the factor perpendicular to the others we find the theme of loss and breakage (cluster n.5) in contrast to that of peer relations and disclosure (cluster n.3).

Discussion

Findley and colleagues (1) referred that the key components of transitional care practices that are associated with positive outcomes are an individual support and a strong and trustworthy relationship with reference health-care figures, as well as indicating the need for appropriate protocols to deal with the transition from adolescence to adulthood. However, there have been few studies that directly address the

perspective of chronically ill patients, specially of adolescent and young adults. Although the traditional medical approach only relies on information and behavioral skills as means to improve adherence to medical prescriptions, we have considered the psychosocial nature of illness and therapy. The present study therefore proposes to explore the main issues relevant to people affected by diabetes during this particular phase of transition. Adolescents and young adult have to deal with psychosocial issues such as conformity, fear of judgment and stigma, feelings of intrusiveness by parents, challenges in school and at work, emotions such as guilt and shame, and with a drop in levels of adherence to treatments (6). In this framework, adherence to therapy needs to be considered a cognitive and affective process of involvement within a relational environment.

In order to increase a patient's engagement, and make it active and responsible, it is necessary that services invest in research aimed at understanding the subjective meanings that substantiate the lives within which the disease is inscribed.

Within this research project in particular, we have seen the support provided by parents and hospital staff as the most important aspect perceived as useful for adherence to treatment. Participants, in fact, emphasize the psychological importance of belonging to a pediatric department perceived as protective, and the difficulty of change envisioned in moving toward autonomy. In a complementary way, some authors have investigated how the change of hospital ward, from pediatric to adult one, is a significant change that must be regulated by specific programs (1, 2).

Findings also highlight that control is considered as completely opposite of autonomy. The issue of control is marked by a medical vision of diabetes and is experienced by patients as a boring performance imposed by an authority. The role provided by the routines is not a protective one, because they are not already internalized into the self (6).

Another theme that emerged is the general feeling of loss and breakage of dreams. It is a small theme, not very representative of the respondents' experience of illness, but it deserves close attention as a risk theme. Scientific literature has in fact shown that it is typical for diabetic adolescents to have a sense of fatalism, a fear of death, and the sense of a threat for the future associated with a denial of self-care (10).

Friends are very important and are associated with issue of living with diabetes. Our results, in line with other studies (22), showed the fear of stigma and the need for giving explanation and receiving comprehension, especially from peers. Finally, the search for a normal life is expressed through the daily routines of every teenager struggling with the process of growth.

Strengths and Limits of the Study

A strength point of the present research lies in its ideographic character that makes it particularly useful in the design of locally organized hospital interventions. A limitation of this

qualitative study is the poorness of numerical composition of the sample.

Clinical Implications

This research could be a useful basis for the organization of psychosocial support groups with young diabetics, with the purpose of promoting adherence and better integration of the illness into the sense of self and daily life. The peer groups could encourage autonomy, problem-solving skills, disclosure, decision-making, and confidence in the self-management of illness, starting from specific data emerged from our study. As pointed out by Martinez (5), it is very important the effectiveness of psychosocial and educational interventions for adolescents with diabetes, beyond a specific care model for transitional care.

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Note

1. The software also allows to know whether some sociodemographic or clinical variables (sex, age, and type of therapy) are associated with particular themes. Given the small number of interviews, we will not discuss this kind of information here, reserving to increase the number of participants. It is important therefore to note that, using this methodology, the thematic analysis reliability is instead due not so much to the number of interviews but to the richness and the length of the collected texts.

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