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Educational needs of type 1 diabetes mellitus T1DM children and adolescents in Morocco: A qualitative study

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Abstract:

BACKGROUND: Type 1 Diabetes Mellitus T1DM is a chronic disease, mainly observed in children or young adults, with a significantly increased incidence in young children. To enable diabetic children and adolescents to lead a healthy life and manage their disease effectively, right from diagnosis, they must benefit from therapeutic patient education TPE whose first stage is an educational diagnosis. This study aimed to identify the educational needs of T1DM children and adolescents through an educational diagnosis.

METHODS AND MATERIAL: A qualitative study was conducted with T1DM children and adolescents, aged 8 to 18, at the pediatric department. This qualitative study was conducted through semi-structured face-to-face individual interviews based on a guide with 20 participants in 2022. The internationally recognized ethical research principles were respected and ethical approval was obtained. Data analysis were carried out according to the principles of the reflexive approach of thematic analysis.

RESULTS: The interviews' thematic analysis revealed five educational themes: Knowledge about T1DM and its complications risks, measures and attitudes for disease monitoring and therapy management, crisis and short-term complications management, diet and physical activity management, and adaptation of daily life to the disease and treatment constraints.

CONCLUSIONS: The educational diagnosis is an essential TPE step to identify the educational needs of children and adolescents with T1DM, and to set up if needed, an educational program allowing them to develop the required skills. Hence, the health policy in Morocco should integrate the TPE approach systematically in T1DM patients' care.

Keywords:

Adolescent, child, diabetes mellitus, educational status, type 1

Introduction

T1DM is a chronic disease mainly observed in children or young adults, with a significantly increased incidence among children at an early age.^[1-3] In 2021 in Morocco, T1DM children and adolescents (0–19 years) were estimated at 43.3 thousand, with an increasing incidence each year estimated at 5.1 thousand.^[1] Furthermore, there is

significant excess mortality of children and young adults diagnosed with T1DM in the first years after diagnosis, largely attributed to acute metabolic complications of diabetes: ketoacidosis and hypoglycemia.^[4,5]

Thus, T1DM requires daily management and can have serious repercussions on the quality of life of the child and his family and his current and future health.^[6-8] The treatment

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should be systematically initiated by a team of specialists and integrate TPE, which is the key to the successful management of diabetes and have a beneficial effect on glycemic control and psychosocial outcomes.^[4,9-12]

TPE is an approach considered as an integral and permanent part of patient care that helps patients, with chronic diseases, acquire or maintain the skills they need to best manage their life. It includes organized activities designed to make patients aware and to “help them (and their families) understand their illness and treatment, work together, take responsibility for their care, maintains and improve their quality of life.”^[13]

An educational diagnosis, called need assessment, is the first stage of the education process of TPE four steps model [Figure 1] and the one that will condition it,^[13,14] which is particularly lacking in the Moroccan context where patient education is done in an unstructured way and without prior assessment of their educational needs. An educational diagnosis is a systematic, detailed, and iterative information collection by the caregiver concerning the clinical, educational, psychological, and social situation of the patient.^[13,14] This information should serve as a basis for setting up a personalized therapeutic education program.^[15,16] The skills they should develop must be established in an order of priority and be broken down into objectives.^[17]

This study aimed to make an educational diagnosis of T1DM children and adolescents in the Moroccan context.

Materials and Methods

Study design and setting

Guided by a constructivist phenomenological approach, we conducted a qualitative descriptive study that established an educational diagnosis of children and adolescents with T1DM, as there are no studies investigating the educational needs of these patients in the Moroccan context, whether using qualitative or

quantitative methods, to set up an educational program allowing them to develop the required skills.

Study participants and sampling

Out of a total of 419 children and adolescents attending their appointments in the pediatric department during the study period, 120 gave written informed consent, and semi-structured individual face-to-face interviews based on a guide were conducted until saturation (n = 20), using a non-probability convenience sampling method, as there was no exhaustive primary list of these patients. The inclusion criteria were: type 1 diabetes, aged 8–18 years, diagnosed with T1DM for at least 6 months, able to understand and speak Arabic language and giving written informed consent. Were excluded: type 2 diabetes, age–8 years, significant inability to verbal communication and comorbidity.

Data collection tools and technique

As required by qualitative studies, data collection continued until data saturation and redundancy, Children and adolescents with T1DM (n = 20) meeting the inclusion criteria were recruited in January–February 2022, during their appointments for consultation in the hospital’s pediatric department. The interviews lasted about 25–35 min each to allow participants to express in their own words their experiences with the disease and their expectations. Besides the questions describing the socio-demographic characteristics of the participants, the guide open-ended questions, based on the literature review, were formulated, including the main ones and the follow-up questions to stimulate the participants’ answers. As each interview was conducted, the data were transcribed as required. Indeed, verbal data transcription is the key interpretative phase of data analysis and a way to familiarize with and create meanings.^[18]

Data analysis

Except for the socio-demographic data of the participants, entered and analyzed on IBM SPSS Statistics 25, all

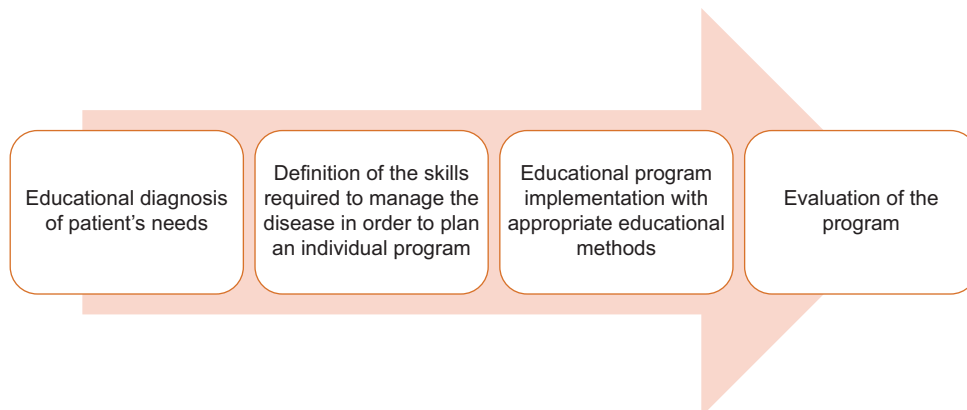


Figure 1: Education process of TPE model^[13,14]

the qualitative data were analyzed manually. Data processing and analysis were carried out according to the principles of the reflexive approach of thematic analysis by Braun and Clarke (2006). It is a six-phase iterative thematic analysis process. After reading and re-reading the transcriptions to become familiar with the content of the data, it was necessary to do a systematic coding during which the elements of interest and significant parts of the data were marked with initial labels/codes (a few words or a short sentence). Then, the defined codes were combined into categories to form themes and sub-themes. These themes were reviewed and revised suited to the data relevant to the research question. The definition of the essence of the themes and the connection between them resulted in a better understanding of the dimensions composing the educational needs of T1DM children and adolescents. The themes considered have been put in a table for an overview.

Ethical considerations

The participants in this study were recruited after receiving oral and written information about the study. Formal written consent was obtained from their parents and carers, as the participants are minors. In addition, ethical approval was obtained from the University Hospital Ethics Committee of Sidi Mohamed Ben Abdellah Fez University (Protocol code: 14/22, date of approval: January 2022). Researchers ensured that the internationally recognized ethical principles for research involving human subjects were respected throughout this research, and all methods were carried out per relevant guidelines and regulations.

Trustworthiness

To ensure the authenticity of the themes developed in this study and to establish their credibility, the researchers engaged in the data check and agreed on the results.

Results

Twenty children and adolescents participated in a diagnosis of their educational needs in January–February 2022. Their main socio-demographic characteristics are presented in Table 1. 0.8% of them are not educated at school because of related disease troubles. All the participants follow an insulin therapy regimen with two injections (morning and evening).

Following the qualitative data processing and thematic analysis principles by Braun and Clarke (2006), five themes emerged [Table 2].

Theme 1: Knowledge about T1DM and its risk of complications

The interviews showed that children and adolescents with T1DM have little knowledge about T1DM and

Table 1: Participants' sociodemographic characteristics (n=20)

	Percentage	Mean (\pm SD)
Age (years)		11.83 (\pm 2.42)
Years with T1DM		4.28 (\pm 3.11)
Sex		
Male	47,5	
Female	52,5	
Urban/Rural area		
Urban area	90,0	
Rural area	10,0	
Study level		
Primary school	63,3	
Secondary school	35,8	
Not educated	0,8	

In this table, categorical variables are expressed in percent (%) and continuous variables in mean (standard deviation)

Table 2: Themes emerging from a thematic analysis of the content of semi-structured interviews with children and adolescents with T1DM

Themes
Knowledge about T1D and its risk of complications
Measures and attitudes for disease surveillance and therapy management
Crisis and short-term complications management
Diet and physical activity management
Adaptation to the stresses of living with the disease and the treatment

its complications. Indeed, most of them had difficulty defining the disease, its type, its causes, its difference from other types, etc., Thus, a good part of the interviewees believes that the disease is caused mainly by the excessive consumption of sweets or being terrified or traumatized during an incident, without being able to identify the type of diabetes from which they suffer.

“I used to eat a lot of sweets at home and school, that’s why I had this diabetes”

“Mum said that I was in shock watching grandfather dying.that’s the real cause of my diabetes”

Regarding T1DM complications (ketoacidosis and hypoglycemia), several participants acknowledge that they can have them and mention some organs that can be altered in the long term without being able to explain how. On the other hand, the majority recognizes that these complications are avoidable if one takes care of one’s diet and physical activity, without insisting on the role of monitoring and insulin therapy for the prevention of complications.

Theme 2: Measures and attitudes for disease surveillance and therapy management

Regarding blood glucose monitoring, most participants regularly use a blood glucose reader despite the inconveniences of the method such as the cost burden

and the generated pain. Accordingly, some excerpts confirm these statements:

“I’m tired of pricking my fingers every time”

“We don’t always have money to buy reader strips”

Additionally, few participants could identify their glycemic goals. For urinary monitoring, none of the participants has ever used urine strips at home to look for glycosuria and ketonuria.

As far as insulin therapy is concerned, the main means of injecting insulin used by the children and teenagers participating in the study is the syringe. Most of them don’t know the names of the insulins used, nor their action mechanisms, distinguishing them only based on their appearance:

“I use two types of insulin: one yellow with a clear appearance and the other cloudy-looking green”

Furthermore, many of these children and teenagers report that they do not prefer to self-inject insulin, either due to a lack of manual dexterity or fear of pain. The knowledge of most children must be consolidated because they don’t pay attention to some steps in injecting insulin and the importance of respecting the cycle rotation of injection sites. The statements in favor of this were:

“We don’t always have alcohol at home, so I often do without it to inject myself with insulin”

“to fill the syringe, sometimes I start with the green bottle, sometimes with the yellow one”

“I always inject it in the armas soon as I inject the insulin, I remove the syringe”

Theme 3: Crisis and short-term complications management

As for hypoglycemia, most of the participants could detect the signs, without being able to identify the exact blood sugar values associated with it. Similarly, most of them were unaware of the exact quantities and nature of foods to eat when they noticed the signs of hypoglycemia and when to do it and do it again. Accordingly, the following statements were reported by the participant:

“I took a tablespoon of caster sugar in a glass of water and measured my blood sugar immediately, if it was still low, I took more”

“My mother gave me 2 or 3 dates and even when the signs of hypoglycemia persisted, she refused to give me anymore because she was afraid that I was going to have hyperglycemia”

“When that happens to me, mum gives me a piece of bread, but we have to admit that it doesn’t help me much”

In the consciousness loss case, none of the interviewees mentioned the injection of glucagon, when the child

is no longer conscious; he is brought back to the emergency.

For the clinical signs indicating hyperglycemia, most of the participants only knew polyuria and polydipsia; and in connection with ketoacidosis, almost all of them didn’t recognize the main clinical signs (acetone breath, abdominal pain, ample, and rapid polypnea, etc.) and do not know that their presence must lead them to carry out an emergency urinary examination.

Theme 4: Diet and physical activity management

Regarding diet, almost all of the interviewees felt the need to deepen their knowledge of the types and quantities of food to eat. Thus, most of them could not identify foods containing proteins or lipids; even if they recognize those with glucose content. For the main meals, many participants admit eating the same meals prepared for the whole family, but in a smaller quantity. In addition, some of them admit that sometimes they cannot help taking sweets. Regarding snacks, most of the interviewees take them, particularly in the morning and afternoon snacks.

In connection with physical activity, most participants don’t do it regularly and think that it is necessary to do it as much as possible to lower blood sugar, without being aware that this can cause hypoglycemia, which can be fatal. None of them mentioned the need to consume some foods before physical activity to prevent hypoglycemia during exercise or late at night.

Theme 5: Adaptation to the stresses of living with the disease and the treatment

Some participants expressed their discomfort at being different from their peers in good health, which leads some of them not to communicate their illnesses to others:

“I would not like my classmates to know that I am diabetic”

Managing their disease requires regular self-monitoring, daily injections, and careful attention to suitable nutrition. Often, they feel some bitterness in this:

“My classmates eat lots of sweets and biscuits at recess, while for me it’s always an apple or a piece of bread with cheese”

“It’s unfair to deprive me of birthdays on the pretext that they are going to serve cakes and sweets”

“I would love to eat whatever I want!”

“Even on vacation, I’m not allowed to have a lie-in, isn’t that maddening?”

“Mom wakes me up at 8 am for my insulin injection, even on vacation!”

Similarly, some participants mentioned their adapting difficulties to scheduled activities at school, which affects their academic performance:

“When I have class early in the morning, I inject myself with insulin, but I can’t swallow anything, I then take my breakfast with me to school, but sometimes I have hypoglycemia before recess”

Discussion

The purpose of this study was to identify the educational needs of children and adolescents with T1DM to be exploited for the implementation of a personalized TPE program allowing them to better manage their disease. To achieve this objective, semi-structured face-to-face qualitative interviews were conducted on 20 children and adolescents with T1DM. The results obtained revolve around five themes emerging from the thematic analysis of the interviews conducted.

The data revealed a lack of knowledge among children and adolescents with T1DM about the disease and its complications, but also the lack of skills to manage them properly. Of note, T1DM is a complex disease requiring the child/adolescent (and his parents) to implement, daily and throughout life, complex actions of different dimensions.^[19] Thus, therapeutic education, not to be confused with information, would allow the patient and his entourage to acquire the skills needed for an optimal life with a disease and its treatment.^[3,20]

Moreover, in terms of measures and attitudes for disease monitoring and therapy management, although it is easy to inject insulin, it must be done according to a rigorous technique, with compliance with the rotation of injection sites to prevent lipohypertrophy.^[21] Furthermore, for good monitoring of diabetes, measuring blood sugar and looking for glycosuria and urinary or blood ketone bodies are fundamental and must be carried out regularly with perfect techniques.^[22]

Similarly, this study reveals that the greatest challenge for participants and their families is the management of their diet in terms of quantity and quality, and meal times. This agrees with Palmer *et al.* (2022),^[23] Lu *et al.* (2020),^[24] Baharvand and Hormozi (2019),^[25] Haugvik *et al.* (2017),^[26] and Colson *et al.* (2016)^[27] studies results. It is well documented that a diabetic child has the same nutritional intake needed for normal growth and development as a healthy child. However, they must be coordinated with the insulin therapy regimen and the level of physical activity.^[28] This could deprive them of the flexibility and variability of food intake characterizing a normal child,^[22] which can lead to poor adherence to eating behaviors and macronutrient and dietary recommendations.^[29] Caregivers also must be sensitive to the experiences of the child who perceives changes in blood sugar after the ingestion of some foods, to be able to adjust his diet.^[30] Physical

activity should be encouraged in diabetic children, but with an appropriate plan, reducing the insulin dose by 10% or increasing the intake of carbohydrates, to prevent hypoglycemia, which is one of its major complications.^[21,31]

On the other hand, the results showed the non-adaptation of some children and adolescents to the disease constraints, particularly regarding their schooling. This is congruent with some previous studies by Palmer *et al.* (2022), Sparapani *et al.* (2017),^[32] Jackson *et al.* (2015),^[33] Sparapani *et al.* (2015), and Meillet *et al.* (2014).^[34] These studies have shown the conflicts experienced by T1DM children between the need to live like a normal child or adolescent and the difficulties encountered in respecting their diet in correlation with insulin injections. Besides, there is also a lack of understanding from their peers and their teachers about the disease demands, which can affect their disease management and their academic results.

In summary, T1DM imposes on the child physiological and psychological changes and challenges that he faces throughout his life.^[35] Indeed, the need to deal with the feeling of difference, blood glucose monitoring, insulin therapy, food restrictions and the limitation of some activities generates contradictory desires in the child which can lead to feelings of sadness, irritation, insecurity, and fear.^[36]

The data of this study were used to plan a personalized educational program and define the skills that best meet the educational needs of children and adolescents with T1DM and their expectations [Table 3]. Those skills revolve around two main categories namely self-care and adaptation.^[14] They constitute the educational objectives of an educational program according to the educational contract established by D’Ivernois and Gagnayre (2008) for T1DM patients. This educational program has been implemented and its impact will be the subject of another research article.

Table 3: Skills meeting educational needs of children and adolescents with T1DM, Fez, Morocco

Skills	Educational objectives
Being able to explain his diabetes	Explain the pathophysiology of type 1 diabetes Explain T1D self-monitoring measures Explain how to take treatment
Being able to react in a crisis	Know how to detect hypo and hyperglycemia Manage a hypo and hyperglycemia crisis
Be able to adapt his diet to the treatment constraints	Explain the principles of a diet for T1D
Being able to express his emotions and his experience with the disease	Expressing his troubles and difficulties in connection with T1D

Limitations and future research directions

The main limitation of this study is related to its qualitative nature which makes it impossible to seek correlations between the characteristics of the participants (gender, age, environment, duration of the illness, etc.) with some needs identified through the interviews. Likewise, some comments of the participants may be biased by their desire to please the researcher. For a better understanding of the educational needs of children and adolescents with T1D, future research must focus on the factors that can influence these needs.

Conclusion

This study showed the importance of letting T1DM children and adolescents express their needs, if unfulfilled, patients may refuse monitoring requirements and therapeutic constraints or present psychological difficulties. Thus, the success of a TPE program is conditioned by a good educational diagnosis leading to the definition of the skills to be developed in correlation with the identified educational needs and with the socio-economic factors of the population concerned. Hence, the health policy in Morocco should integrate the TPE approach systematically into T1DM patients' care.

Abbreviations

- T1DM Type 1 Diabète Mellitus
- TPE Therapeutic patient education.

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Conflicts of interest

There are no conflicts of interest.

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