

## Research Article

# The Perspective of Young Adolescents with Diabetes about Caregivers' Role in Breaking the News of their Diagnosis

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**Abstract**

**Background:** Breaking bad news of a chronic disease that imposes limitations on lifestyle, such as diabetes, is a difficult task, even when the recipient is an adult, more so when the recipient is a youth.

**Objectives:** To identify the caregivers' role in delivering the diagnosis of diabetes, from the perspective of young adolescents diagnosed with diabetes.

**Method:** The study included 63 young adolescents diagnosed with Type I diabetes. Average age was 12.2 years. Patients filled out a 32 items questionnaire addressing three main subjects: who should deliver the diagnosis, what information should be presented, and what should be the supportive patterns used by the caregivers. The internal reliability of the questionnaire was  $\alpha = 0.67 - 0.85$ .

**Results:** Young adolescents are primarily interested to know what they are allowed to eat, what treatment will they be given, why do they have diabetes, if the illness will pass away, who will help them cope with the illness and how will it affect their future. It was found that the most suitable subjects to deliver the diagnosis according to the young adolescent's opinion were the doctor, the mother, and a medical clown. Amongst the communication characteristics defined by them as most important were: telling the truth, clear language free from vague statements, and the use of normalization and guilt removal statements.

**Conclusions:** Support administered to young adolescents with diabetes, which is focused on the concept that the illness does not prevent the continuation of normal life, may ease emotional distress and contribute to the acceptance of the illness, resulting with good compliance.

**INTRODUCTION**

Delivering the diagnosis of a chronic disease that imposes limitations on lifestyle, such as diabetes, is a difficult task, even when the recipient is an adult, more so when the recipient is an adolescents.

Diabetes is one of the most common metabolic disorders in children and adolescents. This work focuses on the type 1 diabetes (T1D), which constitutes two thirds of the diabetes cases amongst children and adolescents, demonstrating a prevalence of one per 700-1,000 children [1]. The disease is characterized by a sharp decrease in insulin secretion, resulting from autoimmune destruction of the pancreatic beta cells [1,2].

Adolescence is a developmental stage between childhood and maturity, defined by the World Health Organization as the period of life between 10–19 years of age [3]. This life stage is characterized, more than any other stage in life, by physical, mental and social changes. During this period, the need for privacy, autonomy and social acceptance develops and long term patterns of health behavior are established [4,5].

The peak for T1D diagnosis among adolescences is between 10 and 14 years of age, meaning that the early years of adolescence are the most vulnerable for developing the disease [6]. It is well known that a chronic disease in adolescence adds an extra burden on this developmental stage, which is already accompanied by

strong feelings of emotional storms. Thus, these circumstances are characterized by low self-esteem, social isolation, and exhibition of risky behavior. Indeed, in series of studies a high rate of risky behaviors, such as: smoking, drinking and use of drugs was found amongst adolescents who suffered from various chronic diseases, in comparison to healthy adolescents [7-9].

The presence of diabetes and the need for the disease to be chronically treated, threaten the routine of the adolescents' life, and make it more difficult for them to cope with both the constant demands of the disease as well as with the developmental tasks of this stage [10-13]. The desire of the adolescents for autonomy and independency may be expressed by a preference of social relationships over keeping up the treatment regimen related to the illness [10-13]. As a result, adolescences with diabetes tend to exhibit low levels of compliance, resulting with a decline of the metabolic control [14,15].

Many reports suggest that the way in which diagnosis or any related bad news are delivered affects the patient's functioning and decision making. When unfamiliar medical terms are being used and the information is vague or burdensome, the patient tends to feel confused, anxious, and even angry. Thus, an appropriate planning of breaking bad news, helps the patient to deal with the new circumstances [16,17].

In the last years, some series of guidelines for breaking bad news, most of them related to adults concerning cancer or death notification, have been published [18-22]. The guidelines reflect a principal approach, manifested by a similarity of their commended steps and actions to be taken, including preparation for the delivery of the notification, meaning: to locate an appropriate place in which the conversation will be held, as well as to find out what the patient already knows and what he wants to know. The actual act of breaking the news should begin with an introductory statement of the bad news, than a gradual delivery of the relevant information, while ascertaining what was understood by the patient. The next step should include embracement of the patient's feelings and answering questions, followed by introduction of the next actions to be taken and closing the meeting [22,23].

The issue of bad news breaking in the pediatric population area is almost neglected, There is a growing need for reliable information concerning guidelines for breaking bad news to children and young adolescents (ages 10 to 14) regarding the diagnosis of an illness [24-26]. It is very important to take into consideration that when dealing with the pediatric/adolescences population the parents and the patients should be referred as one unit [10,27]. In most of the cases, the information supplied by the medical team is directed to the parents and not to the children, in spite the fact that the children have the right to receive information and to be involved in the decision making process, which might have an impact on their health and life [9].

Based on the above, the aim of the study was to assess the caregivers' role in delivering the diagnosis of T1D to young adolescents, from the perspective of the patients.

The research questions:

1) Who should deliver the diagnosis?

2) What and how the information should be delivered?

3) What should be the supportive patterns used by the caregivers (verbal and nonverbal).

## METHOD

### Participants

This was a survey study that included 63 young adolescents diagnosed with T1D, 52.8% were male and 47.2% were female. The average age was,  $\pm 12.214$ , ranging between 10-14 years. The average age for the diagnosis of the illness was  $3.5 \pm 9.7$  years, with no significant differences between the genders.

### Procedure

Following the approval of the study by the institutional ethical committee, the parents and the young adolescents were approached by a nurse from the study team during their routine visits at the pediatric diabetes clinic at the as affHarofe medical center. The aims of the study were explained, and it was clarified that the data collection was intended for research purposes only and that the privacy and the anonymity of the young adolescents will be fully respected. Upon the receipt of assigned informed consent from the parents and the children's' agreement to participate in the study, a self-fill-out questionnaire was distributed to the patients. Upon completion, the questionnaire was put in an envelope and collected by the researchers.

### Research tools

The questionnaire contained 32 items and was designed based on literature review and professional experience in the field. The questionnaire started by collecting demographic variables, such as: age, gender, and the time period since the diagnosis. Following this section, three issues were addressed: 1) who, to their opinion should be the one to deliver the diagnosis and who actually told them about it; 2) What information should be given, to their opinion, regarding the disease. In order to answer this section, a content index was constructed, including 14 common used statements with an internal reliability level of  $\alpha = 0.677$ , graded on a scale ranging from 1 (not important) to 5 (very important). 3) The last issue examined in the questionnaire was focused on the desired supportive patterns to be used by the caregivers (verbal and nonverbal). This part included 16 statements that were to be evaluated on a scale ranging from 1 (not helpful) to 5 (very helpful). Two indexes were built for this part: normalization index based on the average of 6 statements (internal reliability level  $\alpha = 0.732$ ), and encouragement index based on the average of 10 statements (internal reliability level  $\alpha = 0.851$ ).

Content validation of the questionnaire was conducted by the scientist who performed the questionnaire analysis, two pediatric-specialist nurses, and one pediatric endocrinologist. This team examined the tool's compatibility to the research questions, and decided together on classifying the items, according to their respective content categories and expertise. The items of the questionnaire were also validated using a statically factor analysis. To examine the clarity, the questionnaire was handed as a pilot to 10 young adolescents, and then adjusted according to their comments.

## Data analysis

Data analysis was carried out utilizing the SPSS 19 software using the presentation of the distribution and central tendency measure of all the items in the questionnaire. T tests and one-way ANOVA analysis were conducted to examine differences between gender and ages. In addition, a factor analysis of the items was conducted for the entire questionnaire's part.

## FINDINGS

### Who should deliver the diagnosis

Figure 1, 2 show that half of the young adolescents were told about the illness by the healthcare team (45% doctor, 4% nurse) and about one third by the mother. When they were asked who, to their opinion, is the most suitable person for telling them for the first time about the illness, only one third mentioned the doctor, as most suitable for the task, 18% mentioned the mother and 17% mentioned the medical clown (in respect to the age in the time of diagnosis).

### What information should be delivered?

Table 1 presents the information items that were introduced to the young adolescents when they were told for the first time about their diagnosis. The following information was considered by the participant as most important: what will they be allowed to eat (4.8), which treatment will they get (4.5), what is diabetes (4.5), who will help them to cope with the illness (4.5), will the illness pass away (4.4), why do they have diabetes (4.3) and how

**Table 1:** Content information index and its components. Score ranging from 1 (not important) to 5 (very important).

	Average	Std.	Max.	Min.
<b>Content index*</b>	<b>4.2</b>	<b>0.5</b>	<b>5</b>	<b>3</b>
Will the illness affect my activities with my friends	3.6	1.4	5	1
What am I allowed to eat	4.8	0.6	5	2
Will the illness pass away	4.4	0.9	5	2
How will I be different from other	3.7	1.4	5	1
How will the illness influence my future life	4.1	1.1	5	1
What treatment will I get (injections, medication, sticking)	4.5	0.9	5	1
What will be difficult for me to do due to the illness	4.0	1.1	5	1
Why do I have diabetes	4.3	1.1	5	1
What is diabetes	4.5	0.9	5	2
Will the illness impact on my looks	3.4	1.5	5	1
Who will help me cope with the illness	4.5	0.6	5	3
The team uses a clear language and explains to you the information given	4.8	0.5	5	3
The team answers all my questions	4.7	0.7	5	2
Do you have any other concerns now	3.3	1.3	5	1

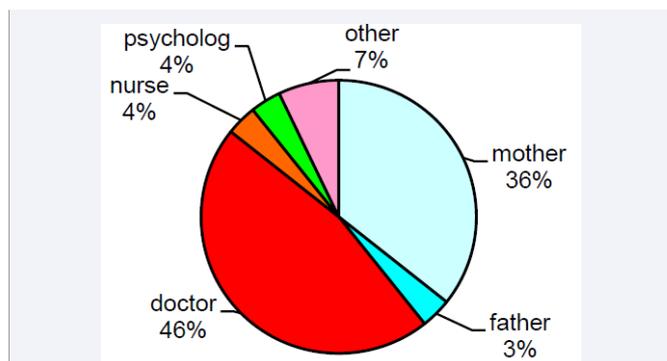
\*The contents index is based on the average of 14 statements (internal reliability index  $\alpha=0.677$  )

will the illness influence their life in the future (4.1). In addition, the participants gave high scores for the statement declaring that the team used a clear language, explained the information that was introduced to them (4.8) and answered all their questions. Statements such as: "you went through many tests, what do you think you have" (2.8), or "I am afraid the test results were not as good as expected" (2.4), were graded with low scores.

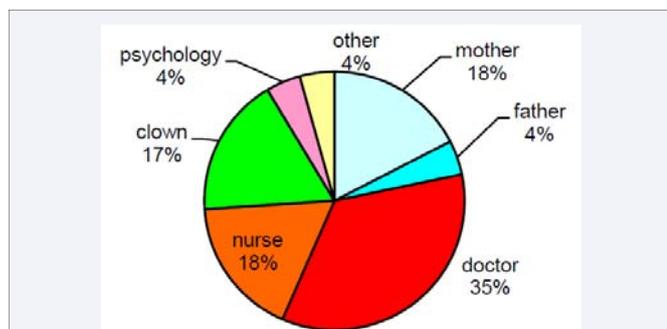
What should be the supportive patterns used by the caregivers (verbal and nonverbal)

As described in table 2, the young adolescents found that the following statements somehow normalize their condition, therefore they defined them as very important when delivering the diagnosis: "Your life doesn't have to change" (4.4); and "A treatment might be found that will cure your condition"(4.5). Additional statements that were graded with high scores referred to the removal of guilt and responsibility for the situation, such as: "You are not guilty for the illness" (4.1), and "It didn't happen because you eat sweets" (3.9). On the other hand, it was less important to the participant to be told that: "Everything will be OK", or that "Many other adolescents live with the illness", as was demonstrated by the low scores given to those statements (3.7 and 3.6 respectively).

Table 3 presents the items perceived by the subjects as encouraging and supportive: addressing them by their first name (4.2), showing appreciation for their courage (4), understanding their feelings (4.0), as well as hugging and patting (3.8). On the other hand, statements ranked as less helpful for coping were: "I see that you are angry/ I hear that you are afraid of the illness/ I am sure this is very difficult for you/ I am very sorry" (2.5 – 2.7). The statement perceived by them as the least encouraging was:



**Figure 1** Type of healthcare team who delivered the diabetes diagnosis notification to the young adolescents (%).



**Figure 2** Type of healthcare team most suitable to deliver the diabetes diagnosis notification according to the young adolescents opinion (%).

**Table 2:** Normalization and guilt removal index.

Score ranging from 1 (not helpful) to 5 (very helpful).

	Average	Std. deviation	Max.	Min.
<b>Normalization index*</b>	<b>4.1</b>	<b>9.</b>	<b>5</b>	<b>1.5</b>
Your life doesn't have to change	4.4	1.0	5	1
A treatment might be found that will cure your condition	4.5	1.0	5	1
Everything will be OK	3.7	1.3	5	1
Many adolescents live with this condition	3.6	1.5	5	1
The illness is not your guilt	4.1	1.2	5	1
It is not because you ate sweets	3.9	1.3	5	1

\*The contents index is based on the average of 6 statements (internal reliability index  $\alpha=0.732$ )**Table 3:** Encouragement index and its components.

Score ranging from 1 (not helpful) to 5 (very helpful).

	Average	Std.	Max.	Min.
<b>Encouragement index*</b>	<b>3.4</b>	<b>0.8</b>	<b>4.9</b>	<b>1.4</b>
I admire your courage	4.0	1.2	5	1
I understand your feelings	3.6	1.5	5	1
I see that you are angry	2.6	1.6	5	1
I see that you are afraid of the illness	2.6	1.5	5	1
It is probably very hard for you	2.7	1.3	5	1
there are hard times ahead for you	1.6	1.1	4	1
Do you have any other concerns now	3.3	1.3	5	1
I am really sorry	2.5	1.6	5	1
The team addresses you by your first name	4.2	1.2	5	1
The team hugs/ caresses you	3.8	1.4	5	1

\*The encouragement index is based on the average of 10 statements (internal reliability index  $\alpha=0.851$ )

"There are hard times ahead for you" (1.6).

No significant differences were found between the different gender and age groups regarding who should deliver the bad news, what information should be given and the supportive patterns.

## DISCUSSION

The present study addressed the issue of breaking the diabetes diagnosis to young adolescents, from the perspective of the patients. According to current declarations of patient's rights, a child has the legal and moral rights to receive accurate and reliable information. As with the adult population, it is the professional team's responsibility to introduce to the patient the accurate diagnosis and its consequences, in a clear language, while ascertaining that the patient understands the information [28,29]. Furthermore, children and adolescents have the right to be involved in the decision-making process regarding their health; therefore the communication must be appropriate to their stage of development and level of understanding. Unfortunately, in most cases the communication is directed to the parents over the head of the children [9].

Usually, family members expect the informer to be a physician [16,17,30-32]. It is highly recommended that the news about the diagnosis should be delivered by a person that is close

to the young adolescents, is authoritative and makes them feel safe. Since they are dependent on the support of their parents in coping with the illness, the preferable choice for delivering the news should be the physician accompanied by one of the [5,31].

The findings show that the three most suitable individuals the participant pointed out that should deliver the diagnosis were the physician, the mother and a medical clown.

The common opinion is that in order to accurately support the patient, a multidisciplinary team must participate in the process of breaking the bad news. It is preferable that the healthcare professional that is going to accompany the patient during the disease management over the years should participate in this mission. It seems that nurses are most suitable for this task, since they establish a long term treatment relationship with the patients. Nurses are able to interpret and translate the information for the child and the parents, thereby playing an important role in offering help and support. Therefore, it is suggested that nurses should participate in the notification meeting so that they will be updated with the meeting context [20,31,33].

Adolescents tend to attribute a higher importance to the characteristics rather than to the roll of the informer. The high importance that was demonstrated by the participants in the current study to the presence of the medical clown during the notification process supports this notion. The clowns represent

a different type of figure in the frame of the hospital milieu that offers a possibility to create an un-usual kind of relationship. The clowns are able to establish an alternative communication with the children, which is adapted to the specific needs of the child, and refers to the age, physical disabilities, and mood preferences for playing and to the people around him. This kind of communication empowers the children, and connects them to the reality of the external normal, healthy world, thereby helping them to cope with the illness and all that is involved with [34].

Amongst the communication characteristics rated as most important by the young adolescents that participated in the study were: telling the truth and the use of a clear language. It is generally agreed that a clear language is a vital component in the process of breaking the news about the diagnosis. The information and the clarifications must be administered in a simple and clear language, for both the child and the parents, and the professional terms must be ascertained that they were fully understood [18,35,36].

A unique aspect that characterizes the notification of the diagnosis to children and adolescents is that they might need more or a different kind of information than their parents. This is based on the perception that children are less available to cope with bad news and on the desire of the professional staff to protect them from bad news. However, the diagnosis and its consequences will eventually reach them and they will be willing to cope with it much more effectively when the real facts are presented to them, together the appropriate support. Illusions and un-real facts could result with loss of their confidence in the parents and the caregivers, leading to cooperation refusal [31,37].

The study participants found much comfort in normalization statements, as well as in guilt and responsibility removal statements. In children and adolescents with diabetes, positive coping strategies which are focused on the concept that the illness does not interfere with their normal life, the use of humor and normalization of the situation may decrease the levels of frustration and despair. This could ease their emotional distress, enable them to accept the illness and the need for treatment, there by contributing to better medical results [2,13].

The participants in the current study stated that emotionally supporting actions were considered by them as helpful in coping with the diagnosis. The use of first names was interpreted by them as a special attitude of the professional staff towards them, pointing out that they are important, special, and are treated with respect [18,25].

There is no general consent in the literature regarding the importance of a touch in comforting the recipients of bad news. Some consider this as a vital component of the relationship the caregivers establish with the news recipients, while others claim that this component is commonly used for consoling children, but is not welcomed by adults in distress [26,18]. Although understanding the meaning of the diagnosis depends on the age of the child, the anxiety that arises up on diagnosis notification is common to children and adolescents, independent of their age. When the notifier offers an emotionally supporting environment, the anxiety does not disappear, but the subjects feel that they

received the support they needed to cope with it. Therefore, mental and physical closeness while breaking the news inspire the adolescents with a sense of trust and safety.

To sum up, in light of the findings in the current study it is recommended that:

- The diagnosis should be delivered to the young adolescents in a clear language, free from medical terms, and without vague statements.
- The main information that must be delivered should include: explanations about diabetes and its causes, dietary restrictions, treatments modalities and schedules, who will help them to cope with the illness and how will the illness affect their future. In addition, it is very important for them to know if the illness will pass away some day. The young adolescents should be encouraged to ask questions and require as much information as they want. Nevertheless, the necessary information should be provided with attention and caution so that it will not overburden or elaborate the patients.
- The verbal communication should be based on encouraging statements, which normalize their condition, as well as removal of guilt and responsibility for the situation. Accordingly, avoiding the use of statements that try to encourage in a negative approach is suggested.
- The notifier should stick to the truth, while providing emotional support and legitimization to the whole range of feelings that might arise, including: anger, anxiety, or sadness.
- It is recommended to address the adolescent by the first name in order to create closeness.
- A multidisciplinary approach could promote support for the adolescent and parents.
- Finally the pediatric nurse should play an important role in the process of delivering the news to the young adolescents and parents. Additionally, in order to be able to offer the suitable support, nurses have to be aware about the possible responses that might be displayed by the young adolescents upon the notification on the cognitive, behavioral and emotional levels.

Taken together, this study was focused on the process of delivering the diabetes diagnosis from young adolescents' perspective. It might be suggested that the findings as well as the concluding remarks of the current study could serves as a base for designing guidelines to break news to young adolescents on the diagnosis of diabetes in particular, and as well as on other chronic diseases

This study has several limitations: the group sample is small and was enrolled at one medical center. Among the age range of children and adolescents only a group of young adolescents (ages between 10-14) was examined. Therefore, it is recommended that future studies in the field should broaden the range of the participants and their ages.

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