

# Young Adults Living with Type 1 Diabetes Experience of Other Persons Reception

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**Abstract:** The aim of this study was to describe how young adults with type 1 diabetes experience other persons reception. Living with a long-term illness such as type 1 diabetes influences daily life for young adults and their close relatives to a great extent. In order to live and manage daily life with a long-term illness, support is important and crucial. The study has a qualitative design. A purposive sample of twelve young adults (eight women and four men) with type 1 diabetes were interviewed. The interviews were analysed using a qualitative thematic content analysis. Young adults with type 1 diabetes experience both support and being discredited when meeting others. They emphasise the support they receive from parents, co-habitants and young adults in a similar situation. This entails feelings of a natural understanding and not being alone. In contrast, young adults with type 1 diabetes also experience being misunderstood and the problematic situation that relates to a lack of knowledge from people around them and healthcare personnel. This entails feelings of not being confident when meeting others and healthcare personnel. This study highlights the need for support and understanding amongst young adults with type 1 diabetes and their families from first and foremost the healthcare services. Society and healthcare services need more knowledge about type 1 diabetes so young adults with type 1 diabetes can receive support and care matching their needs. This is important for strengthening their health and well-being.

**Keywords:** Nursing, Other Persons, Qualitative Thematic Content Analysis, Reception, Type 1 Diabetes, Young Adults

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## 1. Introduction

This study is part of a larger research project focusing on living with type 1 diabetes (T1D), from the perspective of young adults. Diabetes is currently one of the largest global health problems. Its yearly incidence, appears to be rising steadily by about 3 percent in high income countries [1-2]. In Sweden, there were approximately 45,000 adults with T1D registered in the year 2017; of these, about 10,000 were young adults [3]. This study emphasises the experience of young adults with T1D when they enter the presence of a social group.

Young adults and their close relatives experience T1D as an always-present actuator in daily life. Despite this, young adults try to live as normally as possible with the illness [4]. Abdoli et al. [5] stated that young adults with T1D struggle to grow and take on more responsibility of diabetes management. Earlier studies [6-8] have shown that managing daily life with a long-term illness increases the importance of

support from family, friends and healthcare personnel. It has also been shown that people with long-term illnesses often encounter others with a lack of knowledge about their individual needs [6-8], which in turn can lead to a loss of self-esteem [9] and feeling deeply discouraged [8]. On the other hand, being recognised by others most likely can help those with a long-term illness to feel well despite their limitations [9-11]. People living with long-term illnesses who have support from family and professionals manage to seek alternative options to the emotional losses in their daily life compared to people who lack such support [12].

Becoming an adult can be a perplexing developmental step; and when you add to that living with a long-term illness such as T1D, it might result in even more challenges [13-16]. The period between youth and adulthood is fluid [17]. Normally, young adulthood is characterized by gradual separation from parental support, adaption to adult roles and leaving the parental home [18]. Research [19-21] has shown how people

with long-term illnesses who are met and received openly and warmly by others obtain positive reinforcement that is beneficial for their health and well-being.

Striving for as normal as possible blood glucose levels is the main goal for T1D management and daily life. The blood glucose levels are in turn affected by external mechanisms such as feelings of being supported, stress or anxiety [22-23]. Thus, a review of the literature implies that young adults with T1D frequently experience being received in their surroundings by people with a lack of awareness of their condition. Increased knowledge in the society would provide more opportunities to support young adults with T1D in line with their needs so that they feel confirmed and more comfortable when meeting with others.

#### *The study*

The aim of this study was to describe the experiences of young adults with T1D when they are met and received by others.

## **2. Methods**

### **2.1. Design**

This study is part of a large research project focusing on living with type 1 diabetes (T1D) from the perspective of young adults. The method is based on the aim of this study, to describe the experiences of young adults with T1D and thus a qualitative design was used. In order to achieve this aim, personal interviews were performed with the participants. The interviews were analysed with a qualitative thematic content analysis [24].

### **2.2. Participants and Procedure**

A purposive sample of twelve young adults (eight women and four men) with T1D participated in the study. They were aged between 19 and 30 years (md=23). The participants had been aged between 3 and 14 years (md=9.5) when diagnosed and had lived with the illness for 3 to 14 years (md=14). Eight of the participants were cohabiting and four were single. Eight had a high school educational level and four had a university education.

Criteria for participation were a diagnosis of T1D, age between 18 and 30 years, and speaking and understanding the Swedish language. The participants were recruited from a hospital in the middle of Sweden. A diabetic nurse at the hospital sent out invitation letters with preposted answering letters to potential participants. The young adults that were interested in participating were asked to send the preposted answering letter back, and then contacted personally by phone by the first author, in order to decide which day they could meet for an interview.

### **2.3. Interviews**

One-to-one personal interviews were conducted with young adults with T1D. The participants were asked to describe their experiences of being received and met by

others and to describe a good and a less than good encounter. When needed, clarifying questions were asked, such as 'What happened next?' and 'Can you give an example?' The interviews lasted between 40 and 70 minutes (md=44), and were audio-recorded and transcribed verbatim. The place for the interview was in agreement with the participant's choice. Two interviews took place in the participant's home and ten in a quiet room at the researchers' workplace. The interviews were conducted between 30 May and 22 June 2017.

### **2.4. Data Analysis**

The interview texts were subjected to qualitative thematic content analysis [24]. Thematic content analysis can be explained as identifying, coding and categorizing primary data in order to provide knowledge and understanding of the topic under study [24-25]. The analysis started by reading the transcribed interviews several times to get a sense of the content by forming an overall impression of the young adults' outlook towards living with T1D. Then, meaning units – i.e., one or several sentences related by content to the aim of the study – were identified. The meaning units were then condensed and sorted into categories of units related to each other. The categories were organized into four themes based on similarities and differences in content [24]. The first author performed the analysis which was then checked by the second author, and the agreement was almost complete.

### **2.5. Ethics**

All participants were informed about the nature of the study and were guaranteed confidentiality and the anonymity of the findings. Written informed consent was obtained from each participant. Furthermore, the participants were informed that they could withdraw from the study without offering any explanation. The study was performed in accordance with the Helsinki Declaration (2013). Ethical approval was obtained from the Regional Ethics Review Board, Umeå, Sweden (DNR 2017/79-31M).

### **2.6. Rigour**

Trustworthiness concerning qualitative research is more about the quality of the interviews than the quantity. According to Sandelowski [26], the sample size should be big enough to achieve variation of experiences and small enough to permit a deep analysis of data. In this study, the participants were chosen by purposive sampling, that is, the participants were selected with the knowledge of their youth and daily life with T1D. The number of participants should hold adequate information power to develop new knowledge referring to the aim of the study [27]. Thus, twelve interviews were judged to be enough as they were rich in information related to the aim of the study. In the Findings, referenced quotations from the interviews were used to help the reader to establish the trustworthiness of the study [28]. Both authors independently coded the interview texts and differences were discussed until consensus was reached.

### 3. Results

The analysis resulted in the following four themes: Getting help and support from others, The significance of meeting people in the same situation and being recognized, Society and healthcare staff lacking knowledge in T1D and Meeting the misunderstanding and lack of understanding of others. The themes are presented below and are illustrated with referenced quotations from the interviews.

#### 3.1. Getting Help and Support from Others

The young adults with T1D described most of the other people in their lives as directly involved in their daily care, such as taking their blood glucose level, managing their glucose monitoring systems and insulin pumps or giving insulin injections. Highly involved significant people others were described as giving invaluable support, functioning under a kind of security agreement. One young adult expressed the support in this way:

My partner is fantastic, he wants to learn everything and he wants to join every meeting and everything...he has even asked if he can try one of these [sensors] in order to know the feeling and he can also give me my injections and everything. (Interview 7)

Significant others providing advice, help and emotional support were described as very appreciated helpers, looking out for the person with T1D and constantly ready to proceed into action if necessary.

They [the parents] are very, very attentive and in the middle of the night they got up and scan my blood-glucose and things like that. (Interview 6)

The young adults emphasized the importance of the great support and inspiration their family – and in particular parents – had given them during their entire childhood. They described the caring actions they appreciated, such as making supportive phone calls, calling an ambulance, taking them to hospital or providing sweets or sugar in emergency situations. Young adults found it of the utmost importance that people around them understand when they need help from them. This gave them a feeling of security and protection. One young adult said:

...so, I was low...like, I mean really low and he wasn't able to shake life into me, he got contact with me but at the same time no contact and I really refused to take dextro-energy into my mouth. So, it ended up with him feeding me with honey until I came to my senses again, like...BOOM...What's happening here? Why are you feeding me? It was scary, and at the same time, it felt safe because he was there for me. (Interview 12)

Participants described that as long as they could remember their parents felt a great responsibility for their illness and well-being. Parents were involved in spreading information and knowledge, for example, at school, to friends and during spare-time activities. Some young adults with T1D described how motivated and ready they were when moving from child healthcare services to adult services:

It was like a walk in the park... adult services...it was like

more responsibilities...they don't do everything for you, but I like it, I was ready for it, I was done with the other ones. (Interview 4)

#### 3.2. The Significance of Meeting People in the Same Situation and Being Recognized

Young adults with T1D described how involvement with other persons with T1D was enriching and energizing. They found it important and fun to meet people with T1D, especially young adults. In this meeting, they realize that they are not alone with their illness and they can exchange experiences. This was expressed by a young adult in the following way:

It is fun to meet others, like... How do you handle exercise? Things like that, really a lot of fun, actually. The best part is to realize you are not alone and to talk... How do you manage?... Do the injections sting your skin, too? ...Yes, they do? That's draggy! (Interview 7)

The participants describe how every once in a while they unexpectedly meet people in the same situation. Some participants found those meetings perplexing, unknown and confusing. However, one young adult described the natural understanding and connection to other persons with T1D that can arise. One participant pictured one such occasion:

Then I saw! Oh, my God, that person looks very confused. Then I walked up to him and asked – 'Do you want some Coke? You have T1D, haven't you?' He drank the Coke in one gulp and said, 'Thank you for noticing!' ...Shit, it felt good to help a bro! (Interview 5)

The young adults explained that more anonymous ways to get in touch with other people living with T1D were through websites, web groups and different forms of social media. They mentioned that this way of communication and obtaining knowledge could lead to increased confidence and a sense of belonging for the participants. One participant explained it in these terms:

It's kind of a special form of connection to others in the same situation... I can tell things that others don't even know about and immediately get several answers that help me in that special situation... concerning injections or emotional stuff kind of... (Interview 3)

Young adults described the adult healthcare setting as a personal, nice, safe and welcoming environment. Some of the young adults expressed satisfaction with the informal, calm and friendly atmosphere that they felt was characteristic of their healthcare setting. They explained that they appreciated it when healthcare personnel recognized them and knew their name. One young adult expressed in this way:

There's an assistant nurse who recognizes me now...She knows my name and almost my date of birth by heart!... It's kind of more or less familiar... I think! (Interview 8)

#### 3.3. Society and Healthcare Staff Lacking Knowledge in T1D

Young adults with T1D emphasised that that they experienced a lack of knowledge among people they met and

sometimes even among those in the healthcare services. They described that they quite often experienced being accused of having eaten too much or having lived too unhealthily. This was expressed by one young adult in the following way:

I just hate the question, I want to scream at them right in the face... 'Did you eat a lot of sweets when you were a kid?' I mean really! Is this 2017? (Interview 10)

They described arguing with others on several occasions about whether they ate sugar or not. The young adults were in many cases surprised and concerned at the way others interfered in their eating habits or self-management. One young adult pictured a conversation with a relatively unknown woman at a party:

'No, you cannot eat the candies.'

'...Ehhh, it's pretty simple adjusting the carbs with insulin'.

'No, you cannot eat them!' the unknown woman replied. (Interview 15)

Young adults described situations when they had to defend actions and circumstances related to T1D. They pictured relatives, unknown people or co-workers sometimes trying to teach them how to exercise, eat or medicate themselves to be cured of T1D. Stabilizing a hypoglycaemia episode in public by eating or drinking at meetings or in class was described as uncomfortable and awkward. One young adult described what happened while shopping:

It was like...at the grocery store and I've felt really, really low and, like...I will have to rip open the package of dextro-energy...And someone says, 'WHAT are you doing? You cannot eat that before you pay for it!' (Interview 2)

Participants expressed having experienced such feelings of frustration and shame in other similar situations, such as at school or at work.

Then they came towards me and said, 'You will have to come with us'. I was forced into the police car and they told me to blow into the alcometer. I said 'NO, never!' At this point, I could hardly talk or tell them my name and, of course, they took me for a drunk. I managed to give them my glucose meter, and then suddenly they were like, 'Ohh...something's wrong here...' (Interview 12)

Young adults explained that they did not like the feeling of being different from others in relation to their T1D, for example, in school or at work. They described how their particular T1D operated. Some young adults with TD1 said they chose not to tell everyone about their T1D, just a few friends or a limited number of colleagues:

They are used to the fact that I can take care of myself... So we don't talk about it! They know I can handle it! And friends... eh, people don't know a bit about diabetes. That's just how it is! (Interview 5)

### ***3.4. Meeting the Misunderstanding and Lack of Understanding of Others***

Participants described how they repeatedly faced misconceptions about their illness. One common misunderstanding they described was people thinking that

there is no difference between type 1 and type 2 diabetes. Another was that there is most certainly a cure to T1D. Another misconception that they met was when people said to them, 'So you can't eat sugar?' They expressed a heightened sensitivity to these misconceptions. One young adult said:

'Eh, you cannot eat sugar!'

'Yes, I can, I can adjust with insulin'.

'No, you can't. You're not allowed they say'.

The thing is... they don't understand, and that's very, very painful. (Interview 5)

A source of irritation was how T1D was presented in the society and the media, according to the young adults. They pictured media presentations of T1D that are commonly based on tragic examples of the illness. Participants described being frustrated about the absence of positive illustrations of T1D: 'I just wish people in general knew more, like... how to handle it' (Interview 6).

Participants expressed their feeling that the absence of comprehension and the will to accommodate by other people could be described as troublesome, time consuming and in some cases degrading. One participant said:

If you are low, like really low and someone argues with you... what the heck are you doing? Or 'Why are you acting like that?'... they have not the slightest clue...I'm low. 'I'm just going to eat first! Then we can talk!'... 'Eat first? No, you can eat later'. 'No, I'm afraid I cannot eat later'... (Interview 9)

Young adults described complex feelings and emotions living with T1D. First, they said people may think the condition is due to bad choices in life and then they try to teach healthy lifestyles. The participants described how important it is that other people know how much the illness, day in and day out, affects their daily life and that support from others is one of the main issues. One young adult explained that, even though they were grown up, they wished for some sort of interest from others around them:

Mm, I've always kept it to myself, they are used to me taking care of myself and we don't talk about it! I have always had a desire that they would ask me... just... How are you? Are you coping with your diabetes? But... they just don't... Well, engagement from my parents, from my point of view, I've missed it. (Interview 3)

## **4. Discussion**

This study focuses on how young adults with T1D experience react to being met and received by others. The findings show that young adults with T1D described that people close to them gave invaluable support, especially their parents and cohabitants. They also highlighted the natural understanding they could experience when meeting people in the same situation as theirs. On the other hand, young adults with T1D described common misunderstandings about T1D and the lack of knowledge among people in their surroundings, in the media and among healthcare personnel. This was troublesome for

young adults with T1D.

The findings show that young adults with T1D especially appreciate support from parents and cohabitants. This is in line with Scholes et al. who have shown that supportive and involved friends and family are an essential part of everyday life of young adults living with T1D [29]. Young adults with T1D appreciated that their parents and cohabitants had taken them to hospital or provided sweets or sugar in emergency situations. This gave them feelings of security and protection. Studies have shown that family involvement was important for people living with long-term illness, especially in urgent situations [30-31]. Moreover, social support is recognized as an essential feature that contributes to health-related quality of life for people living with a long-term illness [32-33]. This seems to be true also for young adults with T1D in this study.

Young adults with T1D found it important to meet people in the same situation particularly other young adults with T1D. They expressed a natural and mutual understanding, a direct connection to other young adults with T1D. These meetings were valuable, enriching, gave energy and engendered feelings of not being alone. It is recognized that meeting people in the same situation creates intimacy and kinship. Participants who preferred not to reveal their identity, explained that web-based forums were valuable arenas for exchanging experiences. According to Balfe et al. [13] and Abdoli, Hardy & Hall [5], participants in their studies expressed the view that other people with T1D had empathy and understanding for their experiences. It was also a positive experience for young adults when healthcare personnel recognized them, for example, by knowing their name. This can be regarded as a way for their identity to be confirmed. According to Cissna and Sieburg [34], confirmation means for others to give the message to me that you are significant and how you are experiencing your daily life is valid. A meeting based on confirmation gives a feeling of being valued and respected, something that can increase feelings of well-being [35].

A good healthcare encounter when healthcare personnel show genuine interest when seeing the patient is important [19]. In contrast, young adults in this study all too often experienced a lack of knowledge of their situation both in society and in the healthcare services. They emphasized that other people's lack of knowledge and misunderstandings influenced them in an undesirable way. In turn, this made the young adults feel ashamed and frustrated as a result of other people stigmatizing them. Studies have found that being discredited and encountering other people's unresponsiveness to learn more about T1D can trigger a downturn in young adults' health and well-being [36-37]. Being shown disrespect can negatively affect the young adults' feelings of safety and confidence and can leave them feeling insulted. This in turn can influence their health and well-being in an undesirable manner. Feelings of being misunderstood and treated in an undignified manner are in accordance with previous studies studying long-term illnesses [10, 32, 35]. The results imply that the loss of comprehension and

misconceptions from other people and healthcare personnel were troublesome, and degrading for young adults living with T1D. This can be seen as a lack of confirmation. Lack of confirmation can give feelings to young adults with T1D that they are not valuable people. Healthcare personnel are important for young adults with T1D to give support. A prerequisite for giving support is that healthcare personnel have knowledge about what it means to live with T1D. Also, knowledge is the basis for communication between young adults with T1D and healthcare personnel which in turn leads to shared understanding.

This study has some limitations. The results of this study cannot be generalized. Nevertheless, if the results were re-contextualised they could be transferable to similar conditions [38]. The findings are in line with previous studies, which might indicate that the findings are transferable to other young adults living with T1D and possibly also to other persons living with long-term illness. This study demonstrates results from a limited group of people living with T1D. Thus, the results do not claim to represent the opinions of all people with T1D. People with an interest in sharing their experiences might have agreed to participate, while persons with completely different opinions declined to take part in the study. This selectivity by potential participants might affect the results of the present study.

## 5. Conclusion

Young adults in the present study have both positive and negative experiences when meeting others (i.e. being confirmed and lack of confirmation). On the one hand, in supportive surroundings, one's own motivation and a sense of belonging act to strengthen the young adult with T1D. On the other hand, misunderstandings and a lack of knowledge of their condition influences the health and well-being of a young person with T1D in negative ways. The findings demonstrate the importance of significant friends, family, health professionals and society in general to understand, support and strengthen young adults with T1D in order to increase their health and well-being in daily life. In order to establish updated knowledge, understanding and support to young adults with T1D, it is of great importance to continuously educate health professionals and the society in general. Effective, cost efficient and confirmative education possibilities need to be established for health professionals.

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## Conflict of Interest

The authors declare that they have no competing interests.

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