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Research: Educational and Psychological Aspects

Developing a hierarchy of needs for Type 1 diabetes

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Abstract

Aims The aim of this study was to use the concept of Maslow's hierarchy of needs and apply this to Type 1 diabetes.

Methods Qualitative methods were employed using semi-structured interviews with 101 people from 13 countries. Grounded theory was used for data collection and analysis, with thematic analysis employed to identify the interviewees' needs.

Results Sixteen needs were identified and links between these were mapped. Aligning these with Maslow's hierarchy allowed for a hierarchy to be developed for Type 1 diabetes with 'Policies', 'Organization of health system', 'Insulin', 'Delivery of insulin', 'Control', 'Healthcare workers' and 'Information and education' at the base, as they were needed for survival. Next came 'Community, family and peers' and changing roles for 'Healthcare workers' in their approach to care and delivering 'Information and education'. This enabled people to learn how to use 'Insulin', 'Delivery of insulin' and 'Control' flexibly. People's 'Experience' and 'Personality' then helped them 'Adapt' and 'Be open' about their diabetes, allowing for 'Acceptance' and viewing 'Diabetes as something positive'.

Conclusions Despite limitations, this work highlights that some needs are required for survival and others for well-being. Some are tangible as they can be directly provided, whereas others are intangible and cannot be provided directly by the health system. These results might be used for policy and practice in identifying needs that are met within a health system or what needs are lacking for the individual to then implement targeted interventions.

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Introduction

As Type 1 diabetes is a chronic condition, the health system has to focus on trying to prevent complications and the negative psychosocial impact of this condition [1,2]. From the healthcare worker's perspective, the focus is on clinical outcomes, such as blood glucose [1]. For the individual, being diagnosed with Type 1 diabetes is a 'biographical disruption', as management includes changes to daily life and how the person views themselves, but that person still wants to be able to do what they want and not be limited by their diabetes [1,3,4]. Some of the factors necessary for this fall outside the health system and therefore there is a need to shift the perspective of health and disease to take into account the individual's needs [5].

Abraham Maslow developed a hierarchy of needs and proposed that, as basic needs are met, the satisfaction of higher needs is sought [6]. This hierarchy is often presented as a pyramid including five levels: (1) physiological needs; (2) safety needs; (3) love/belonging needs; (4) esteem needs; and (5) self-actualization. Maslow's hierarchy has been utilized for prioritizing needs, as a theoretical framework, and policymaking [7–11]. In relating Type 1 diabetes to Maslow's pyramid, some people with Type 1 diabetes still face physiological or 'survival needs' of accessing insulin, syringes and testing equipment [12]. In parallel, others compete in the Olympics and climb Mount Everest [13], which are clear examples of self-actualization, as they live in settings where survival needs are met because of economic development, organization of the health system and government policies. The aim of this research was to gain insight into what the needs of people with Type 1 diabetes are and to use the concept of Maslow's hierarchy and apply this to Type 1 diabetes.

Research design and methods

'Grounded theory' was used for data collection and analysis as it is flexible and helps create theories 'grounded in the data' [14–17]. Theoretical sampling was used, as in grounded theory unrelated groups can be sampled and compared in order to get an overall picture of a given topic [18].

A topic guide was developed as grounded theory uses open questions to enable the interviewee to discuss all issues

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What's new?

- Very few studies have looked at the needs of people with Type 1 diabetes in multiple settings.
- To address this, a qualitative study in 13 countries comprising 101 individuals with Type 1 diabetes was designed to identify their needs.
- The aim of this research was to develop an initial conceptual framework of ideas around the issue of needs for people with Type 1 diabetes from their perspective and also prioritize these in a hierarchy.
- The resulting hierarchy of needs for Type 1 diabetes could be used in policy and practice to address needs that are lacking.

around a given topic [15]. The investigator (DB) piloted the tool in Belgium, France, Mozambique, the UK and USA. This allowed for more focused areas of questioning to be developed and the concept of 'abnormal days' to be included. 'Abnormal days' were described during the pilot as days when the individual's routine was changed and impacted diabetes management. The final tool used 'Grand tour questions' [19], which included the following areas:

1. diagnosis;
2. consultations;
3. daily life;
4. 'abnormal' days.

Interviews were organized by DB in 13 countries representing different health systems and socio-economic development (Table 1). Eight people with no specification of age, age at diagnosis, duration of disease or sex were asked by local contacts to participate. When children and adolescents were interviewed, this was carried out with their parents present and authorization, or a joint interview with parents and children or just parents. Other studies have used parents instead of children to assess care [20].

Ethical clearance was obtained from University College London (project 0025/001). In Singapore and South Africa, additional ethical requirements were complied with. The concept of 'voluntariness' was applied for this research, as agreeing to participate in research amounts to consenting [21].

All participants were informed by DB about the study, emphasizing that they were free in their participation. Participants were then asked if the interview could be recorded, highlighting that no note would be taken of any personal details and that any mention of names in the actual interview would not be included in the transcript. In Indonesia and Singapore, only three and seven people were interviewed, respectively, because of logistics. In South Africa and Argentina, nine and 10 people were interviewed, respectively, as they expressed an interest in participating. Interviews lasted an average of 52 min and took place in a single meeting. Prompts were used throughout the discussion to gain a better understanding of the person's needs, which also enabled interviewees to discuss the range and scope of their experience.

Individuals were identified with a code highlighting their country (AR, CH, IN, KG, MZ, NIC, SA, SIN, TH, TZ, UK, USA and VT), sex (F, female; M, male) and age; for example, CHF24 is female, age 24 years from Switzerland.

In Indonesia, Kyrgyzstan, Thailand and Vietnam, DB used professional translators for all interviews. When using translators, DB asked the question in English, which was

Table 1 Locations of sampling for interviews

Country	Income level [23] (International gross domestic product per capita; $US) [28]	Location of sampling	Number of interviewees
Argentina	Middle (17 700)	Diabetes association and hospital in capital city	10
Indonesia	Middle (4700)	Individuals	3
Kyrgyzstan	Low (2400)	Diabetes association	8
Mozambique	Low (1100)	Diabetes association and main referral hospitals	8
Nicaragua	Middle (3200)	Diabetes association	8
Singapore	High (59 700)	National Children's Hospital	7
South Africa	Middle (11 000)	University Teaching Hospital	9
Switzerland	High (44 500)	Diabetes association	8
Tanzania	Low (1600)	Diabetes association	8
Thailand	Middle (9400)	Diabetes association	8
UK	High (36 500)	University Teaching Hospital, diabetes association and individuals	8
USA	High (48 300)	Diabetes association and individuals	8
Vietnam	Middle (3400)	Main paediatric referral hospital	8

then translated, with the interviewees' response translated back into English. For interviews in English, French, Portuguese and Spanish, the discussion guide was translated into the relevant languages and administered by DB.

Interviews were transcribed verbatim and entered into NVivo software (NVivo 7; QSR International, Melbourne, Vic., Australia) by DB and analysed using thematic analysis. This approach in qualitative research allows themes to be identified, analysed and reported within transcripts [17]. A theme is an element from the transcripts that 'captures something important' in terms of a research question [17]. There is no set measure to state that one theme carries more weight vs. another, unlike in quantitative research where this would be the number of occasions of this theme [17]. Coding was verified by an expert with vast experience looking at chronic diseases in children, using both qualitative and quantitative research methods.

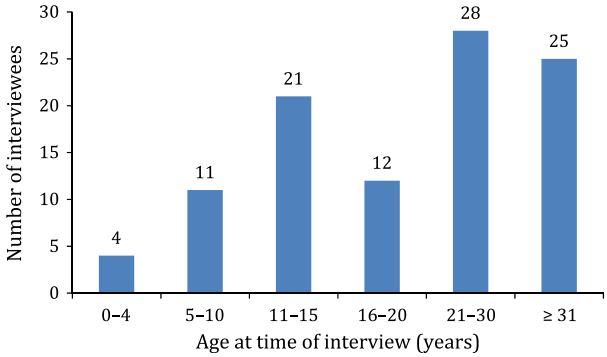

FIGURE 1 Age at time of interview.

Results

A total of 101 interviews (56 female; 45 male) were carried out with an age range of 1.2–61.0 years of age (median 22.0 years) (Fig. 1). Thirty-two interviewees came from 'low', 38 from 'middle' and 31 from 'high' income countries [22]. Median age at diagnosis was 11.0 (range 0.1–36.0) years. Of the sample, 33.7% had Type 1 diabetes for more than 10 years (range: newly diagnosed–55.0 years; median duration: 7.0 years). Sixteen needs were identified. By mapping the different needs in each interview, linkages were found, highlighting that some were required for others to be as described in Fig. 2.

Health system

'Policies' impact the 'Organization of the health system' (Fig. 2, link A) as these determine the environment in which the person will be diagnosed in and cared for. 'Insulin', 'Control' and 'Delivery of insulin' are also impacted by 'Policies', as these may need to be paid for (links B–D). For example, in Argentina, social insurance covers all of these elements, albeit imperfectly, compared with Vietnam where these elements have to be bought. In other settings, insulin and syringe access was problematic, highlighting problems with the 'Organization of the health system'.

'Control' was either present at health facilities or people had their own blood glucose meter. Interviewees in Mozambique and Vietnam did not have access to blood glucose meters, mainly because of cost. In addition, the health system needs to have 'Healthcare workers' (link E) able to identify diabetes, provide initial treatment and 'Information and

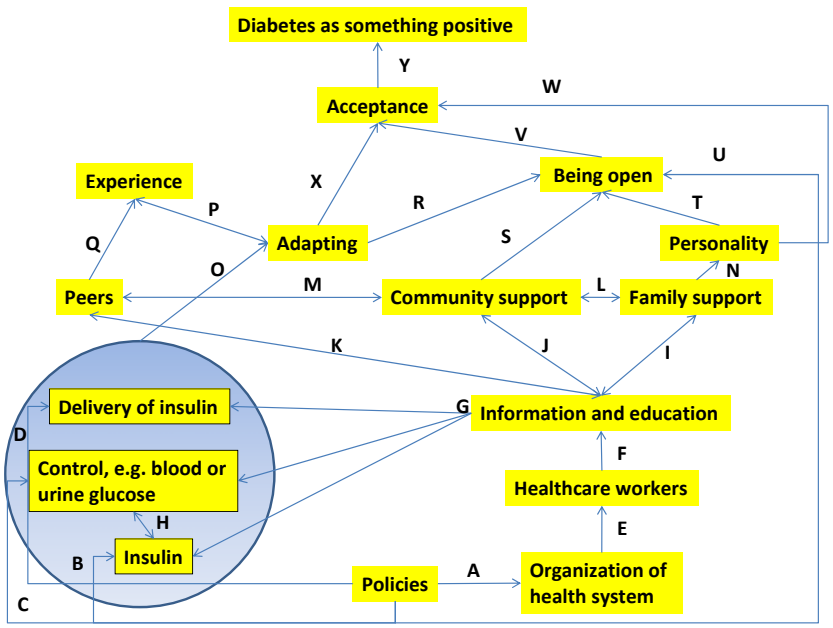

FIGURE 2 Links between the themes.

education' (link F). This 'Information and education' needs to enable the person to know enough to 'survive' (link G).

Tangible tools and skills and the role of support

Interviewees had different management of their insulin dosage, from strict to completely flexible. This change happened using the blood glucose meter, not just as a way to measure blood glucose, but in a more operational way (link H). This was highlighted by a 39-year-old man from Thailand (THM39), 'back then the use was for control, but right now I use it to adjust the dose [of insulin]'. Also, 'Information and education' (link G) delivered by 'Healthcare workers' in an adapted way to the individual with active support and interactions helped with this. As stated by a 47-year-old man from the USA (USAM47), it is important not to have the 'typical physician transaction where you go to the doctor's office and they go hey you didn't do this right, where they are dictatorial if you will. It's really got to be a partnership and a series of learning'.

'Family support' (link I), 'Community support' (link J) and 'Peers' (link K) also help with day-to-day management, 'Information and education' and the opportunity to share experiences. 'Community support' was influenced by 'Family support' (link L) and 'Peers' (link M) with and without diabetes. A major element of 'Community support' is the diabetes association. The overall support from community and family was depicted by a 27-year-old man from Argentina (ARM27) as 'the environment around me that helped [me manage my diabetes]'. Family support forms part of what a 24-year-old woman from Switzerland (CHF24) described as a 'protective environment at home'. An 18-year-old woman from Switzerland (CHF18) said that the people with diabetes she interacted with were her 'second family' and that this was 'something that helped her' manage and accept her diabetes. Peers without diabetes also helped the interviewees, with an 18-year-old woman from Singapore (SINF18) telling how her friends are 'understanding' and an 18-year-old man from Nicaragua (NICM18) saying that his friends 'look out for me'.

Individual factors

'Family support' influences the 'Personality' of the person (link N) helping with diabetes management, which is also shaped by 'Experience'. As a 27-year-old man from Thailand (THM27) said 'I learnt from experience' and a 22-year-old man from the USA (USAM22) added 'once you get experience with the disease you are able to make these decisions for yourself'. This experience helped with insulin dosage, managing diet, exercising and 'Knowing your body' (42-year-old man from Mozambique; MZM42) (i.e. the symptoms of hypoglycaemia and/or hyperglycaemia). Personality traits that people used to describe themselves that had an impact on their diabetes were a 41-year-old man from Argentina (ARM41) describing himself as 'optimistic', a 34-year-old man from Switzerland (CHM34) having a 'fighting spirit', a 61-year-old man from Switzerland (CHM61) being a 'perfectionist', a 24-year-old woman from Nicaragua (NICF24) a 'fighter' and a 42-year-old man from the USA (USAM42) describing himself as having 'strong internal drive'. 'Maturity' was described by a 19-year-old man from Argentina (ARM19) and a 15-year-old young woman from Singapore (SINF15) as helping them manage their diabetes.

'Adapting' (link O) includes both the adjustment to day--to-day use of insulin and other 'treatment' aspects of diabetes, but also the change in perspective the person has, as they now have a chronic condition. A 42-year-old man from Mozambique (MZM42) expresses how he 'had to adapt to this reality'. Another aspect of 'Adapting' is how 'Insulin', 'Delivery of insulin' and 'Control' are used. In looking at 'Insulin', it goes from being something for survival to something that can be used more actively to 'adapt' to any situation. 'Adapting' and 'Experience' are joined in that they mutually help each other (link P) and, as said by a 27-year-old man from Thailand (THM27), 'the dosage [of insulin] will be adapted to my eating and activity and it is also based on my experience'. 'Adapting' helps people gain 'Experience', and through this 'Experience' they are able to adapt to new and different situations. A significant element that impacted 'Experience' was learning from others with diabetes (link Q).

'Being open', 'Acceptance' and 'Diabetes as something positive'

'Being open' was a secondary result of 'Adapting' (link R) in that, by fully participating in 'normal' life and activities, for example, school, meant that teachers needed to be informed. 'Being open' was described by a 22-year-old man from the USA (USAM22) as 'almost part of a hello in our conversation. I did not feel like I had to hide something'. A 61-year-old man from South Africa (SAM61) stated 'you can't hide it [having Type 1 diabetes]'. A 54-year-old man from the UK (UKM54) describes how 'I don't hide it, which I used to do at one time' and 'I am open with it'. 'Community support' helped in both serving as an example that 'Being open' was not a problem through the experience of peers with diabetes, or strong support from family and friends (link S). 'Personality' also had an impact on 'Being open', with some people saying they were very open whilst others were not (link T). Another factor needed for 'Being open' was the need for 'Policies', not to cause people with diabetes to be stigmatized or discriminated against; for example, with regards to employment health checks in Argentina or diabetes still being considered a disability in Kyrgyzstan (link U).

'Acceptance' required, on the one hand, practical aspects of diabetes management ['Adapting' (link X)] and, on the other hand, social aspects of the individual ['Being open'

(link V) and 'Personality' (link W)]. A 24-year-old woman (ARF24) and a 19-year-old man (ARM19), both from Argentina, an 18-year-old woman from Switzerland (CHF18) and a 27-year-old woman from Thailand (THF27) describe acceptance as a process. Family support, healthcare workers and peers play an important role in 'Acceptance'. The importance of healthcare workers was highlighted by a 60-year-old woman from the USA (USAF60): 'One of the most helpful things is that if healthcare workers are honest with people, telling them that diabetes can be a very hard disease and it is a life-changing disease, but if you follow what you are supposed to do [it can be managed]… [this] will help someone gain acceptance about having what they have'. A 39-year-old woman from Argentina (ARF39) describes how, at a diabetes camp, 'we were 40 children all with Type 1 diabetes of different ages and the basic thing they taught us was that we were normal children'.

Once all these needs were met, the interviewees then viewed 'Diabetes as something positive' (link Y). This was described by the interviewees not only as accepting their 'intrinsic situation', but also helping others through being diabetes counsellors, creating diabetes associations or support groups, fundraising for diabetes-related organizations, or deciding to work in the area of diabetes.

Linking Maslow's hierarchy with the findings above is presented in Table 2 and allows for a presentation of these results as the hierarchy of needs for Type 1 diabetes presented in Fig. 3. The first level of Maslow's hierarchy relates to survival needs; for example, food and shelter. The elements from the hierarchy of needs for Type 1 diabetes include 'Insulin', 'Delivery of insulin' and 'Control', 'Healthcare workers' and 'Information and education', 'Policies' and 'Organization of health system'. The next level in Maslow's hierarchy of needs is 'Safety'. In the hierarchy of needs for Type 1 diabetes, this 'Safety' is provided through support from family, peers and the community, but also through increased information and education from this community, as well as healthcare workers.

Following from the hierarchy of needs for Type 1 diabetes and the link to 'Safety' needs, it could be argued that the

Table 2 Comparison between Maslow's hierarchy of needs and hierarchy of needs for Type 1 diabetes

Maslow's Hierarchy of Needs	Hierarchy of Needs for Type 1 diabetes
Physiological needs	'Healthcare workers' and 'Information and education' 'Insulin', 'Delivery of insulin' and 'Control', e.g. blood or urine glucose 'Policies' and 'Organization of health system'
Safety needs	'Healthcare workers' and 'Information and education' 'Community support', 'Family support' and 'Peers'
Belonging needs	'Experience' and 'Personality' 'Insulin', 'Delivery of insulin' and 'Control', e.g. blood or urine glucose 'Adapting' 'Being open'
Self-esteem needs	'Acceptance'
Self-actualization needs	'Diabetes as something positive'

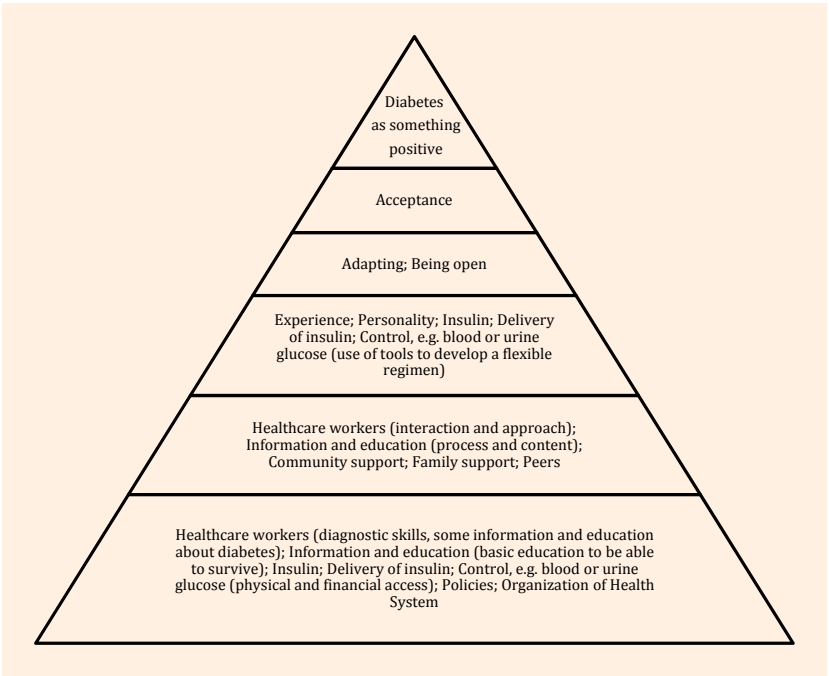

FIGURE 3 Hierarchy of needs for Type 1 diabetes.

support from family, peers, community and healthcare workers also form the basis of 'Belonging'. The main need identified with regards to 'Belonging' in the hierarchy of needs for Type 1 diabetes is 'Being open'. 'Belonging' also happens when people are able to 'Adapt' and take part in 'normal' activities. As described by Malsow, the limits between levels of the hierarchy are not meant to be rigid and there may be overlap [6].

Self-esteem needs include 'desires for strength, achievement, adequacy, mastery, competence, confidence, independence and freedom' [6]. These elements are part of the 'Acceptance' needs detailed in the hierarchy of needs for Type 1 diabetes, in that all these factors contribute to people 'accepting' diabetes. Self-actualization is the highest need defined by Maslow and is described as 'acceptance of the person's own intrinsic nature' [23] and the 'desire of self-fulfilment to push ones potential to the limit' [6]. The people that describe 'Diabetes as something positive' do this, in that they not only accept their 'intrinsic situation' of having diabetes, but also help others and, in some cases, as a 25-year-old man and a 42-year-old man from the USA (USAM25 and USAM42) push the limits in terms of athletics to a level that most cannot achieve.

This study has many limitations. As the individuals participating were self-selecting, this may lead to bias in terms of the type of individual responding. In addition, they are not a representative sample of people with Type 1 diabetes in their respective countries. The economic bandings by country do not reflect individual variations in income, but the aim was to look at health systems in these different countries, which are impacted by the overall country income level. Cultural factors were not taken into account and may impact on perceptions of care. However, the aim of this research was to get the experience of individuals, and each individual and their experience is unique. Again, this overall impression of needs meant that analysis by age group was not carried out.

Conclusions

Because of the design and limitations, further work would need to be carried out to assess if these 16 needs can be used universally. However, this work offers an insight into the varying needs that individuals have and how these can be presented as a hierarchy.

Bay [24] argues that Maslow's hierarchy of needs can be used in order to provide a framework for meeting needs and setting priorities. Therefore, it helps in defining political development, as more basic needs need to be met before higher needs [7]. The higher up the pyramid, the less meeting that particular need is required for survival and necessary for well-being [25]. Not meeting the needs of belongingness, esteem and self-actualization lead to poor social well-being, whereas not meeting physiological need leads to ill health and death [26]. The same is true for the hierarchy of needs for Type 1 diabetes, with insulin needed for survival, but 'Being open' requisite for social well-being.

Some needs are also tangible, in that the health system can provide these; for example, insulin. 'Experience' and 'Personality' are intangible and cannot be provided by the health system. However, healthcare workers need to take into account 'Experience' of the individual and their 'Personality' in order to adapt their approach to providing care.

The hierarchy of needs for Type 1 diabetes can have implications for policy and practice. From a policy perspective, the important messages are that:

1. survival needs go beyond purely providing insulin and syringes;
2. once these survival needs are met other needs are required;
3. higher needs are more difficult for only a health system to address.

For example, Nicaragua has to a certain extent achieved the first level of the hierarchy and is well advanced into the second segment with 'Community support' being well developed, but the other two elements demanding further work [27]. Therefore, policies and programmes need to strengthen the first element of the pyramid and start working on the second level.

For clinical practice, an assessment of where the individual is on the hierarchy of needs for Type 1 diabetes could be carried out during a consultation. For example, given the result of a self-assessed questionnaire based on the hierarchy of needs for Type 1 diabetes, a healthcare worker may see that the need of 'Being open' is not met. The 'intervention' would then be the healthcare worker finding ways to facilitate or help this person 'be open'.

Maslow [28] argued that society plays a role in meeting the basic needs of its people. He stated that the definition of a 'good society' is the degree to which it satisfies the basic needs and offers the possibility of self-actualization to its population. By using the results from the hierarchy of needs for Type 1 diabetes in both policy and practice to improve diabetes care would help towards making 'Diabetes as something positive' for all people with Type 1 diabetes.

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Competing interests

None declared.

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