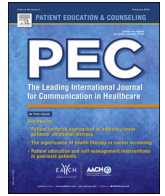




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Research Information

Initial versus ongoing education: Perspectives of people with type 1 diabetes in 13 countries

David Beran^{a,*}, Alain Golay^b

^a Division of Tropical and Humanitarian Medicine, University of Geneva and Geneva University Hospitals, Switzerland

^b Division of Therapeutic Education for Chronic Diseases, Geneva University Hospitals and Director, WHO Collaborating Centre for Reference and Research in the Field of Education and Long-Term Follow-up Strategies for Chronic Diseases, Switzerland

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ABSTRACT

Purpose: To understand the perspectives of people with type 1 diabetes with regards to the diabetes education they receive within the health system.

Methods: Grounded Theory was used for the collection and analysis of data from interviews with 101 people with type 1 diabetes from 13 countries.

Results: There are two aspects to education, namely initial education received when diagnosed and the ongoing education people continue to receive. Within these two categories content and process of diabetes education are important as are factors linked to the healthcare worker and setting.

Conclusions: Tangible elements are the “what” that is delivered and are the different skills and information needed for people to manage their diabetes. Process elements are the “how” this is delivered. Finally intangible elements are those, which were found to be specific to certain contexts and health professionals. These could be the hardest to replicate, but possibly the most important.

Practice implications: Health systems can provide the tangible elements and organize themselves to have processes in place to deliver education. The challenge is how can the intangible elements be seen as important and developed and delivered to improve management, but also meet the needs of people with diabetes.

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Introduction

The International Diabetes Federation's (IDF) International Standards for Diabetes Education state that, “Every person with diabetes, no matter where they live in the world, deserves access to high-quality diabetes education delivered by skilled clinicians [1].” The IDF adds that the role of education is to help the individual make informed decisions, cope with the daily demands of diabetes management and provide individuals with the information they need to manage their diabetes and that this should be provided on an ongoing basis [2].

Education does not necessarily have as its aim to make the individual more knowledgeable about diabetes, but allow them to manage their diabetes in their everyday life [3]. Education and information can take many delivery forms, oral, written guidelines, booklets, group teaching sessions, role playing, audiovisual materials, peer groups, diabetes association meetings and diabetes camps [4]. This education and information and the way it is

delivered should be adapted to the person with diabetes, their age, family situation and be culturally appropriate [5].

As the majority of time managing diabetes happens outside of the formal health system, the burden of care is the responsibility of the individual and their family [6]. This requires education about diabetes delivered within the health system to enable its proper management thereby placing a large responsibility on the health system to educate and inform people with diabetes sufficiently to take an active role in their care [7–9]. However, challenges remain in practice and it is argued that this is due to a disjuncture between what health professionals feel is the best way to manage type 1 diabetes and the capacity of people with type 1 diabetes and their families to manage this condition [10]. Therefore the aim of this article is to understand the perspective that people with type 1 diabetes have with regards to the education they receive within the health system.

2. Methods

In-depth semi-structured interviews were carried out using a tool that was developed following piloting in Belgium, France, Mozambique, UK and USA. The questionnaire served as a

* Corresponding author.

E-mail address: David.Beran@unige.ch (D. Beran).

discussion guide and used “Grand Tour Questions” [11] which aim to get the person interviewed to give a “verbal tour” of the area under investigation. Prompts were used throughout the discussion in order to discuss the range and scope of their experience [12]. Ethical clearance was obtained from University College London (Project 0025/001). In some settings (Singapore and South Africa) additional ethical requirements were necessary and were complied with.

2.1. Sample and setting

Eight individuals with type 1 diabetes were chosen using a convenience sample from the 13 countries from 2007 to 2010. Due to logistical issues in Indonesia only 3 people were interviewed and 7 people instead of 8 were interviewed in Singapore. In South Africa and Argentina 9 and 10 interviews were conducted respectively as more people expressed an interest in participating. The other countries included: Kyrgyzstan, Mozambique, Nicaragua, Switzerland, Tanzania, Thailand, UK, USA and Vietnam. In each of these countries centers of excellence and diabetes associations were used as places for sampling.

2.2. Procedure

Interviewees were invited by local contacts based at centers of excellence for management of type 1 diabetes to participate. Individuals were informed about the project in these centers and invited to participate. Interviews were carried out with children and adolescents with their parents present and authorization, or a joint interview with parents and their children or just parents. In reporting these interviews where possible it has been indicated who said what (parent versus child). Interviews were either carried out in person or via telephone. Prior to the start of the interview all participants were informed about the study and its aims with an emphasis that they were free to participate prior to being interviewed. They were then asked if the main researcher (DB) could record the interview 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 or

reporting. Individuals were identified with a code highlighting their country (see Table 1), sex (F, female; M, male) and age, for example, interviewee CHF24 is female, aged 24 years from Switzerland.

The first author carried out all the interviews with in some cases assistance from a translator (See Table 1). Interviews were transcribed verbatim once completed with notes and emerging themes included in the transcript and used to help inform further interviews in terms of questions and areas to investigate in more depth. The analysis used initial codes, which were developed by “word by word” coding using NVivo software (NVivo 7, QSR International, 2006). Coding enabled similar pieces of data from different sources to be identified and broke up the data into parts that can be summarized by a given code [13]. Quotes were identified from interviewees to show their way of explaining things and relate these to the emerging concepts from the research. The focus in the analysis was to look at specific sections of text where individuals mentioned aspects and issues relating to the education and information they received.

2.3. Data analysis

Grounded Theory was used as it provides a systematic framework for the collection and analysis of qualitative data that allows for the development of theories “grounded in the data collected” [13–16]. This enabled the quotes and words used by the interviewees to remain and a joint analysis, comparison and grouping of these to be done by both authors [14]. Constant comparative analysis was also used to compare quotes between different interviews, identify similarities between the interviews and then compare these to existing constructs around diabetes education [13]. The full process of analysis is detailed in Fig. 1.

3. Results

3.1. Interviewee characteristics

The characteristics of the 101 interviewees are presented in Table 2. In analyzing the data from the interviews there are two

Table 1
Countries where research was carried out.

Country (Country code for interviews)	Selection of respondents	Language and Translation	Face to face versus telephone	Location of interview	Individual versus group interviews
Argentina (AR)	Healthcare worker at diabetes association	Done in Spanish by DB	Face to face	Diabetes association and hospitals	Individual
Indonesia (IN)	Identified by translator	Translator	Face to face	Neutral locations	Individual
Kyrgyzstan (KG)	Diabetes association	Translator	Face to face	Diabetes Association	Group
Mozambique (MZ)	Diabetes association	Done in Portuguese by DB	Face to face	Diabetes Association	Individual
Nicaragua (NIC)	Diabetes association	Done in Spanish by DB	Face to face	Diabetes Association	Individual
Singapore (SIN)	Healthcare worker at hospital	Done in English by DB*	Face to face	Hospital	Individual
South Africa (SA)	Healthcare worker at hospital	Done in English by DB*	Face to face	Hospital	Individual
Switzerland (CH)	Diabetes association	Done in French by DB	Face to face and telephone	Diabetes Association, neutral locations and telephone	Individual
Tanzania (TZ)	Diabetes association	Done in English by DB*	Face to face	Diabetes Association	Individual and group
Thailand (TH)	Identified by translator	Translator	Face to face	Neutral locations	Individual
United Kingdom (UK)	Contacts and ad in a diabetes association newsletter	Done in English by DB	Face to face and telephone	Hospitals, neutral locations and telephone	Individual
United States of America (USA)	Contacts	Done in English by DB	Telephone	Telephone	Individual
Vietnam (VT)	Healthcare worker at hospital	Translator	Face to face	Neutral locations	Individual

* – During some of the interviews assistance was given by a healthcare worker when some individuals felt more comfortable answering in their native language.

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