Diabetes education: a global perspective

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Abstract
Diabetes education has been acknowledged as the cornerstone of good diabetes care and management. Although evidence to support the need for diabetes education has grown in recent years, many people with diabetes remain unable to access or choose not to attend diabetes education for a variety of reasons. In order to improve the likelihood of success, diabetes education needs to be adequately resourced and tailored to meet the needs of specific populations. This paper seeks to offer a global perspective on the current status of diabetes education. Insight is provided into recent evidence suggesting poor integration of diabetes education across the globe. Finally, issues such as the need to tailor education and increase international collaboration are addressed. Copyright © 2015 John Wiley & Sons.

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Key words
diabetes; self-management education; adolescents; tailoring diabetes education; health service provision

Introduction
Diabetes is one of the most common global non-communicable diseases, and is estimated to be the fourth or fifth leading cause of death in most high-income countries. Current estimates suggest there are 387 million people with diabetes worldwide, a figure set to increase to 592 million by 2035 if current trends persist.¹ Many health care professionals will be familiar with these figures which are often quoted within diabetes literature. Conceptualising the impact of diabetes can at times be difficult and thus it may be easier to visualise figures such as those quoted at a much more local level. Currently, 1 in 12 people around the world are estimated to have diabetes and, if present trends continue, by 2035 this figure will have increased to 1 in every 10.

The cost of diabetes may be viewed as both financial and personal. Financial costs may include increased use of health services, reduced productivity and increased levels of disability, due primarily to complications such as amputation or blindness. Current estimates suggest that 10% of the NHS budget is spent on diabetes care and management, with the majority utilised for the treatment of diabetes complications.² The personal cost of diabetes is more difficult to assess and may include various aspects such as reduced life expectancy, increased risk of cardiovascular disease, reduced quality of life, discrimination and social stigma. In addition to costs of diagnosed diabetes, a recent study from the USA has estimated the cost of undiagnosed diabetes to be as high as 18 billion USD in one year.³ Spiralling costs and recognition of the increasing burden diabetes places upon society have led to diabetes being viewed as one of the biggest public health concerns of our time, causing a proactive shift in recent years from treatment and management of diabetes, to prevention.

Diabetes self-management education
For those diagnosed with diabetes it remains a complex condition requiring effective self-care behaviours underpinned by knowledge of diabetes itself and the impact different lifestyle choices such as diet and exercise may have on an individual’s glycaemic control. Diabetes is often seen as restrictive and behaviourally challenging, with many individuals struggling to attain optimal glycaemic control while maintaining a good quality of life. Despite this complexity, diabetes remains primarily a self-managed condition with the average person with diabetes estimated to receive 4 hours of direct health care professional contact per year. For the remaining 8756 hours, each individual is required to make effective diabetes management decisions in respect of diet, medication, exercise, sickness, travel and any additional lifestyle...
choices or activities in which they engage. In order to undertake this role of effective self-management it is imperative that every person with diabetes receives high quality diabetes education both at diagnosis and at regular intervals over subsequent years.

The International Society for Pediatric and Adolescent Diabetes offers one of the most comprehensive definitions of diabetes education, advocating it to be:

"The process of providing the person with the knowledge and skills needed to perform diabetes self-care, manage crises and to make lifestyle changes to successfully manage the disease." 14

There are few health care professionals working within diabetes who would argue that diabetes education forms the cornerstone of diabetes care and management. Without high quality diabetes education those diagnosed often rely on less reliable sources of information which are all too easily accessible through the World Wide Web or other media outlets. Newspaper headlines such as ‘Chocolate can beat diabetes’ or ‘New diet to beat diabetes’ can present confusion for those ill-informed and lead to detrimental consequences for those who venture to try the latest fad in the hope of attaining improved control or even a cure. The existence of these other forms of information, often unsubstantiated, misconstrued or poorly researched, provides further weight to the need for health care professionals to ensure that people with diabetes receive effective diabetes education and feel confident in their ability to manage their condition successfully.

Although it has received more attention over the past decade, diabetes education is not a new concept. Indeed, the history of diabetes education can be traced back to 1918 when it was first encapsulated by Dr Elliott P Joslin in the publication of his book ‘A diabetic manual for doctors and patients’. Joslin believed the key to managing diabetes lay with patient involvement, education and empowerment, a belief that remains as relevant today as it did almost 100 years ago. Box 1 outlines the history of diabetes education over time and highlights the many changes that have been required in order to ensure the model of diabetes education remains up to date and relevant to ever changing health care delivery systems. As diabetes education has progressed and gained recognition it has undergone many transformations, from the introduction of a simple checklist or ad hoc education to today’s programmes of structured diabetes education, which are assessed against strict criteria set down within countries such as the United Kingdom by the National Institute for Health and Care Excellence,5 and the USA by the American Diabetes Association.6

Table 1. The evidence to support education

Recent years have seen the development of a substantive collection of evidence to support the effectiveness of diabetes education for self-management.6-8 In addition, there have been a number of systematic reviews undertaken to establish the effectiveness and validity of psycho-educational interventions for diabetes.9-11 Each of these reviews has in turn highlighted a lack of empirical evidence to support the long-term benefits of diabetes education primarily due to the short duration of studies with most lasting for 6–12 months’ duration.

However, evidence does exist to support the view that diabetes education has a long-term benefit within adults. The Dose Adjustment For Normal Eating (DAFNE) programme has now been able to demonstrate ongoing benefit after four years, though deterioration in the magnitude of impact on HbA1c was noted.12 In addition, Shearer et al.13 conducted a cost-effectiveness analysis of the DAFNE programme within the UK utilising data from two other similar programmes in Germany14 and Austria.15 Results indicated that structured diabetes education programmes are likely to save approximately £2200 per patient treated and increase life expectancy by 19 days per patient after 10 years. They further suggest that structured diabetes education will outperform routine care after approximately 4.5 years. Figures reported allowed for development of long-term complications and increased service utilisation. In parallel with the growth in evidence to support diabetes education, there has been a shift in policy change within the UK. Documents such as the National Service Framework for Diabetes16 recognise the need to provide a health care environment in which both health care professionals and patients act in partnership to achieve best possible outcomes.

Table 2. Current provision of diabetes education

Despite all of the evidence developed and willingness on the part of both health care professionals and policy makers to integrate diabetes education into diabetes care, recent research suggests this is still not happening. The International Diabetes Federation (IDF) conducted the first-ever global survey of diabetes services in 2013.17 The indicators for the
survey were based on the commitments of the Political Declaration and the targets of the Global Monitoring Framework. The details were developed through consultations with an Informal Advisory Group, including IDF Regional Chairs, representatives of IDF Member Associations and external experts.

Of the 230 Member Associations contacted, 125 participated within the survey, representing a total of 104 countries worldwide. Responses were analysed and then included in the Scorecard report. In cases where more than one Member Association from the same country participated, they were requested to complete the survey jointly. Of the 104 countries who replied, only 14 indicated that they had a fully integrated diabetes education system in place for people with diabetes. Of these 14, only five were located within Europe.

Given the recent evidence described above and the recognition that diabetes education forms the cornerstone of diabetes management, it is very disappointing that it seems to remain a low priority for the majority of countries. Many countries did report availability of diabetes education but, as it had not been integrated fully into the health care system, it was often inaccessible to many individuals and dependent upon the goodwill and determination of local health care professionals, often seen as champions of their service.

In March 2015, the all-party parliamentary group published its long-awaited report on the state of diabetes education and support in England. In addition to recognising the value of diabetes education, the report highlighted many of the current barriers impeding the integration of diabetes education into diabetes care across England. Despite the advances in diabetes care, the report found emotional and psychological support to be almost non-existent; support for children and families with diabetes was cited as inconsistent, and use of new technologies to be patchy. Disappointingly, the report was congruent with the survey undertaken by IDF in that it found many people with diabetes do not received any diabetes education after diagnosis.

The report highlighted the figures from the National Diabetes Audit 2012–2013, which found that only 15.9% of people newly diagnosed with diabetes had been offered structured diabetes education. Furthermore, of those offered, only 3.4% of people actually attended.

For many people working within the area of diabetes, these figures will give rise to great concern. Considering that diabetes education is fundamental in the achievement of optimal diabetes control, there is a need to fully explore why the current level of engagement is so low. Many health care professionals will argue that the findings of the National Diabetes Audit are inaccurate and do not reflect the reality of the diabetes education in their area. Even if this is the case, few would suggest there is not room for improvement and that figures are well below what should be achieved.

In addition to the often quoted reasons of finance, time, resource and competing priorities, one of the less recognised reasons for non-attendance at diabetes education highlighted by the all-party report was the manner in which diabetes education was presented. It would seem that health care professionals need to become more adept at selling education to those newly diagnosed if higher engagement is to be achieved. Simply asking an individual newly diagnosed with diabetes if they would like to attend an education programme may present the view that education is an optional extra. Health care professionals need to become familiar with and present the many benefits to diabetes education, tailoring it to the individual’s needs in order that they comprehend the importance of such education for the effective management of their condition.

One possible way of highlighting the importance of education would be to view it as a prescription in the same way we view medication. Thus, every person diagnosed with diabetes should at the time of diagnosis be prescribed structured diabetes education as part of their treatment. This may assist in achieving higher levels of engagement, reinforcing the importance of diabetes education in assisting individuals to manage their diabetes more effectively, improve their quality of life and reduce the potential for long- and short-term complications.

Adolescent diabetes and education

Adolescents represent one of the most difficult groups to engage with diabetes education. Given the longevity of their condition, poor diabetes control and potential for complications at a young age, the education of children and adolescents has been the focus of much research in recent times. Life expectancy of those diagnosed with type 1 diabetes is reduced on average by 15 years, with those diagnosed before the age of 15 years having substantially worse retinopathy and neuropathy than those developing diabetes in later life.

As part of a previous piece of research, the opportunity arose to undertake a number of focus groups with this young population, in an effort to establish their needs and wishes in respect of diabetes education. Figure 1 offers a visual representation of the findings of these focus groups. A more detailed description of the findings has previously been published elsewhere.

In brief, the findings of these focus groups highlight the wishes of adolescents to develop their independence, recognising the need for parental involvement. In addition, one of the most prominent themes to evolve was the need to move from a negative system of education to a more positive approach by advising adolescents of what they could do, as opposed to what they could not do. Health care professionals being positive, practical and real to life was seen by most as a basic requirement in any form of education. Confusion, frustration, fear, guilt and restriction remained everyday occurrences for this population and were further complicated by feelings of isolation and stigma. These findings only serve to reinforce the requirement for education tailored to the specific needs of adolescents.

Tailoring diabetes education

Although the information underpinning diabetes education remains consistent irrespective of location,
the manner in which this information is delivered or portrayed must be tailored to local context and culture. The issue of tailoring education was never more apparent than within a recent project, Kids and Diabetes in School (KiDS) at IDF. The aim of this project was to foster a school environment that creates a better understanding of diabetes and supports children with diabetes in school. It was decided to pilot the project in both India and Brazil, given the increasing incidence of diabetes in both countries. A global information pack on diabetes was developed for schools, with specific units targeted at school staff, parents of children with diabetes, children and parents in general. The project was implemented with the aid of local partners to increase the likelihood of success.

Following development of the information pack at a global level with the aid of an international technical group, the pack was passed to local partners to assist with adaptation. Although many health care professionals will be familiar with the need to change language and writing style when tailoring information, the need to change images and dietary products is often overlooked. In addition, it became apparent that in India there was a need to develop two different packs to represent those within both private and public schools. Following engagement with the local Ministry of Health, the need to change the dress code of characters within the pack, remove the school bus from the cartoon and remove the dining table from images was identified. This was recommended in order that the pack would be congruent with the reality of those from a lower socioeconomic background. In addition, both countries suggested major changes to the dietary sections of the pack, replacing the UK Eat-well plate with food pyramids developed with local food products. Even the skin colour, hair-style and dress code of the cartoon character developed for the pack required different changes for both

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**Figure 1. What adolescents want**

What do adolescents want?

- ‘You can do’
  - Be positive
- Independence
  - Need to be independent
- Practical
- Short
- Real life
- Contact by text
- Any room will do

What young people want

Why do they want these things?

- Striking the balance
  - Insulin
- It’s a guessing game
  - Food
- You’re on your own
  - Isolation
- You’re always different

Why do they want these things?

- Reduction of frustration
  - Removal of guilt
- Take control
- Reduce restriction
- Eliminate confusion

- Increase knowledge
  - Remove the fear
- Reduce restriction

- Balance of involvement
  - Trust
- Parental support

- Why do they want these things?

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countries. These changes added an additional six months to pack development and were deemed essential if the pack was to be adopted by local communities and schools. Following successful tailoring of the pack for both India and Brazil, assistance was sought from other Member Associations of IDF to create additional packs for international use. As a result, the KiDS pack is now available in eight languages and tailored to many different populations. The pack may be downloaded free of charge at www.idf.org/education/kids.

The lessons learned from this experience are no doubt transferable to the many existing educational programmes throughout the world. Unfortunately, all too often programmes are developed for local populations with limited tailoring for those emanating from different ethnic backgrounds. Where programmes have been tailored, this tends to be limited due to both available resources and finance. The need for tailored education programmes is increasing rapidly given the diversity of cultures and societies around the world. The days of a homogenous society have long since disappeared, with the majority of countries experiencing increased multi-cultural diversity.

Joining the dots
Despite the advances in diabetes education in recent years, programmes are often developed in isolation with little sharing of experience or programme details. Anecdotal evidence suggests that it is not uncommon for two people with diabetes living within a short distance of each other to have completely different access to diabetes education. Thus there is a need to create an environment in which best practice may be shared and effective programmes of diabetes education disseminated, in order to utilise resources efficiently and prevent constant duplication of material. By facilitating such a transfer of information and best practice, health care professionals will have the opportunity to avail of many different education programmes, making it easier to meet the needs of people with diabetes for whom they care.

Within IDF there are a number of initiatives that may be utilised to assist in this transfer of information, including D-NET, Centres of Education and the Diabetes Education Consultative Section. D-NET is an online platform that offers health care professionals the opportunity to discuss important diabetes issues with colleagues from around the world. In addition to bi-weekly discussions which are moderated by an expert within the field, the platform also offers a library, calendar of events and opportunity to ask questions to international colleagues. These facilities may all be accessed at http://d-net.idf.org/en/ and are free to use.

The Centres of Education are made up of eight international centres located in Portugal, India, Columbia, Bolivia, Brazil, Australia, Pakistan and Hong Kong. Each centre is considered a centre of excellence and has been chosen because of their contribution to diabetes education and high standard of delivery. These centres offer the opportunity to act as reference centres to all health care professionals and would no doubt be of invaluable assistance when tailoring diabetes education for individuals from different ethnic backgrounds.

Finally, the Diabetes Education Consultative Section of IDF is a committee made up of nine eminent diabetes educationalists from around the world. This committee is responsible for guiding IDF in the production and dissemination of educational material and the future needs of people with diabetes across the globe.

Each of these initiatives offers the opportunity to act as a bridge for health care professionals, offer guidance in the development of culturally appropriate educational material, facilitate dissemination of best practice and reduce duplication.

Conclusion
Diabetes education remains the cornerstone of diabetes care and management. Despite the increasing evidence to support the effectiveness of diabetes education, many barriers remain leading to poor integration of diabetes education within the health service internationally. Even where access to education is not an issue, uptake by individuals with diabetes is well below target. Recent reports have indicated the need for health care professionals to be more informative about diabetes education when advocating participation. It may be argued that diabetes education should be provided in the form of a prescription along with other medications in an effort to relay the importance attributed to this aspect of care.

A single education programme will not meet the needs of all people with diabetes, thus there is a requirement to listen and understand the needs of specific populations in order that appropriate programmes may be developed. Tailoring of education is paramount if it is to be successful. This must include not only language and writing style but also images, food products, cultural preferences and recognition of the socioeconomic background of the target group. Although a lot of work has been undertaken within the area of diabetes education, few programmes or experiences have been shared either nationally or internationally. There is a need to harness existing tools and use them to facilitate wider dissemination of best practice internationally. Diabetes is a global issue which presents many challenges; only by working collaboratively can we hope to meet the needs of those affected.

References
References are available in Practical Diabetes online at www.practicaldiabetes.com.
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