

A team approach to caring for a refugee child with type 1 diabetes and comorbidities

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Article points

1. Language barriers and cultural differences can present problems for healthcare providers when treating refugee children with type 1 diabetes.
2. Educational literature must be made relevant to the child and their family if good diabetes management is to be achieved.
3. The multidisciplinary team must work closely with families of children with diabetes in order to maintain good diabetes management.

Key words

- Culturally-specific health education
- Healthcare for refugees
- Type 1 diabetes

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This case report describes the care of a child with type 1 diabetes who had severe vomiting and diarrhoea after travelling to the UK from a refugee camp in north-east Africa. It highlights the problems the multidisciplinary team faced when providing relevant education about diabetes management to a non-English speaker who was unfamiliar with British culture. It shows the need for culturally-specific training materials and strong, supportive collaboration between the clinical team and the family of the child with diabetes.

The patient was a 14-year-old girl who had travelled with her father, her pregnant mother and her seven siblings from a refugee camp in north-east Africa to northern England to start a new life. The child presented with symptoms of diarrhoea, vomiting and pyrexia upon entering the UK, which were suggestive of an infectious disease. The family were promptly transferred to a local hospital where the child was cared for on a paediatric ward.

It was subsequently communicated to the paediatric diabetes team by a tuberculosis specialist nurse, who was working with the family, that the girl had type 1 diabetes. Further evidence emerged when an unlabelled insulin vial was discovered among the family's possessions, although diagnosis in the form of a blood test would be necessary for confirmation of the condition. It is recommended best practice for the paediatric diabetes team to provide care to children and young people within 24 hours of presentation to the ward if type 1 diabetes is suspected (NICE, 2004). A senior paediatric consultant with a special interest in diabetes took the lead clinical role for the child's care and initiated intravenous fluids and arranged for blood, faeces, urine and plasma serum samples

to be tested including screening for coeliac disease. This is an autoimmune condition and its incidence in people with type 1 diabetes can be as high as 8.2% (NICE, 2009). Most tests revealed a negative result, but it was detected that the child had been infected with *Salmonella* and she also had pneumonia. The former is normally contracted by eating contaminated food and typically has acute symptoms of vomiting and diarrhoea. The latter can occur as a secondary response to food-borne infection (NHS Choices, 2013a).

The vomiting and pyrexia may have indicated the life-threatening condition, diabetic ketoacidosis (DKA), that can be precipitated when blood glucose levels are consistently high and the internal biochemistry of the body is altered because of uncontrolled gluconeogenesis and lipolysis, resulting in high blood pH levels (NHS Choices, 2013b). This was ruled out by blood tests.

A random (non-fasting) blood glucose test result showed a positive type 1 diabetes diagnosis at 19.1 mmol/L, which the family verified had been diagnosed 4 years earlier and had been managed by daily insulin injections by a healthcare professional.

In accordance with recommendations made by the Best Practice Tariff (BPT), the paediatric

diabetes specialist nurse (PDSN) visited the ward the day after admission to give the child and her family essential equipment to monitor and regulate her diabetes. The Department of Health, responsible for BPT, have devised 14 minimum standards of care to ensure that adequate time and resources are given to the management of paediatric diabetes in order to improve national diabetes outcomes (Randell, 2012). The money generated from the BPT is a flat rate with additional finance provided due to what are termed “unavoidable costs”. This takes into consideration the different needs of hospital trusts. For instance, additional funding may be necessary for a department if the trust’s catchment area has high deprivation levels and lower educational attainment levels than the national average. This is particularly relevant as there is a clear link between low socioeconomic status and poor diabetes control (Chaturvedi et al, 1996). In the context of this individual, many of these challenges existed. Regular support by the paediatric diabetes team, beyond what was usually required, would need to be provided in order to ensure that her diabetes could be safely and effectively managed by the child and her family.

After the administration of intravenous fluids and insulin therapy, the girl was metabolically stable and alert. Training was given to her and her family on the use of a Freestyle Optium blood glucose meter (Abbott Diabetes Care). NICE (2004) recommends that children and young people with type 1 diabetes and their families should be offered a choice of appropriate equipment for undertaking blood glucose monitoring. The PDSN felt it was inappropriate to offer the family a range of blood glucose meters to choose from and instead gave the child a relatively simple operational device. This decision was based on the assumption that not only would the family be unfamiliar with electronic technology, but they had not previously had to manage the condition, which may have resulted in confusion and, therefore, adversely affected compliance.

In this case, training was also provided for use of the NovoPen Echo[®] (Novo Nordisk) insulin pen, which can deliver doses in 0.5-unit increments. This is useful for children who require smaller amounts of insulin in comparison to adults and is a relatively straightforward device to operate.

The child was initiated on the analogue insulin Novomix 30, which contains a combination of rapid-acting (30%) and long-acting (70%) insulin. The two contrasting time-action profiles are designed to ensure that the body receives sufficient coverage to counteract the rising blood glucose levels over a 24-hour period, providing it is injected twice daily. It does not truly mimic the actions of the pancreas and clinical outcomes are not as effective compared with more intensive therapy (Diabetes Control and Complications Trial; DCCT, 1993). However, additional injections require more commitment, which can compromise compliance.

Conventional treatment for patients with type 1 diabetes is multiple daily injection therapy (MDI), which has been proven to be the most clinically effective in reducing the overall rate of long-term complications (DCCT, 1993; NICE, 2004). This requires at least four insulin injections each day and for the patient and their family to learn how to count carbohydrates as the meal-time injection is adjusted based upon the amount and type of food eaten. It was felt in this case that the responsibility of managing multiple injections would be too great for the child and her family.

Novomix 30 works more effectively when taken with three carbohydrate-based main meals with a similar quantity of carbohydrate. These need to be supplemented with a further three carbohydrate-based snacks, eaten between main meals and before bedtime to ensure that stable blood glucose levels are achieved (Smart et al, 2009). For instance, if her country’s staple food, ugali (a carbohydrate-heavy cornmeal porridge), was eaten at breakfast, this would be fine, providing a similar amount of carbohydrate was eaten at lunch and in the evening too.

The family’s mealtime routine in Africa was ascertained through an interpreter. It consisted of breakfast, midday lunch and an evening meal, with staple carbohydrate-rich foods being accompanied by a protein source, such as meat or beans.

Concomitant illness

After further medical investigations it was revealed that the child had cardiomyopathy, also known as an enlarged heart. This can cause a thrombus, which results in a clot forming in the blood vessels, increasing the risk of a heart attack or stroke (British Heart Foundation, 2014). During the same medical

Page points

1. Low socioeconomic status is linked to poor diabetes control.
2. An insulin therapy regimen that was appropriate for a child whose family was adapting to a new life in the UK was chosen.
3. The child was found to have cardiomyopathy which was thought to be unrelated to her diabetes.

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investigation, it was discovered that she had a couple of infarctions, which the team attributed to the heart condition. The dead tissue was found in the renal and cerebral areas of her body. Damage to the microvascular system, particularly the kidneys, is a known complication of diabetes. However, it tends to manifest after a number of years and is normally seen in older patients. Since this child was young and her diabetes was relatively recently diagnosed, this was unlikely to be the cause (Diabetes UK, 2012). Warfarin therapy was initiated to reduce the blood viscosity and the child was transferred to a specialist hospital to receive further treatment for her heart condition.

Social issues

The family's transfer to the UK had been supported by an immigration charity. A support worker was assigned to the family to assist with their adaptation into the country. While the child needed long-term inpatient care because of the complication of her heart condition, the family were housed in a modest four-bedroom terraced property which was not big enough for them, which meant that they were living in extremely cramped conditions.

Refugees and asylum seekers, who are commonly exposed to high levels of deprivation and possibly stress, have been found to be less likely to access healthcare provision (Jayaweera, 2010). This was a concern when it came to discharging the child as her existing multipathology would mean that she would need rapid access to healthcare services if her condition worsened. Anxiety could also have made control of her blood glucose levels more difficult. However, her family proved to be able to support her diabetes management, they were keen to learn about their child's condition and they responded well to the multidisciplinary team's advice. Current evidence suggests that a child that is supported to self-manage their condition is more likely to avoid hospital admissions due to complications, have better diabetes outcomes and an improved quality of life (Diabetes UK, 2009).

Delivering diabetes education despite a language barrier

Since none of the family was able to communicate in English and were unable to read or write in their own language, interpreting services (efficiently

provided by the hospital trust via an agency) were required whenever contact was made with the family. Education was delivered using core topics, such as examining the link between food and blood glucose level, why poor control is a catalyst for the onset of osmotic symptoms and how insulin therapy is able to promote glucose uptake into the body's cells (Smart et al, 2009).

Diabetes education increases skills and confidence which enables self-control and has a positive impact upon clinical outcomes and quality of life (Department of Health and Diabetes UK, 2005). Educating patients in hospital can be challenging as the environment is usually busy and there is little privacy, which can affect concentration levels. Although ward meals are structured, they are seldom representative of what is prepared at home and people often find it difficult to attach relevance to diabetes education based on hospital meals. However, the Department of Health (2007) suggested that problem-based learning has been shown to be effective in delivering the core principles of education ensuring that the person becomes skilled in that discipline.

A visual teaching aid, supplied by a pharmaceutical company, was used to educate both the family and the child about diabetes core topics. Used by the team with all families with a newly diagnosed child, the aid comprises a magnetic board featuring the outline of a human body and the organs responsible for digestion. Additional pieces represent carbohydrate foods, glucose molecules, cells and insulin. Other illustrative teaching aids included the “eatwell plate” (Department of Health, 2011), which displays British staple foods and drinks. This was useful to discuss the benefits of healthy eating and to identify carbohydrate sources. However, many of the foods (such as yoghurt, chips, cereal, sliced bread and roast potatoes) were unrecognisable to the child, which meant that additional time had to be spent trying to describe what they were. Typical carbohydrate sources for the family included injera flatbread, chapattis, rice and ugali. This highlighted the need for resources translated into African languages, although the child and her family had relocated to an area where the proportional representation of families from Africa was quite low, and justifying the expense of producing such a resource would

have been difficult. Accompanied by the family and interpreter, a supermarket tour of the local halal supermarket was carried out to ascertain typical food choices and used as an opportunity to educate them about carbohydrate foods, healthy eating and suitable snacks to use in the event of a hypoglycaemic episode.

A visual aid was produced for little cost after speaking with the girl and her family about their eating habits. It emphasised the importance of meal structure and regularity, and contained a combination of African and British foods placed next to the time of day. NICE (2004) recommends that education should be customised to the child's needs. This may include factors such as age, maturity and culture. This method of education had to be demonstrated to the girl in the hospital ward and whole family at their home, as the parents would largely make the decisions about meals and meal times. The girl, who had not received diabetes education before, was attentive and learnt quickly. Her father was also keen to learn, while her mother appeared happy to allow him to take responsibility for his daughter's diabetes care – the team were not able to find out the reason for this.

Discharge

Several multidisciplinary meetings occurred to decide how the girl's discharge could be practically managed (*Box 1*). Concerns were shared over who would be responsible for measuring her international normalised ratio (INR) and how and where the warfarin should be dispensed. Equally, there was a worry over the obvious clinical risks concerning her insulin therapy and the importance of a treatment routine. For instance, each injection would require a 6-hour gap, as anything less could result in a higher risk of hypoglycaemia. Conversely, if one of the injections was delayed or even missed, her blood glucose level could become dangerously raised.

In 2011–12, a median of nearly 10% of children with diabetes in England aged 10–19 were admitted to hospital due to DKA. Similarly, admissions due to the incidence of hypoglycaemia were just over 5% within the same age group (National Paediatric Diabetes Audit Project Board and Royal College of Paediatrics and Child Health, 2014). Good glycaemic control would reduce this risk and it was hoped that this child – who had been used to

Box 1. Members of the multidisciplinary team involved in the discharge process and their responsibilities.

- **Lead consultant**
The overall decision-maker during in-patient care and discharge planning.
- **Cardiac consultant**
To liaise with the medical team at the specialist hospital and lead on heart-related treatment.
- **Paediatric diabetes team dietitian and nurse**
To ensure that diabetes control was stable based upon assessment and monitoring of the insulin dose and quantity of carbohydrates eaten. To educate the family about the practical management of diabetes.
- **Pharmacist**
To ensure that the appropriate type and dose of heart and diabetes-related medications were prescribed.
- **Community nurses**
To gain an understanding of the child's medical and social situation and to plan the provision of supportive care in the home.
- **Support worker**
To continue to support the family in their social needs (e.g. housing, financial benefits, English language education and medical appointment attendance).
- **Ward nurse**
To inform the team about the child's progress on the hospital ward.
- **Education department representative/special educational needs coordinator (SENCO)**
To discuss school transition planning, and healthcare and educational needs.

daily visits to hospital for injections – would be able to adhere to the treatment regimen. She was discharged after 6 months and a care plan was constructed to ensure that information could be distributed to the team involved in her care. This also contained details of twice-weekly hospital visits for INR monitoring and to continue warfarin.

Future issues

The child is now waiting for a secondary school place in a UK school. It is hoped that this will enable her

Page points

1. NICE recommendations state that diabetes education should be customised to a child's needs, such as their age, maturity and culture.
2. Starting school in the UK would help to provide a structure to the child's day which may boost her compliance to her treatment regimen.
3. Adolescence can often see a rise in more high-risk behaviours that can interfere with diabetes management.

“As the child grows older there will be fresh challenges for the family and the clinical team.”

to integrate into British culture and adapt to life in this country. It will help to formulate a day-to-day routine, which is particularly beneficial with regard to the timing of insulin injections around regular meal-times. Furthermore, it will provide her with the opportunity to learn English, which it is hoped will promote a sense of belonging among her peers, increase her confidence and help her to have a better quality of life. Emotional well-being is extremely important, particularly as there is a well-documented link between diabetes and depression, especially if control is markedly poor (Lustman and Clouse, 2005).

She has recently entered adolescence and this is a period when diabetes control can deteriorate. Adolescence sees young people embark on a journey of self-discovery where they seek out an identity for themselves. It is often a time when they engage in high-risk behaviours, such as excessive alcohol drinking and drug-taking, which all have a direct effect on blood glucose control. The multidisciplinary team – particularly the children’s diabetes team – will have a responsibility to promote awareness and provide support during this period (Court et al, 2009).

Conclusion

The multidisciplinary team found this to be an extremely complex case and this was largely because the team had very little experience of treating a child from Africa, despite a large proportion of their caseload relating to families from an ethnic background with English as a second language. The team were unfamiliar with the cultural traditions and eating habits of the child’s particular culture, and learning more about this was quite difficult because of the pronounced language barrier. It is unusual for the team to be caring for a family with no English speakers. Furthermore, the concomitant illnesses complicated the discharge planning, which was carefully and gradually phased from an initial few hours’ home leave.

The whole process gave the team a valuable opportunity to learn about providing appropriate care for patients from other countries who are seeking a new life in the UK, and to reflect on the value of a multidisciplinary team. It highlighted the importance of delivering diabetes education that can be adapted to have relevance to the food and customs of people from different ethnic minority groups.

Valuable experience in overcoming the challenges

of helping to organise the transition to school of a child with diabetes was gained by the team. This was a complicated process involving consideration of health and safety issues, liaison with representatives of the school and education of school staff.

As the child grows older there will be fresh challenges for the family and the clinical team. Adapting to a new country and its language, culture and health system will take time but, with continuing support from the clinical team and the child’s family, there is no reason why good diabetes management cannot be achieved. ■

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