

Managing children with type 1 diabetes in collaboration with primary care

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The most recent NICE guidelines suggest that “children and young people with type 1 diabetes should be offered an ongoing integrated package of care by a multidisciplinary paediatric diabetes care team” (NICE, 2004). Traditionally, paediatricians and paediatric healthcare professionals have managed the care of children with diabetes, although data from serial reviews of UK paediatric service provision suggest that there has been variable input from adult-trained diabetologists, specialist nurses and dietitians (Edge et al, 2005). This article discusses the role of primary care in caring for children with diabetes and the ideal structure of an integrated paediatric diabetes service.

Primary care is often the first port of call when a child presents with symptoms of diabetes, and it is likely that the GP will be the first to explain the possible diagnosis. The GP may know the family well and be aware of the potential impact such an overwhelming diagnosis will have on family dynamics and stability.

The primary care team will also be aware of other factors that may affect the ways in which the child and family cope with the diagnosis and the condition. The GP may have a greater understanding of the possible barriers to engagement with diabetes management, will consult with the child for non-diabetes-related episodes of ill health and also provides repeat prescriptions. Thus, the GP and practice nurse may have insights into concordance with medication and management advice as well as other relevant issues. The primary care team may also be more aware of the mental and physical wellbeing of parents and other family members.

UK national audit data suggest that children and young people with diabetes have poor diabetes care as judged by the average HbA_{1c} level (NHS Information Centre, 2007). There are likely to be many reasons for this, but could the care of the child with diabetes be improved by closer working with primary care?

In answering this question it is important to consider the opportunities for joint working between paediatric healthcare professionals and primary care teams based on the key priorities for children and young people made clear by the NICE (2004) guidelines.

Integrated care

1. Diagnosis

“Children and young people with suspected type 1 diabetes should be offered immediate (same day) referral to a multidisciplinary paediatric diabetes care team that has the

Article points

1. It is important to consider the opportunities for joint working between paediatric healthcare professionals and primary care teams based on the key priorities for children and young people made clear by the NICE (2004) guidelines.
2. Good lines of communication need to be developed between primary and secondary care so that discussions can be had without delay regarding any child who may be creating diagnostic uncertainty.
3. There is a great deal of scope for integrated working between primary and secondary care in the management of childhood type 1 diabetes.

Key words

- Paediatric services
- Education
- Transitional care

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Page points

1. Children with dominantly inherited forms of diabetes, such as maturity onset diabetes of the young (MODY) and those with type 2 diabetes, are increasingly being recognised and cause diagnostic dilemmas even for experienced paediatric diabetologists.
2. Paediatricians are very familiar with diagnostic uncertainty, and in the authors' experience, are always happy to support other healthcare professionals where the clinical picture may be ambiguous.
3. A special area of teaching that is often provided by primary care is education regarding sexual health, contraception and preconception care.

competencies needed to confirm diagnosis and to provide immediate care" (NICE, 2004).

Children presenting with symptoms consistent with type 1 diabetes (polyuria, polydipsia and loss of weight) constitute a potential medical emergency and should be referred for a paediatric assessment immediately. Good lines of communication need to be developed between primary and secondary care so that discussions about any child who may be creating diagnostic uncertainty can be had without delay. The hospital-based paediatric diabetes nurse specialist can play a role in facilitating admission and dealing with clinical and practical management problems.

Children with dominantly inherited forms of diabetes, such as maturity onset diabetes of the young (MODY) and those with type 2 diabetes, are increasingly being recognised and cause diagnostic dilemmas even for experienced paediatric diabetologists. There is no doubt that paediatricians are more than happy to accept calls from primary care at any time of day as an early phone call is much easier to deal with than a child brought in, seriously ill, with diabetic ketoacidosis. Paediatricians are very familiar with diagnostic uncertainty, and in the authors' experience, are always happy to support other healthcare professionals where the clinical picture may be ambiguous.

2. Education

"Children and young people with type 1 diabetes and their families should be offered timely and ongoing opportunities to access information about the development, management and effects of type 1 diabetes. The information provided should be accurate and consistent and it should support informed decision-making" (NICE, 2004).

There are currently no evidence-based structured education programmes for children with diabetes or their families, although there are a number of studies underway that will be reporting in the next few years (Murphy et al, 2006; Waller et al, 2008). Diabetes education is therefore normally provided in a semi-structured way by paediatric healthcare teams. Education also occurs opportunistically during clinic appointments. This practical advice at

the time of difficulty or change, which may be new information or the consolidation of old knowledge, is very well received and well retained.

People with diabetes and their families will go to see their GP for a variety of non-diabetes-related problems, but issues regarding diabetes may arise out of these conversations. However, it is unreasonable to expect GPs to be knowledgeable about all aspects of diabetes care. Clinicians in primary care will have the skills to identify the concerns of the child with diabetes and their family, but may not have the knowledge to provide the correct answers. Good relationships between practice nurses and diabetes specialist nurses will facilitate communication and help to ensure that information is accurate and appropriate. Referring people back to their main diabetes team is likely to be helpful but there are other resources which are listed at the end of this article.

A special area of teaching that is often provided by primary care is education regarding sexual health, contraception and preconception care (Donovan et al, 1997). Adolescents, normally girls, may rarely ask their paediatric team for this advice and are often prescribed contraceptives by their GP or practice nurse. Many practices now have easy-to-access clinics so that adolescents can consult with a practice nurse in confidence about their worries or needs. Although a number of paediatricians will ask about sexual health matters, many adolescents may not want to discuss these issues in a "paediatric" setting and prefer to go to what may be perceived as a more "adult" environment (Jacobson et al, 2002).

Adolescence is a time when young people may experiment with drugs and when exam stresses can influence behaviour. It can be helpful for the clinician in primary care to give the child with diabetes, or their family, time to focus on these issues, leaving the diabetes in the background. There are a number of studies that highlight the importance of aiming for very tight glycaemic control during pregnancy, and the importance of preparation for pregnancy for girls with diabetes cannot be overstated (NICE, 2008). In the authors' opinion there is no doubt that GPs do provide an essential service in preventing obstetric disasters in young girls with diabetes.

3. Monitoring glycaemic control and screening for complications

“Children and young people with type 1 diabetes and their families should be informed that the target for long-term glycaemic control is an HbA_{1c} level of less than 7.5% without frequent disabling hypoglycaemia” (NICE, 2004).

NICE (2004) recommends that glycaemic control is measured every 3–6 months in children with type 1 diabetes. Many children have measurements of HbA_{1c} performed using capillary sampling of blood rather than formal venepuncture which appears to suit most children and young people; it seems appropriate that this is performed by the same team on each occasion to avoid duplication of blood tests and repeated sampling for young people. In addition, children and young people should be screened for evidence of microvascular complications from the age of 12 and for associated autoimmune conditions (thyroid disease and coeliac disease) from diagnosis (NICE, 2004). As most children are managed in secondary care, testing and reporting of results is best done by this team of professionals. Any abnormal results can also be dealt with more effectively.

In every clinic there are children and young people and their carers who find it difficult to engage with or prioritise their diabetes management, and some also fail to attend clinic appointments. They may still go to primary care for other illnesses or advice and this may provide a reasonable opportunity for GPs to discuss diabetes management. This may also be a good time to offer an annual review to make sure that the child with diabetes remains healthy, even at a time of poor adherence. The paediatric diabetes nurse specialist can be a very helpful link, alerting practices to people who need to be followed-up and, where available, testing them at home.

Screening for complications is important at any age, but the primary care team must be careful when dealing with prognosis and their worries about what may happen to the individual whose diabetes control is suboptimal. The agendas and priorities of young people are usually very different from those of adults and they need to be respected so that a good clinician–patient relationship is maintained.

4. Diabetic ketoacidosis (DKA)

Children and young people with DKA should be treated according to the guidelines published by the British Society for Paediatric Endocrinology and Diabetes (Edge, 2004).

Studies from the UK suggest that up to 40% of cases of DKA occur in children newly presenting with diabetes (Warner et al, 1998; Edge et al, 1999), which implies that the diagnosis of some cases of diabetes may be missed in primary care. Diabetes is becoming more common in children under 5 years of age and DKA is more prevalent in this younger age group (Warner et al, 1998; Edge et al, 1999; Neu et al, 2003). Young children, especially infants and toddlers, will not be able to help themselves to the extra fluid that they need to compensate for the polyuria that accompanies glycosuria and present seriously ill with dehydration and hyperglycaemia.

5. Psychosocial support

“Children and young people with type 1 diabetes and their families should be offered timely and ongoing access to mental health professionals because they may experience psychological disturbances (such as anxiety, depression, behavioural and conduct disorders and family conflict) that could impact on the management of diabetes and wellbeing” (NICE, 2004).

The extent to which a chronic medical condition will have a negative impact on the individual’s ability to manage their condition will depend on the personality traits of that individual and their wider support mechanisms (Silverstein and Johnson, 1994). Developing such a condition in childhood or adolescence will also have a significant impact on family and carers.

Emotional problems are well recognised in childhood diabetes, especially in adolescents, but frank psychiatric disorders are rare (Dovey-Pearce et al, 2007; Helgeson et al, 2007). Many paediatric services have limited access to mental health professionals and probably manage some less severe problems within the diabetes service. Healthcare professionals in primary care may also be approached during times of difficulty as some young people may prefer to talk to staff who are not directly involved with their diabetes

Page points

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Resources for information on diabetes in childhood.

Diabetes UK:
www.diabetes.org.uk

International Society for Paediatric and Adolescent Diabetes (ISPAD):
www.ispad.org

Children with Diabetes:
www.childrenwithdiabetes.com

management; not all problems are as a result of diabetes but many will impact on diabetes self-care. The GP can help, liaising with or referring to the local children and adolescent mental health service team, discussing problems with the health visitor or school nurse, for example. GPs and practice nurses support many families through the challenges of adolescence and this experience is available to the young person with diabetes (Jacobson et al, 2002).

Other areas of joint working

Transitional care

“Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated healthcare systems” (Rosen et al, 2003).

The standard models of transitional care involve variations in working between adult and paediatric secondary care services, yet a number of young people who need to graduate to adult care do not attend hospital services at all. The role of primary care does not appear to have been explored at all.

In Coventry we would ask primary care teams to review those individuals who are unable to come to our clinic appointments or to arrange meetings with our diabetes nurses. However, although copies of all correspondence from secondary care go to primary care, it is very unusual for any reciprocation if our patients are reviewed by their GP. Opening uncomplicated lines of communication between services may be of benefit for these “lost” individuals. The implementation of electronic health records will facilitate two-way communication at this important time.

The primary care team may take some time to identify young people who have lost contact with their paediatric team. The monitoring of repeat prescriptions is a useful way of identifying people who have “fallen through the gaps”. Some practices will limit the issuing of prescriptions as a method of drawing the young person into contact with the practice nurse, establishing a relationship and then moving on to monitoring and helping with the management of the diabetes.

Geography

In some parts of the UK children live a great distance from their local diabetes clinic. With a greater emphasis on services being provided closer to patients (Department of Health, 2008), the role of primary care in managing childhood diabetes may need to be considered. Some paediatric services will provide outreach clinics and some of these could occur in primary care centres. It may then be possible for joint clinics to be held, which would expand the multidisciplinary team and is likely to improve the clinical skills of all concerned. However, it would be important to have well considered protocols for all of the practical aspects of management so that a consistent message is provided by all members of the team.

Families from ethnic minority backgrounds

National audit data suggests that only 7% of children with type 1 diabetes come from Black and minority ethnic groups (NHS Information Centre, 2007). The majority of these families are likely to congregate in relatively discrete geographical locations and present to a small number of paediatric services.

Interpreters are essential to aid accurate communication of information. A number of these children will also come from families with significant experience of type 2 diabetes and there may be misconceptions about the nature, treatment and long-term outcomes for the child with type 1 diabetes. These other relatives will be managed by the GP who will be able to provide extra support, advice and information to the families to help to adjust to the new diagnosis and advise about management.

Conclusion

There is a great deal of scope for integrated working between primary and secondary care in the management of childhood type 1 diabetes. Both teams have strengths that are mutually supportive and complementary. More work needs to be done to develop closer links between primary and secondary care and to develop robust care pathways to improve the lives of children and young people with diabetes. ■

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