

Innovative approach to improving care for diabetic adolescents

Carol Carson

ARTICLE POINTS

1 Adolescents face increased risks of long term complications due to their normal age-specific behaviours.

2 Social and psychological well being are important factors in the management of adolescents with diabetes.

3 By improving the glycaemic control of this group, long term health and economic savings can be made.

4 The role of the diabetes specialist nurse for adolescents can enhance the support, education and care of this group.

KEY WORDS

- Adolescents
- Diabetes nursing
- Client-centred approach

Carol Carson is Diabetes Specialist Nurse (Adolescents) at the Royal Hospital for Sick Children, Edinburgh. She was previously Diabetes Specialist Nurse (Adolescents) at the Royal Infirmary of Edinburgh.

Introduction

Adolescents with diabetes are at high risk of long term complications due to their lifestyle and increased risk-taking behaviours. By giving individual support, addressing social and mental health issues, self-confidence can be increased leading to improved self management and long term health and economic savings. The introduction of a dedicated nurse for adolescents in Lothian has been successful in meeting the challenges offered by this demanding group.

The Diabetes Focus Group in Lothian identified a need to improve services for diabetic adolescents. They recognised that the care of this high-risk group fell between the paediatric and adult services, and felt that the long-term outcomes of this group could be improved by individualising care for these patients, by providing education, care and support appropriate to their needs.

The post of specialist nurse for diabetic adolescents was created in 1996 to care specifically for the needs of 14–18 year olds. Although many specialist nurses care for patients in this age group, it is thought that this is the only post dedicated purely to looking after this vulnerable group. The general aims of the post are shown in *Table 1* and a more detailed description of functions is given in *Figure 1*.

The post covers five hospital trusts within a large area, including urban, rural, affluent and deprived areas. *Table 2* shows the dimensions of the post. The post offers many challenges, ranging from denial of diabetes to over-protective families, drug experimentation and alcohol use, to obsessive control. Many of the challenges are related to normal adolescent behaviour, which is the opposite of the behaviour needed for good diabetic control.

Background to the post

Adolescent behaviour

The adolescent group is one of the most demanding to work with and difficult to support. Some of the reasons for this

are outlined by Thomson et al (1995), who recognise that normal adolescence involves emotional and physical turmoil, and culminates in resentment and rejection of authority, which includes parents and teaching, medical and nursing staff. As this is normal behaviour in adolescents, the adolescent with type 1 (insulin-dependent) diabetes has even more to come to terms with and manage. Apart from difficult normal behaviours, this group also suffer from common problems which can cause further management problems (*Table 3*).

Main factors in poor control

Failure to keep contact with the clinic can lead to disaster (Thomson et al, 1995). It is important for the adolescent with diabetes to maintain some form of contact, even if he/she does not attend the clinic. This leaves the way open for more formal contact in the future.

Another important cause of poor control in this group is self-mismanagement, as recognised by Weissberg-Benchell et al (1995). Omission of insulin as a deliberate means of weight control is common among adolescent females, as is omission for other reasons such as rejection of diabetes. The organisation and foresight needed for good diabetic control are alien to the normal disorganised lifestyle of adolescents.

Importance of psychological and social wellbeing

The inherent difficulties in this group, coupled with high-risk behaviour such as

smoking, drinking alcohol to excess and taking drugs, indulged in by many, results in chronic, poor glycaemic control. Hentinen and Kyngas (1996) advocate giving more attention to adolescents as individuals, and adopting a client-centred approach to care and education. If patients are involved in planning their care they are more likely to keep to agreed plans.

Nichols (1996) recognises that the psychological wellbeing of clients maximises their potential to benefit from care, support and education. Without support, the potential of an individual may not be fully realised, and self-care will deteriorate. Fosbury et al (1996) stress the importance of psychological care, while Gardner (1997) recognises that both social and psychological wellbeing are important. It is therefore essential to address the mental and social health of patients, offer them appropriate support and refer them on to other agencies, if necessary, for the support they need.

Psychological wellbeing cannot usually exist without social wellbeing — without them we cannot expect optimum self-care, motivation, compliance or attendance. There is a high clinic default rate within this group. Sufficient time must be taken with individual clients to carry out a holistic assessment. Care and education plans must be negotiated with individuals to set achievable targets for the individual, and must be offered in an acceptable manner.

With this client-centred approach, individuals can achieve their goals at their own pace; their responsibility and self-confidence increase as the sense of failure and guilt that accompanies poor control is reduced.

Potential health and economic savings

The British Paediatric Association Working Party (1990) reviewed some of the literature from the previous 20 years on the prognosis of young diabetics. The findings are shown in Table 4. This review emphasised the appalling outcomes for this group and the undeniable need to improve them.

There are great potential savings to be made, in terms of health and quality of life, for this client group, as well as savings from the costs of treatment and resources required for their future care. The Diabetes Control and Complications Trial (DCCT Research

Table 1. General aims of the post

- To develop services for this group, focusing on specific educational needs
- To implement seamless service from childhood to adulthood
- To maximise the enjoyment of this stage of life
- To reduce dangerous practices of this client group
- To reduce long-term complications
- To enable clients to live longer and healthier lives

- A.** To identify all patients with type I (insulin-dependent) diabetes between the ages of 13 and 18 years in Lothian
- B.** To select the most suitable adolescent clinic for these patients and to arrange transfer at appropriate times
- C.** To identify the 'at-risk' patient, i.e. those with chronically poor glycaemic control, those with evidence of early microvascular disease and those who have defaulted from specialist supervision
- D.** To reintroduce defaulters to an appropriate adolescent clinic
- E.** To focus on the particular needs of adolescent clients with type I diabetes with particular reference to:
 - (i)** Changing from a paediatric to an adolescent and subsequently to an adult clinic, stressing the need for the individual's commitment to his/her diabetes and no longer relying on parental input, to establish the need for diabetes re-education on an individual basis
 - (ii)** Problems relating to management of diabetes in adolescence, e.g. leaving school, starting a job, commencing higher education, sport, cigarette smoking, family planning, exposure to drugs, driving, life insurance and other insurance
 - (iii)** Further liaison with other professionals who have contact with adolescents with type I diabetes, for example:
 - Diabetes Specialist Nurses
 - School and college teachers
 - Family planning staff
 - Practice nurses

Figure 1. Aims of the position and role of the post-holder.

Group, 1994) advocates investment in the adolescent group to reduce these costs and suffering. Many of the costs are hidden: examples include personal, emotional and social costs, costs incurred through absences from work, costs to the benefits system, and costs to carers, family and friends.

The DCCT Research group (1993) linked improved diabetic control with a reduction in long-term side-effects. The trial emphasised the importance of good glycaemic control in delaying the onset of microvascular disease and reducing its incidence in people with diabetes. The trial also proved that intensive support of

Table 2. Dimensions of the post

- Across five hospital trusts
- Working with eight consultants
- Area of 1,753 km²
- Population of 724,000
- Approximately 150 adolescents with diabetes
- Annual turnover of 20%
- One weekly clinic
- One monthly clinic
- Two 3-monthly clinics
- 95% of contact in the community (apart from clinics)
- 98% of contact outside school or client's work hour

Publisher's note: This image is not available in the online version.

Figure 2. The annual Furbush Project, funded by Novo Nordisk and attended this year by the author, allows health care professionals to educate adolescents about their diabetes in an informal environment.

PAGE POINTS

1 Staff have been allowed to expand their skills and develop their services.

2 An improvement in glycaemic control, with a resultant reduction in the incidence of long-term complications, will have financial as well as personal benefits.

3 The care of young people with diabetes will be improved by the education of their parents, carers, teachers and social workers.

diabetics was effective in improving their overall control — increasing input equating with better outcomes.

Nursing achievements after 18 months in post

All aims of the post (as described in *Table 1*) were met within the first 12 months of it being set up. Additional developments within each trust have been facilitated, which have not only benefited adolescents with diabetes, but also, by releasing staff, allowed individuals to develop their services and benefit other groups with diabetes.

This is particularly evident in paediatrics, where the number of under-5s being diagnosed with diabetes has increased dramatically in the Lothians; the nursing staff are now able to spend more time with the younger patients and their families.

Staff have also benefited by being able to develop their skills in other areas of diabetes care. The clinic sister in the

diabetic outpatients department of the Royal Infirmary of Edinburgh found that her staff had more time for patient education after the post was established and the care of adolescents was taken over by the specialist nurse for adolescents. The post has been viewed with great interest by diabetes teams from other geographical areas.

With the incidence of type 1 diabetes in young people estimated to double every 20–30 years (Lothian Health, 1995), the need for specialist staff for this group is clear.

Evaluation of the post

The specific needs of adolescent diabetics have long been recognised. The creation of this post has, in a short period, improved the quality of care provided to this group in Lothian. An improvement in glycaemic control, with a resultant reduction in the incidence of long-term complications, will have financial as well as personal benefits.

It is inappropriate to use conventional measurements of clinical outcome so early in this project. However, certain outcome indicators suggest early success — increased contact with the diabetes clinic, identification and follow-up of chronic defaulters, identification and contact with those who were lost to the service, the reduction in glycated haemoglobin (HbA_{1c}) of those with intensive input, the increased uptake of diabetes and specific health education along with psychological and nursing support, uptake of client-led care and the use of holistic assessments.

Indirect benefits

The education of carers, including parents, school staff, social work staff and staff from voluntary organisations, will also improve the care of young people with diabetes, as will the improved coordination of services and communication within the diabetes teams. The long-term outcomes of educating carers in the community have not been formally assessed, but the uptake of education has been high. In many cases there is an enthusiasm to learn more about diabetes and great relief has been expressed, particularly by teachers, when the mystique of diabetes has been removed. It has helped teachers to understand the needs of their diabetic pupils and has reduced absences

Table 3. Common problems in adolescence

- Emotional problems
- Sexual problems
- Behavioural problems
- Trouble with the law
- Eating problems
- Drug, solvent and alcohol abuse

Source: Royal College of Psychiatrists, 1995

Table 4. Findings from the British Paediatric Working Party, 1990

- Life expectancy of young people with diabetes was 29 years
- 60% were dead within 40 years of diagnosis
- 34% died of renal failure or myocardial infarction
- 30% were blind or visually impaired
- 12% had gangrene or had undergone lower limb amputations
- The list of complications includes those affecting all major systems of the body, leading to poor quality of life, lengthy hospital admission, expensive treatments and death

from school which were blamed on diabetes.

The post-holder leads pre-clinic meetings, which the entire team attends, at which she presents summaries of contact with the patients attending the clinic. These summaries form the basis of discussion about the patient; they enable the team to share ideas, learn from each other and plan the care that will be offered to and discussed with the patient. This has greatly improved communication within the diabetes team by keeping the team well informed about the patients and by creating a forum for the discussion of each patient individually.

Meeting local and European standards

All of the above improvements in care go some way towards meeting the standards set out in Diabetes Care and Research in Europe (Krans et al, 1995), The St Vincent Joint Task Force for Diabetes (Department of Health and British Diabetic Association, 1995) and the Report on Good Practice in the Care of Children and Young People with Diabetes (Scottish Intercollegiate Guidelines Network, 1996). The post also encompasses the strategic objectives and principles of Lothian Health's Children and Young People's Health Strategy (1997). It is clear from the work done by the DCCT that input appropriate to the needs of adolescents with diabetes improves diabetic control and outcomes. However, it must be ongoing to maintain improvements.

Conclusion

The post of specialist nurse for diabetic adolescents was created in recognition of the specific needs of this group, outlined above. It was not possible to provide this specialist service within the constraints of existing staffing levels. The Diabetes Focus Group

therefore advocated the establishment of the post in the hope that it would be successful and become an established part of the diabetes services for Lothian. ■

British Paediatric Association Working Party (1990) The Organization of Services for Children in the United Kingdom: Report of the British Paediatric Association Working Party. *Diabetic Medicine* 7(9): 457-63

DCCT Research Group (1993) The effect of intensive treatment of diabetes on the development and progression of long term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine* 329(14): 977-86

DCCT Research Group (1994) Effect of intensive diabetes on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus: Diabetes Control and Complications Trial *Journal of Paediatrics* 125(2): 177-88

Department of Health and British Diabetic Association (1995) *St Vincent Joint Task Force for Diabetes: The Report*. Department of Health and British Diabetic Association, London

Fosbury J, Moore S, Kidd J, Sonksen PH, Amiel S (1996) Psychological issues in the diabetic clinic. *Practical Diabetes International* 13(3): 92-3

Gardner P (1997) Social and psychological implications of diabetes mellitus for a group of adolescents. *Practical Diabetes International* 14(2): 43-6

Hentinen M, Kyngas H (1996) Diabetic adolescents' compliance with health regimens and associated factors. *International Journal of Nursing Studies* 33(3): 325-37

Krans HMJ, Porta M, Keen H, Johansen KS (1995) *Diabetes care and research in Europe: the St. Vincent Declaration*. 2nd edn. The World Health Organisation, Copenhagen

Lothian Health (1997) *Children and Young People's Health Strategy: A Consultation Document*. Lothian Health, Edinburgh

Lothian Health (1995) *Health in Lothian 1994. Annual Report of the Director of Public Health and Lothian Health Annual Report 1994/1995*. Lothian Health, Edinburgh

Nichols K (1996) Diabetes education and psychological care. *Practical Diabetes International* 13(3): 83-5

Royal College of Psychiatrists (1995) *Surviving Adolescence*. Dista Products Ltd, London

Scottish Intercollegiate Guidelines Network (1996) *Report on Good Practice in Care of Children and Young People with Diabetes*. Scottish Intercollegiate Guidelines Network (SIGN), Edinburgh

Thomson C, Greene S, Newton R (1995) Diabetes and adolescents *Diabetes Reviews International* 4(4): 2-5

Weissberg-Benchell J, Glasgow A, Tynan D, Wirtz P, Turek J, Ward J (1995) Adolescent diabetes: management and mismanagement. *Diabetes Care* 18(1): 77-82

PAGE POINTS

- 1 Team discussions of patients enable the team to share ideas, learn from each other and plan care for the patients.
- 2 Input that is appropriate to the needs of adolescents with diabetes improves diabetic control and outcomes but must be ongoing to maintain improvements.
- 3 The Diabetes Focus Group advocated the establishment of the post of Diabetes Specialist Nurse for Adolescents in the hope that it would prove successful and form an intrinsic part of the diabetes services for Lothian.