

Adolescence to adulthood: how to keep adolescents in the system

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ARTICLE POINTS

- 1** The diabetes nurse specialist has a pivotal role in the care of adolescents with diabetes.
- 2** Relationships between patients and staff are the key to effective care.
- 3** Listening to patients and taking their views and wishes into consideration when planning and delivering care are essential parts of patient care.
- 4** Joint transitional care offers an effective model of care to adolescents.
- 5** Transfer to and from adolescent services should be planned and negotiated.

KEY WORDS

- Adolescents with diabetes
- DSN for adolescents
- Patient participation
- Consistency of care
- Joint transitional care

Introduction

Much has been written about young people with type 2 diabetes, including a plenitude on the difficulties of working with this particularly vulnerable group (Thomson et al, 1995). The difficulties incurred are often related to a lack of understanding or agreement, between practitioners, on the service itself. An effective service must be acceptable and accessible, meeting the needs of the group for whom it is intended. There must be agreement and collaboration between practitioners, with clear understanding of each other's roles in providing the knowledge and expertise required for the service. The patient should be a central participant in the planning and delivery of his/her care.

Recent publications emphasising guidelines and frameworks include: The Scottish Intercollegiate Guidelines Network (2001), Department of Health (2002); Scottish Executive (2002); Clinical Standards Board for Scotland (2002) and National Institute for Clinical Excellence guidelines (2001). These have placed a lot of emphasis on targets and outcomes, without necessarily looking at the process.

Policy or patient driven?

There is a danger that patient participation may receive less prominence than intended. As a consequence, the small but significant group of adolescents with diabetes (2000 aged <16 years in Scotland, according to the Scottish Intercollegiate Guidelines Network, 2001) may have a nationally target-driven service that does not meet their specific and well-documented age-related needs (Carson and Kelnar, 2000).

The human element, which is perhaps the most important factor in supporting young people with diabetes, must not be underestimated (Kyngas et al, 1998). There is a great risk that the clinical agenda set by professionals will not meet patients' needs and may become disempowering for patients, leading to low satisfaction and poor uptake of services. Many centres report high default rates at adolescent clinics, without looking at the reasons why.

Adolescent services

Adolescents are recognised as a group that requires specialised care from a specialist service (British Diabetic Association, 1995; Scottish Intercollegiate Guidelines Network, 2001). This dictates that an adolescent service should be provided by secondary care specialist teams. As yet, primary care services do not have the expertise to lead in this specialist area, although their diabetes services are evolving and developing.

Primary care services are, however, an important part of the service provided for adolescents with diabetes as they have intimate knowledge of the adolescent, his/her family, the local area and culture, and the ability to access patients when they are not attending secondary care services.

It is also advocated that adolescent services should bring together specialists from paediatric and adult services to provide effective transitional care. The adolescent team should be multidisciplinary, including paediatric and adult diabetologists, specialist nurses, dietitians and psychologists, and have access to other services such as podiatry and ophthalmology.

Other staff are also crucial to the smooth running of any service. The clerical and reception staff, for example, play an important role, ensuring that notes are available and clinic lists are provided. The welcome that adolescents receive from reception staff can be a significant factor in the

success and uptake of clinic services. Biochemistry services are crucial for ensuring that rapid, accurate results are available. Other support staff enable specialist staff to concentrate on patients as opposed to tasks.

If all adolescent services could provide the above specialist personnel, staffing requirements and resourcing would soar. Managed clinical networks, which can be both cross-trust and cross-boundary, are an effective way of developing services, and provide accessible services across different regions (DARTS, 2001). However, young people with diabetes want consistency of staff and information, and a service run at a time and place to suit them. It is clear from the Scottish Study Group for the Care of the Young Diabetic (2001) that it is not resources alone but the optimisation and utilisation of resources that have to be researched to examine how they affect services.

Adolescent issues

Work carried out in Fife, Scotland, highlighted issues related to its diabetes service (Table 1). Similar issues were highlighted in work carried out in Lothian (Henderson, 2002). Staff attitudes were of concern to adolescents, who felt that some staff were patronising and condescending and did not understand how they felt or the difficulties they encountered. It is not unusual for this age group to feel misunderstood, but if the patient is central to care there must be better understanding and communication between patients and diabetes teams (Royal College of Psychiatrists, 1995).

It is also evident from what patients say that the agenda is driven by the practitioner and not by themselves (Henderson, 2002; Scottish Human Services Trust, 2002). They are left feeling that their issues and

concerns are not being addressed. The risk of this happening is even greater with increasing emphasis on targets – the service is driven by policy and not by the patients' agenda.

Improvement in clinical outcomes does not always correlate with quality of life. This is particularly true during adolescence when young people need appropriate support through the dynamic cycle of dependence, interdependence and independence (Grey et al, 1998). Without appropriate support and understanding, adolescents can be left feeling disempowered and that their efforts have been futile (Dickinson, 1999).

Positive aspects of care

Table 2 lists some of the aspects that young people value from their diabetes service. This information also comes from the work carried out with young people with diabetes in Fife. Again, similar issues were identified in Lothian (Henderson, 2002).

Central to the positive aspects of service were the nurses. They were identified as being the most consistent staff, offering more understanding and flexibility than other members of staff. Young people trusted their nurses more than other members of staff. This trust was built up over a period of time through an effective professional/patient relationship.

Consistency was felt to be important and related not only to information given but also to the member of staff who was most accessible, i.e. who was most often present at the clinic and who carried out home visits. Young people valued this consistency and expressed some resentment towards other staff who did not know them as well (or may not have known them at all) and offered advice or changes in therapy that patients did not feel was appropriate.

PAGE POINTS

1 Young people with diabetes want consistency of staff and information, and a service run at a time and place to suit them.

2 Without appropriate support and understanding, adolescents can be left feeling disempowered.

3 Young people trusted their nurses more than they did other members of staff.

4 Consistency was felt to be important and related not only to information given but also to the member of staff who was most accessible.

Table 1. Young people's issues relating to their diabetes service

<ul style="list-style-type: none"> • Staff attitudes • Dietitians not listening • Annoying doctors • Eye-drops • More understanding doctors • Don't always need to see a doctor: may prefer to see the nurse 	<ul style="list-style-type: none"> • Inappropriate information • Focus on HbA_{1c} • Staff speak to parents not patients • Better things to do than go to clinic • More flexible regimens 	<ul style="list-style-type: none"> • Doctors not listening • Blood tests • Going to the clinic • More flexible service • More understanding
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Table 2. Positive aspects of young people's diabetes service

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| • Drop-in clinics | • Clinic activities | • Meeting similar people |
| • Nurses listen to you | • Nurses care | • Informal discussions |
| • Young people's clinic | • Understanding by some staff | |

A balance has to be found between training staff and giving them appropriate clinical experience along with meeting the needs of the patients. Clearly, this patient group places relationships with staff high on their needs from the service and found some staff ill-informed and judgmental. Such attitudes from staff are likely to alienate patients and their families.

This may not necessarily be the sole responsibility of the practitioner, if the system does not allow for adequate information sharing and discussion pre-clinic. This can be overcome by ensuring that up-to-date information from all practitioners is clearly recorded in the notes. In many instances this does not occur, e.g. when different services use different notes (medical and nursing services).

Addressing some of the issues

Since relationships are valued highly by young people with diabetes at a time in their lives when relationships are changing, it can be beneficial for a new member of staff to take over the responsibility for coordinating their care. This is why the role of the diabetes nurse specialist (DSN) for adolescents has developed. The role can be tailored to meet the needs of the area: it can cover a hospital, or an area, or be part of a managed clinical network.

Relationships take a long time to build up and develop, and it is therefore helpful if the DSN for adolescents has some contact with young people during their paediatric care. However, the DSN should not be responsible for paediatric care or interventions, but should be part of the team and information sharing, so that by the time of agreed transfer the nurse is well informed about the patient, his/her issues, concerns, family and history.

During their last year of paediatric care, young people with diabetes should slowly be introduced to the idea that

ultimately their care will transfer to an adolescent service and that they will have the opportunity to begin to build up a relationship with the DSN for adolescents. The DSN can take responsibility for informing patients about the adolescent service, support them in making choices about which clinic to attend and negotiate their transfer at an appropriate time.

Once patients are in the adolescent system, the DSN for adolescents is responsible for coordinating their care until they are transferred to the adult services, again at a point that should be negotiated between the patient and staff. If the joint transition care model is used, patients will also have continuing contact with members of the paediatric team as they build up relationships with the adult team. This offers combined and integrated care that is part of an ongoing seamless process.

During the patients' journey through the adolescent service, the DSN for adolescents should remain the coordinator of their care, support and education. The DSN is in an ideal position to bring together the information from everyone involved in the care of the young person and keep the rest of the team informed. This can be done by writing a summary on all contacts between each clinic visit and making sure that this is available to all staff through central notes which everyone has access to.

A pre-clinic meeting to discuss issues and concerns related to individual patients is of great value, bringing together ideas and suggestions on how to best support patients. Also valuable is a post-clinic meeting where all salient points are fed back to the DSN for adolescents, who can act on them immediately and appropriately. Follow-up of all patients who default from clinic is an essential part of maintaining relationships and ensuring that patients know that they are not just a number.

There are some patients who seldom attend clinic and it is even more important

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1 It is helpful if the adolescent nurse has some contact with young people during their paediatric care.

2 The nurse is ideally placed to bring together the information from everyone involved in the care of the young person and keep the rest of the team informed.

3 Follow-up of all patients who default from clinic is an essential part of maintaining relationships.

for the nurse to maintain contact with them, either through home visits or by telephone. This ensures that there is ongoing contact, patients are not lost to follow-up and patients know that the clinic door is always open to them.

Conclusions

Adolescence remains one of the most difficult times to support people with diabetes. Joint transition care coordinated by a DSN for adolescents can offer a supportive environment, enabling young people to progress through this period with extended support. Using this model, patients continue to have contact with the service regardless of their uptake of clinic appointments. The nurse has a pivotal role in ensuring that patient care is individualised and that no-one is lost to follow-up. Listening to patients, involving them and building up positive staff/patient relationships is the most effective foundation for lifelong diabetes care. ■

British Diabetic Association (1995) Report on Good Practice and Care of Children and Young People with Diabetes. British Diabetic Association, London
 Carson CA, Kelnar CJH (2000) The adolescent with diabetes. *Journal of the Royal College of Physicians of London* 34(1): 24-7
 Clinical Standards Board for Scotland (2002) Clinical Standards Diabetes. 2nd edn. The Scottish Clinical

Standards Board, Edinburgh
 DARTS (2001) Managed Clinical Networks Service Report: Children and Adolescents Sub-group Report. DARTS, Dundee
 Department of Health (2002) *National Service Framework for Diabetes: Standards*. DoH, London
 Dickinson JK (1999) A critical social theory approach to nursing care of adolescents with diabetes. *Issues in Comprehensive Paediatric Nursing* 22: 143-52
 Grey M, Boland E, Chang Y et al (1998) Personal and family matters associated with quality of life in adolescents with diabetes. *Diabetes Care* 21(6): 909-14
 Henderson B (2002) Diabetes in Scotland 2002. The way forward. Glasgow (conference)
 Kyngas H, Hentinen M, Barlow JH (1998) Adolescents' perceptions of physicians, nurses, parents and friends: help or hindrance in compliance with diabetes self-care? *Journal of Advanced Nursing* 27: 760-9
 National Institute for Clinical Excellence (2001) Guideline Development Process - Information for the Public and NHS. National Institute for Clinical Excellence, London
 Royal College of Psychiatrists (1995) *Surviving Adolescence*. Dista Products, London
 Scottish Executive (2002) *Scottish Diabetes Framework*. The Scottish Executive, Edinburgh
 Scottish Human Services Trust (2002) *Hearing the Voices of People in Scotland who have Diabetes*. A Partners in Change Report. Scottish Human Services Trust, Scotland
 Scottish Intercollegiate Guidelines Network (2001) SIGN 55 Diabetes Scottish Intercollegiate Guideline Network, Edinburgh
 Scottish Study Group for the Care of the Young Diabetic (2001) Factors influencing glycaemic control in young people with type 1 diabetes in Scotland. *Diabetes Care* 24(2): 239-44
 Thomson C, Greene S, Newton R (1995) Diabetes and adolescence. *Diabetes Review International* 4(4): 2-5

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1 Joint transition care for adolescents allows patients to have contact with the service regardless of their uptake of clinic appointments.

2 The nurse has a pivotal role in ensuring that patient care is individualised and that no-one is lost to follow-up.

3 Listening to patients and building up positive staff/patient relationships is the most effective foundation for lifelong diabetes care.