

What do adolescents require from a diabetes service?

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Introduction

Diabetes can be an added stress for teenagers during the stormy years of adolescence. They may see health professionals as authoritarian and indifferent to their needs. This study, carried out in the Royal Victoria Hospital, Belfast, attempted to discover the views and opinions of adolescent patients, with a view to providing a more patient-led service. Nineteen teenagers took part in the study. The results of the study led nursing staff to conclude that they needed to examine their practice with regard to these patients, particularly all aspects of education.

Adolescence is a period of rapid physical and psychological development. Erickson (1979) described it as a period of 'storm and stress' for the adolescent and his/her family. This age-group frequently challenges authority and established behaviour at home, school and in society generally (Gardiner, 1997). Weissberg-Benchell et al (1995) point to various studies which have shown that adolescents are the age-group least likely to adhere to their prescribed treatment regimens.

Henkinen and Kyngas (1992) maintain that adolescents with diabetes may feel that health professionals are guided by routine, are authoritarian and indifferent, and are interested only in diabetes and not in the adolescent personally.

In 1989, the World Health Organization (WHO) urged the health services to take into account the special needs and sensitivities of adolescent patients. This initiative has gained momentum in recent years, with organisations such as the Royal College of Nursing (RCN) (1994), WHO (1995) and the British Diabetic Association (BDA) (1996) supporting the view that adolescent care should be structured, relevant and patient led.

Against this background, the diabetes specialist nurse (DSN) in the Royal Victoria Hospital (RVH), Belfast, decided to study the

care given to the adolescent patients seen in their clinics.

The RVH runs two diabetic clinics per week, each with 55–65 people attending, and one Saturday clinic a month, which was initially intended as an adolescent clinic, but in reality is also attended by older patients who have work commitments during the week. The number of adolescents attending the clinics is relatively small, with only one or two at the weekday clinics and five to eight at the Saturday morning clinics.

Aim of the study

The aim of the study was to improve the care given to our adolescent patients, by taking into consideration their views and opinions on the service currently provided.

Patients and methods

The onset of adolescence varies from person to person, but is commonly defined as the teenage years. For the purpose of this study it was decided to include patients from 13 years of age (13 being the youngest age of clinic attenders) to 19 years inclusive.

Over a 12-week period, all patients within this age group who attended for their diabetic appointment were given a questionnaire on arrival at the clinic and asked to complete it and return it to the receptionist before leaving the clinic. All of the 19

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1 Diabetes can add to the stress of adolescence for many teenagers.

2 The needs of teenage diabetics may easily be overlooked in a large adult clinic.

3 A study was undertaken to elicit the views of adolescent diabetics on a number of issues relating to their care and support.

4 The results highlight inadequacies in the education currently provided to teenage diabetics.

5 Following discussion of the results by all members of the multi-disciplinary team, an action plan for a more patient-led service was drawn up.

KEY WORDS

- Adolescence
- Diabetes
- Patient-led service

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Table 1. Extract from interview schedule for patients, with frequency of responses

1. Were you admitted to hospital to commence insulin?	Yes (19)	No (0)	
2. Would you have preferred to commence insulin as an outpatient?	Yes (8)	No (4)	
3. Would it have been helpful to speak to someone of your own age who has diabetes, when you were diagnosed?	Yes (9)	No (5)	Don't know (5)
4. Would you be prepared to speak to someone of your own age who has recently been diagnosed as having diabetes?	Yes (11)	No (8)	
5. Would you prefer a clinic solely for people of your own age?	Yes (11)	No (5)	No preference (3)
6. When would you prefer the clinic to be held?	A weekday morning (5)	A weekday afternoon (0)	A weekday evening (0) A Saturday morning (14)
7. Does your mother or father see the doctor with you?	Always (7)	Sometimes (8)	Never (4)
8. Would you prefer to see the doctor on your own?	Yes (6)	No (4)	No preference (9)
9. Do you have contact numbers that you can use if you need advice between clinic visits?	Yes (18)	No (1)	
10. Have you ever made use of these numbers?	Yes (11)	No (8)	
11. Would you like the choice of seeing the diabetes specialist nurse in place of the doctor at some of your clinic visits?	Yes (9)	No (0)	No preference (10)

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1 Almost half of the teenagers studied would have liked to have spoken to someone their own age, with diabetes, at diagnosis.

2 Three-quarters of study patients would prefer to attend a Saturday morning clinic.

3 Almost half the patients would like to see a DSN rather than the doctor at some clinic visits.

questionnaires given out were completed and returned.

The questionnaire contained 17 questions, both open and closed, on such issues as care at diagnosis, care at routine clinic visits, and support between clinic visits (Table 1).

Results

The ages of the adolescents completing the questionnaires ranged from 14 years to 19 years. The length of time since diagnosis ranged from 9 months to 16 years. Twelve of the adolescents had attended the adult clinic since diagnosis; the remainder had transferred from the paediatric clinic.

All 19 patients had initially been admitted to hospital to commence insulin injections and time spent in hospital ranged from 3 days to 7 days. Eight (42%) stated that they would have preferred not to have been admitted;

seven (37%) had been diagnosed as young children and had answered 'not appropriate at all'. Nine (47%) patients would have liked to have spoken to someone their own age at diagnosis and 11 (58%) would be prepared to speak to someone newly diagnosed with diabetes.

When asked which day and time they would prefer for their clinic visit, 14 (74%) stated Saturday morning and five (26%) a weekday morning. Eleven (58%) would like a clinic solely for people of their own age.

Seven (37%) respondents always saw the doctor with their parents present, eight (42%) occasionally saw the doctor on their own and four (21%) always saw the doctor on their own.

Nine (47%) respondents would like the choice of seeing the DSN in place of the doctor at some clinic visits; the remainder had no preference.

The areas on which the respondents felt they lacked information included:

- Alcohol (12; 63%)
- Sick days (10; 53%)
- Hypoglycaemic attacks (1; 5%)
- Eye testing (1; 5%).

Eighteen (95%) of the respondents had contact numbers if they needed advice between clinic visits, and 11 (58%) had used this service at least once.

In general, the open questions elicited very few responses. No-one could list any videos, books, leaflets, etc. that they found helpful either at diagnosis or since.

There was one suggestion as to how to improve care at diagnosis: 'If in hospital, arrange some sort of physical activity instead of lying around all day'. 'Improve waiting times' was the only comment with regard to improving care at the clinic, and one person suggested that transfer from the children's clinic would have been easier if someone they knew had transferred at the same time.

Discussion

It was difficult to determine the exact number of adolescent patients attending the diabetic clinic, owing to the inability of the hospital computer system to select patients

by age. However, it was estimated that approximately 30 teenagers attended the adult clinic. Although only a small number of patients were involved in the study, the results have served to focus attention on teenage patients whose needs could easily be overlooked in a large adult clinic.

Our practice to date has been to admit patients to hospital to commence them on insulin injections, regardless of their medical condition. Nursing staff have long considered this to be inappropriate for everyone, and this study has provided the stimulus for discussion of this issue among all members of the multidisciplinary team.

Despite the lack of research demonstrating that adolescent-only clinics improves adolescent behaviour (Skinner, 1997), it is generally accepted that they are preferable to any other for adolescent patients (Gardiner, 1997). Fifty-eight per cent of respondents in this study wanted such a clinic, with 14 of the 19 respondents happy with a Saturday morning clinic. One solution proposed was to set aside the first hour of the Saturday clinic solely for adolescent patients.

Results showed that the teenagers in the study lacked information on issues such as alcohol, contraception, and exercise, with those

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1 All but one of the teenagers had a contact number for advice between clinic visits, and more than half had used the service.

2 None of the teenagers could remember any teaching aids they had found useful.

3 Teenagers lacked information on alcohol, contraception, exercise, sick days and footcare.

4 Despite little evidence that adolescent-only clinics improve health behaviour, such clinics are generally accepted as preferable for this age group.

Table 2. Responses to a specific question in the questionnaire

When attending the clinic do you receive the appropriate information on the following?			
Insulin	Yes (15)	No (1)	Don't know (3)
Diet	Yes (19)	No (0)	Don't know (0)
Exercise	Yes (10)	No (8)	Don't know (1)
Hypos	Yes (18)	No (1)	Don't know (0)
Alcohol	Yes (6)	No (12)	Don't know (1)
Sick days	Yes (4)	No (10)	Don't know (5)
Blood glucose meters	Yes (14)	No (3)	Don't know (2)
Contraception	Yes (1)	No (9)	Don't know (9)
Footcare	Yes (6)	No (8)	Don't know (5)

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1 Information which nursing staff believed they were providing was not getting through to the teenage diabetics.

2 The implication was that the whole educational package needed evaluation.

3 Education must be adjusted to the developmental stage of the patient and be consistent, organised, repeated and evaluated.

4 Seeing health professionals without their parents being present may encourage teenage diabetics to take on responsibility for their own care.

5 An action plan drawn up on the basis of the results includes a dedicated adolescent clinic and a 'buddy' system for newly diagnosed teenagers.

diagnosed the longest requesting information on sick days and footcare (Table 2).

These results were of concern to the nursing staff for two reasons. First, they believed that they had conscientiously discussed matters such as alcohol and contraception with this age group. Secondly, they assumed that those with long-standing diabetes would know how to deal with situations such as sick days. Evidently, nursing staff needed to question their practice. Why were patients not receiving information that nursing staff perceived they had given?

Part of the answer perhaps lay in the fact that none of the teenagers could list any teaching aids that they remembered or had found useful. Clearly the whole educational package needed to be evaluated, but how could this information be put across more effectively?

Day (1996) suggested that a computer compact disc was an interactive tool which would ensure that educational programmes were more learner-centred, with materials generated in the main by patients rather than professionals. The BDA (1996) recommend that education should always be adjusted to take into account the developmental stage of the patient and should be consistent, organised, repeated and evaluated. An effective method of evaluation was another area that we needed to address.

Purcell (1995) found group meetings to be an effective method of getting the right information across and of improving relationships between teenagers and health professionals. Interestingly, parents were not included in these meetings. Others have suggested that it is beneficial for adolescents to see health professionals without their parents as it encourages them to take over responsibility for their care (Savage, 1990). Seven of our teenagers stated that they never saw the doctor on their own, and two of these were 19-year-olds who had had diabetes since childhood. Perhaps we should recommend that all adolescent patients see the doctor or DSN at least once a year without their parents being present?

It was gratifying to note that all but one of the respondents had contact numbers in case of an emergency and many had used these numbers when needed.

Action plan

- To discuss the issues raised with all members of the multidisciplinary team, e.g. commencement of insulin in an outpatient setting, providing opportunities for adolescents to see health professionals without their parents, and producing written protocols to guide practice
- To organise a dedicated adolescent clinic
- To produce a structured, written education programme for adolescents that will describe how the programme will be delivered, reinforced and evaluated
- To introduce a 'buddy' system for teenagers who are newly diagnosed with diabetes
- To evaluate the progress made in the above and to audit the effect of changes made in 9 months' time.

Conclusion

The results of this study have not been surprising. The value of it has been to bring adolescent issues to the attention of the multidisciplinary team. It is only the beginning of the development of a patient-led service. The views of all of our adolescents need to be sought on a regular basis and the DSN is well placed to take this initiative forward. ■

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