

A multidisciplinary paediatric diabetes health care team: perspectives on adolescent care

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Abstract

This paper focuses on a qualitative study of the experiences of a multidisciplinary health care team caring for adolescents with type 1 diabetes in a hospital in the North West of England. It builds upon previous research which has explored the lived experiences of young people and their parents/guardians with the aim of better understanding blood glucose control in this age group.

Findings emphasise lack of human resources, the importance of effective team working, and the need for meaningful education which acknowledges adolescents' unique and complex social worlds.

Given these findings we are now developing a computer-based 'Adolescent Diabetes Needs Assessment Tool' (ADNAT study), with a view to individualising self-directed education and support. Copyright © 2011 John Wiley & Sons.

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Key words

diabetes; adolescents; team work; qualitative research

Background

Diabetes in children and young people is growing at an alarming rate of 3–5% per year; it is presenting at an earlier age and continues to be a leading cause of premature death in most developed countries.^{1,2} Cross-sectional studies^{3,4} report high blood glucose levels for a large majority of children and young people, with the UK having one of the poorest records – only 20% of under-16s currently achieve the recommended levels.

To improve outcomes the European SWEET Project has highlighted the need to improve multidisciplinary teamworking.¹ Globally, the importance of this in health care has accelerated over the last 20 years and research has highlighted its effectiveness in both acute and chronic settings.^{5,6} A hallmark of team collaboration is interdependency with other professionals and being able to combine perceptions and skills to synthesise a more complex and comprehensive plan of care.⁷

The management of paediatric diabetes has changed since publication of the Diabetes Control and Complications Trial⁸ which found that habits acquired in the first year after diagnosis are hard to change,

and patients who achieve good glycaemic control in the first five years do better in the longer term. Alongside this, an international systematic review found that clinic attendance, specialist care, and a multidisciplinary team approach were indicators of glycaemic control in children and young people with type 1 diabetes (T1D).⁹

Access to a multidisciplinary health care team is therefore essential, but a recent survey of 18 European paediatric diabetes centres by SWEET¹ found significant differences in levels of and access to such services. Taking the UK as an example, improvements in paediatric diabetes care have been seen over the past decade but there are still marked deficiencies, mainly with regard to the provision of specialist nurses and psychologists,¹⁰ patient education,^{2,11} and transition services.^{12,13} These services have suffered by their inclusion in general paediatric budgets resulting in a lack of investment and staff to deliver the service.¹⁴ Nationally, surveys¹⁵ have illuminated paediatric specialist nurse case-loads above recommended levels of 70,¹⁶ highlighting a critical strain on resources. Such findings emphasise the need to explore what health professionals at

the 'coal face' actually feel is happening in practice.

This study aimed to explore the views of a multidisciplinary diabetes team from a paediatric hospital in the North West of England about the care they provide to adolescents with T1D. It took a qualitative hermeneutic approach¹⁷ to explore their lived experiences. Interviews were conducted by a member of the research team (HC).

Participants

Participants were recruited purposively from a team responsible for the care of approximately 300 children and young people with diabetes (0–16 years). Inclusion criteria comprised health professionals who provided care to participants in the preceding phase of our research exploring the lived experiences of adolescents with T1D and their parents¹⁸ to allow for cross-analysis of the data. Participants comprised three general paediatric consultants, three specialist nurses, a specialist dietitian and a general psychologist. Ethical approval was obtained from the Local Paediatric Research Ethics Committee.

Methods

Interviews were conducted in an 'in-depth' manner in 2008 using a semi-structured interview tool aimed at exploring: team working, job role, working with adolescents, management of diabetes in adolescence, family care and education. Interviews were audio-recorded and transcribed verbatim. Each health professional (HP) is coded numerically to maintain anonymity, except where a quotation is directly linked to an identifiable team member when the numerical code is not given.

Data analysis followed a rigorous, five-step approach underpinned by hermeneutic phenomenology.¹⁹ Involvement of two researchers in the analysis process aimed to give two perspectives on the interpretation, thus reducing interpretation bias. Participants were asked to read the final report and all agreed that it represented the experience of working within this multidisciplinary team.

Results

Team working

The team's approach to care reflected a multidisciplinary model despite describing a lack of training in this area. The consultants were seen as the figureheads of the team and the outreach role of the nurses was instrumental to understanding the family context of patients. Team members acknowledged the pressures resulting from this style of working, including personality clashes and the integration of different professional backgrounds and perspectives. Despite this, however, members felt that their voices were heard when decisions were made. Multidisciplinary working meant that each team member had a degree of responsibility at all times, and maintaining the individuality of roles had positive implications for the team as a whole:

'As a team we are working towards trying to pick out what people's strengths are and using it as an advantage rather than a disadvantage' (HP3).

Regular team meetings were important in enabling reliable communication and discussion. They were structured to allow fair discussion and for each team member to give their perspective.

Adolescent self-management

The team acknowledged that self-management style was an individual trait across the adolescent patient group:

'Some [patients] try to control it ... some try to ignore it, and some manage it in their own way and they take what information they want' (HP2).

Approaches to care were not based on one specific model, but were adapted in relation to the needs of the young people and their families. For example, one nurse described situations in which she went against recommendations in order to prioritise psychosocial well-being:

'Twice in all the time that I've been working I have said to a patient: "don't blood test"; the words could hardly come out of my mouth but they had to because they felt so guilty and it felt detrimental to them. I followed it up by saying: "if you were ill then you must blood test".'

Communication was important to enable health professionals to

provide the right care for patients, particularly when some believed that their care did not always address patients' needs. The team recognised that a young person's family has a key influence on diabetes management:

'It's not what we do so much, it's the dynamics of the family ... we can put the same amount of input into two different families and have completely different outcomes and that is because of how they work, their outlook on life, their coping strategies, routines...' (HP3).

Encouraging independence

The ethos of care was to equip adolescents with the skills to self-manage their diabetes before transfer to adult services at the age of 16. This involved decreasing parental involvement within the clinical setting, but some criticised this approach:

'I am thinking that we are doing more harm than good in removing parent support ... I think for a lot of adolescents that isn't the right thing to do' (HP3).

The hindrance that parental input could inflict on adolescent independence was also recognised. One team member advocated the need to find a balance between encouraging autonomy and keeping the adolescent's parents involved:

'I think it's a question of speaking to young people rather than their parents, but yet make their parents feel a part of what is going on' (HP4).

Most of the health professionals mentioned that transition services were not meeting their needs adequately. In particular, the fact that the hospital fed into a large number of adult clinics made it difficult to maintain adequate links between the services.

Meaningful education

The team believed that patient education had to be meaningful to instigate adaptation and behaviour change. It was therefore important to relate education to aspects of the adolescents' lives for it to be relevant, as this team member described:

'You have to put whatever change into diabetes management that you are encouraging them to make, into the context of their lives ... it becomes a more meaningful conversation' (HP7).

The nurses found that an effective approach to education delivery was following up a significant event with face-to-face communication.

Limited resources

All of the team recognised that care provision was constrained by limited resources, including time, funding and the need to adhere to unrealistic government targets, for example:

'The reality is that we only get 20 minutes with patients ... we would be able to look after patients much better if we had more time to spend with them' (HP6).

Large case-loads also meant that in-depth attention was generally given only to those experiencing crisis situations, reflecting an acute treatment model rather than preventative care. This centre has only 2.6 nursing whole time equivalents for 300 children.

'The number one thing I would like is to have more time with my patients and to be able to see them regularly at home and work ... This only happens at crisis times' (HP1).

Government targets were identified as often being unrealistic to deliver when the individual needs of patients were acknowledged. As one person commented:

'...NICE guidance is required but it's not a be all and end all...' (HP6).

Discussion

The recommended multidisciplinary team approach^{20–22} was adopted by the team and worked well to enable a holistic approach to care with clearly defined roles and responsibilities. Members were able to identify their own roles and the roles of others as unique within the team, and were clear that their different perspectives were respected and united. Team meetings enabled regular and effective communication about patients, and leadership by consultants was implicit but not overpowering. Meetings were important to rectify any discrepancies and supported a less hierarchical way of working, while maintaining the leadership necessary for team effectiveness.

Participants acknowledged that adolescents were a complex patient group, with individual self-management styles dependent upon family context. Thus, care was centred on

individual family lifestyles and behaviour. Parents were involved in the care provision process, given that such involvement has been shown to improve adherence in adolescence²³ and reduce diabetes-related hospital admissions.²⁴ Reducing parental involvement was not viewed favourably by all team members, despite evidence that increased adolescent autonomy relieves parental burden, improves knowledge and confidence for adolescents, reduces parent-child conflict,¹² and in turn improves adherence²⁵ and glycaemic control.²⁶ In support of the views expressed by team members, studies exploring differences between a family-centred approach with responsibility sharing versus the independent approach have found better blood glucose outcomes in the former,^{27,28} suggesting that a similar approach in the UK may have the potential to improve outcomes for young people with diabetes.

Despite the team feeling that they were not always able to grasp the needs of individual patients, our previous research indicated that families, in particular parents, felt completely supported by the team in an outreach context.¹⁸ Communicating with adolescents at their level and making realistic care recommendations enhanced communication and understanding between the health professionals and their patients. This is positive, as research has found that adolescents value health professionals who speak to them in a 'friendly' manner and address other issues aside from diabetes.²⁹

The inadequate transition service described by the team is a widespread issue globally,^{12,13,30} with organisational resources influencing the success of transition strategies.³¹ In this clinic, transfers to multiple adult clinics made transition a difficult task. It is particularly important to address this as clinic attendance decreases in late adolescence, leading to an increase in blood glucose levels.^{3,31}

The team believed that diabetes education was most effective when it was meaningful to adolescents; for example, when it followed a significant event such as severe hypoglycaemia. In line with this, a number of researchers have highlighted experiential learning as instrumental to

Key points

- As a developed country, the UK has one of the poorest records of blood glucose control in young people with type 1 diabetes
- Qualitative research with young people, their parents and the diabetes teams is required to understand reasons behind such poor control; this study focuses on the latter
- Key findings included constrained resources and a need for meaningful, needs-based education. Findings have now been used to develop the Adolescent Diabetes Needs Assessment Tool (ADNAT)

living with T1D.^{32–34} Recent advances in patient education for children and young people^{35,36} prioritise traditional didactic approaches, failing to address the need for multi-episodic learning, inadequate staffing, and changing patterns of learning for young people born into a digital age. The need for a standardised curriculum is obvious, but so is the need for more innovative and cost-effective approaches to diabetes education utilising recent trends in technology.

It was clear that the diabetes team felt constrained by the framework they were required to work within, underpinned by national UK government targets. Each specialist nurse had a case-load of at least 100 patients, which is considerably more than the 70 recommended by the Royal College of Nursing¹⁶ and this impacted upon meeting recommendations for care. Variations in care provision and blood glucose control across UK centres contribute to uncertainty among health professionals, validating the need to establish global standardised models of care for all children and young people living with diabetes. This need is currently being investigated by SWEET which is working on progressing this goal within the EU.¹

In conclusion, given the small sample size our findings are context specific, although similarities to other comparable teams are likely within the UK NHS structure. Despite this limitation, however, findings highlight issues meriting further investigation. Triangulation with

data from our previous research¹⁸ emphasises the need for individualised, needs-assessed education for children and young people, which acknowledges their unique and complex social worlds. Given these findings we are now working on developing a computer-based 'Adolescent Diabetes Needs Assessment Tool' (ADNAT study),^{37–39} with a view to individualising self-directed education and support.

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Declaration of interests

There are no conflicts of interest declared.

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