

Psychological support and care for young people with diabetes in the 'transition' period

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Introduction

There is consistent evidence of elevated rates of depression and anxiety disorders in people with diabetes, with a review of 18 controlled studies showing that the rate of depression is doubled for people with diabetes compared with controls.¹⁻⁵ In addition, depression is often undetected, being missed in 30–50% of cases in primary and secondary care.^{4,6,7} As a result of its negative impact upon diabetes self-care and medication adherence,⁸ depression is associated with hyperglycaemia⁹ and a consequent increase in risk of secondary medical complications,¹⁰ and the increased health care costs associated with this.¹¹ In addition, other specific psychological conditions such as eating disorders can impact significantly on diabetes management, also leading to poor glycaemic control and subsequent complications.¹²⁻¹⁴ Needle phobias and fear of self-injecting are also associated with poor glycaemic control and a raised HbA_{1c}.¹⁵ Overall, it has been estimated that some 41% of people with diabetes suffer from poor psychological wellbeing.^{16,17} However, importantly, treatment for psychological conditions, including depression, has been shown to reduce symptoms and improve glycaemic control,¹⁸⁻²² as well as reductions in both psychological distress^{23,24} and the costs of health care.²⁵

Transition can be described as 'the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems'.²⁶ Management of diabetes in children and young people in the transition

ABSTRACT

The aim of this survey was to determine the availability of psychological support and care for young people with diabetes in secondary care services in the Yorkshire and Humber NHS Region during the transition period (i.e. ages 16–25 years).

The survey was developed in line with both National Institute for Health and Clinical Excellence (NICE) guidance and National Service Framework (NSF) standards specific to children and young people with diabetes. It was distributed to the diabetes services in all 20 centres within the Yorkshire and Humber NHS Region.

The response rate for this survey was 100%. All centres were aware that children and young people with type 1 diabetes may develop anxiety and/or depression, and all (100%) or virtually all (95%) of the teams in the 20 centres agreed with the various key requirements stipulated in the relevant NICE guidance and NSF standards. However, many centres lacked key service elements, or indeed any plans to introduce them.

The findings of this study are of national significance given the nature and size of the region studied and the likelihood that the national picture is similar to this. There is a general sense of awareness among diabetes services and teams regarding the need for psychological support and care for young people with diabetes in the transition period. Despite this, multiple gaps exist in services in relation to the already existing requirements and standards. The implications, including those for service commissioners, are discussed. Copyright © 2010 John Wiley & Sons.

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KEY WORDS

diabetes; transition; young people; psychological; emotional; care

stage (i.e. ages 16–25 years) is arguably more complex than it is for adults. Outcomes for children with diabetes regarding glycaemic control are often poor, so that in the Yorkshire and Humber NHS Region only 15% of children reach the recommended HbA_{1c} target of 7.5% or below (as per National Institute for Health and Clinical Excellence [NICE] guidance). Also, in adolescents with diabetes, whilst coping with their biological, psychological and social changes individuals must also manage their diabetes appropriately. The impact of emotional and physical demands means that they are more susceptible to non-concordance, which may result in worsening glycaemic control. The need to focus upon the psychological care of children and young adults in this

age range is not just due to the known psychological and emotional difficulties at that stage of life, but also because transition from paediatric to adult health care services can be particularly problematic.

There is an increasing focus upon the relatively high prevalence of psychological and psychosocial difficulties experienced by people with diabetes in the transition stage, by both national and regional working groups which are calling for the provision of specific physical and mental health services to come in line with existing requirements within the diabetes NICE guidance and the National Service Framework (NSF).²⁷⁻²⁹ As stated by Diabetes UK in 2008, behaviours that improve health outcomes in later life are laid down in adolescence so public

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health policy and clinical focus on the health of young people would have important long-term health benefits.^{30–32} Specific evidence exists regarding the importance of effectively managing the transition period from paediatric to adult services with diabetes, including knowledge that transition programmes improve health outcomes and quality of life,^{30,33,34} and that inadequate transition has been associated with poor prognosis.³⁵ For example, poor clinic attendance has been linked to inappropriate transition, with between 10 and 69% of young people receiving no medical follow up after transfer to adult services,^{29,36–40} and those lost to follow up are known to have poorer diabetes control.^{27,37,41}

In the light of all of this, and the likely need to improve and develop transition services for young people with diabetes, we decided to carry out a survey to determine the availability of psychological support and care for young people with diabetes in secondary care services in the Yorkshire and Humber NHS Region during the transition period (i.e. ages 16–25 years).

Method

An internet search was conducted to identify all existing NICE and NSF guidance relevant to the psychological care of young people with diabetes. NICE Guidance CG15 (type 1 diabetes in children, young people and adults) and the diabetes NSF (National Service Framework for Diabetes: Standards) were identified and examined. The 10 standards directly relevant to psychological care in the transition stage were extracted from these documents and a survey questionnaire was constructed from these standards (see Appendix 1, available online at www.practicaldiabetesinternational.com).

The questionnaire was sent to each of the 20 diabetes centres in the Yorkshire and Humber NHS Region. In each case, and in order to maximise the chance of receiving a response from that centre, one copy was sent to a diabetes specialist nurse (DSN) and one to a diabetes paediatrician (consultant). This was done by e-mail, with a request for the

questionnaire to be completed and returned either electronically or by post. A reminder was sent out after four weeks to any non-responders. Where the reminder failed to gain a response, the centres or individuals concerned were contacted and a telephone interview conducted.

Where there were two responses from any one centre and a discrepancy between the answers provided by the DSN and the consultant, the appropriate DSN was contacted and their answers confirmed, with the reasons for any discrepancies clarified in relation to discussion of current practice. This was so that a single final answer could be decided upon. (After the reminder stage, responses from all 20 centres had been received but there were discrepant answers in the case of four centres which necessitated telephone interviews.)

Results

These are displayed below as the responses, summarised in percentage terms, to each of the survey questionnaire items.

1. 'Diabetes care teams should be aware that children and young people with type 1 diabetes may develop anxiety and/or depression.'

- 100% of centres are aware of this.

2. 'Children and young people with type 1 diabetes who have persistently poor glycaemic control should be offered screening for anxiety and depression.'

- 100% of centres agreed that this is necessary.
- 20% of centres provide such screening.
- The remaining 80% do not.
- Of those that do not, 25% are taking steps in order to provide this.

3. 'Diabetes care teams should be aware that poor psychological support has a negative impact on a variety of outcomes of type 1 diabetes in children and young people including glycaemic control and self-esteem.'

- 95% of centres are aware of this.

4. 'Children and young people with type 1 diabetes, especially young people using multiple daily injection regimens,

should be offered structured behavioural intervention strategies because these may improve psychological wellbeing and glycaemic control.'

- 100% of centres agree that this is necessary.
- 5% of centres have implemented such strategies.
- Of the 95% that have not, 30% were taking steps in order to provide this.

5. 'Young people with type 1 diabetes should be offered specific support strategies such as mentoring and self-monitoring of blood glucose levels supported by problem solving, to improve their self-esteem and glycaemic control.'

- 100% of centres agree that this is necessary.
- 60% of centres are providing such support strategies currently.
- Of the 40% that do not, 10% are currently taking steps to provide this.

6. 'Young people with type 1 diabetes should be encouraged to attend clinics on a regular basis (three or four times per year) because regular attendance is associated with good glycaemic control.'

- 100% of centres agree that this is necessary.
- 100% of centres actively encourage regular attendance.

7. 'Paediatric diabetes care teams should organise age-banded clinics for young people and young adults jointly with their adult specialty colleagues.'

- 95% agree that this is necessary.
- Of the 95%, 85% provided such a service in their clinics.
- Of the 10% that weren't, 5% were taking steps in order to provide this.
- 5% of centres didn't agree with the specific statement, did not provide such a service and steps were not being currently taken in order to provide this.

8. 'Young people with type 1 diabetes who are preparing for transition to adult services should be informed that some aspects of diabetes care will change at transition. The main changes relate to targets for short-term glycaemic control and screening for complications.'

- 100% of centres agree that this is necessary.
- 100% of centres are delivering this information to service users.

9. *'All young people with diabetes will experience a smooth transition ... the transition will be organised in partnership with each individual and at an age appropriate to and agreed with them.'*

- 100% of centres agree that this is necessary.
- 95% of centres currently provide such a service.

10. *'Paediatric and adult diabetes teams should liaise closely during the period leading up to and following the transfer of care. The provision of joint consultations enables the young person to be introduced to the new team that will be supporting them in the future.'*

- 100% of centres agree that this is necessary.
- 80% of centres currently provide such a service.
- Of the 20% that do not, steps were being taken in order to provide this in 10%.

Discussion

This study was carried out in a very large NHS region with diverse and differing populations and services. At over five million, this region accounts for approximately a tenth of England's population, covering an area of over 15 500 square kilometres. This includes major cities such as Leeds, Bradford, Sheffield and York, as well as a number of large towns and also rural areas with scattered populations. All of this suggests that it is reasonable to extrapolate from our results to provide an estimate of the national situation.

As described in the results section, there were 10 elements to the survey questionnaire which were those elements of the relevant NICE guidance and NSF relating specifically to psychological issues in children and young people with diabetes. There are several positives, but also some negatives, in relation to the results.

Regarding the positives, it is very encouraging that all responders reported an awareness that children and young people with type 1 diabetes may develop anxiety and/or depression and also that all, or virtually all, acknowledged that:

- Those with poor glycaemic control should be offered screening for anxiety and depression.

• Poor psychological support has a negative impact on a variety of outcomes of type 1 diabetes, including glycaemic control and self-esteem.

• Especially those using multiple daily injection regimens should be offered structural behavioural intervention strategies.

• Young people with type 1 diabetes should also be offered specific support strategies to improve their self-esteem and glycaemic control.

• Young people with type 1 diabetes should be encouraged to attend clinics on a regular basis; all or almost all of the centres agreed that the paediatric diabetes care team should organise age-banded clinics jointly with the adult specialty colleagues, and all are delivering information to young people with type 1 diabetes for preparing for transition to adult services in relation to that service change. In addition to this, all centres agreed with the need to provide a smooth transition experience, in partnership with each individual and at an age appropriate to them, with 95% of centres already providing such a service. Finally, all centres agreed with the need for paediatric and adult diabetes teams to liaise closely during the period leading up to and following the transfer of care.

Despite this encouraging range of positives, there are continuing and very significant areas of concern:

• 80% of services do not, despite the agreement mentioned earlier, offer screening for anxiety and depression and of these only 25% are taking any steps to try and provide this.

• Again, despite all centres agreeing that it is necessary, 95% have not moved to be able to offer structured behavioural intervention strategies, and only 30% of these are taking any steps in this direction.

• Although all centres agree with the need to offer specific support strategies to improve self-esteem and glycaemic control, 40% do not provide such help, and of these only 10% are currently taking steps to do so.

There is an interesting theme which appears to run through these problematic areas. The elements of care which are acknowledged as necessary but still not provided are those

which might be expected to be difficult for health care professionals to address if they themselves are not psychological experts. The introduction of screening, structured behavioural interventions and specific support strategies regarding self-esteem etc would require at least advice, as well as education and training and in some cases perhaps direct service provision, from psychological experts. In contrast, the care elements which are already being provided are those which might be expected to be possible from the perspective of non-psychologically trained diabetes team members. These include encouraging regular attendance, organising clinics in appropriate ways (jointly between paediatric and adult specialties), providing adequate information, and engaging patients in the transition process. It is interesting to note that of the four DSNs contacted for brief telephone interviews, three spontaneously commented that the reason their services had not proceeded with certain key requirements and standards was due to not having a psychologist or psychological expert in or associated with their team. The existing diabetes team members did not feel they had the necessary knowledge or skills to be able to proceed with introducing those service elements. They were trying, within the scope of their own skills and expertise, to provide high quality services but were identifying a skills gap within teams.

The comprehensive survey of the provision of psychological support and care for adults with diabetes in the UK which was published in 2008 by Diabetes UK ('Minding the Gap'¹) has previously detailed the lack of specialist psychological services for people with diabetes in the UK. That report showed that some 85% of people with diabetes in the UK either have no defined access to psychological support and care or at best only in the form of local generic services. Where psychological services do exist, they are provided by a range of disciplines and there is no clear plan or rationale for developing such services – so it is highly likely that the majority of the



services in the Yorkshire and Humber NHS Region will not have specialist psychological input, hence the lack of certain key service elements for people in the transition period. It was also found in the 'Minding the Gap' survey that diabetes teams feel they need help with managing almost all psychological presentations and an opportunity to involve, or refer on to, specialist services for a whole range of conditions. It is therefore unsurprising that the areas noted to be lacking in the services examined are those which diabetes teams are likely to feel they need help with to address and to initiate.

As evidenced by the list of positive actions already taken, in relation to the NICE requirements and NSF standards, the Yorkshire and Humber NHS Region clearly benefits from high quality diabetes services and teams and this is very likely to also be the case in other regions across the UK. It is also true, however, that some key requirements and standards which have existed for some years in national documents are not being provided in many existing services. This cannot be acceptable. One obvious conclusion to draw would be that commissioners of diabetes services, in this case

Key points

- Diabetes teams are aware of the clear and established need for psychological support and care for young people with diabetes in the transition period
- Multiple gaps in services are evident, despite the established need and the relevant NSF standards and NICE requirements which already exist
- Commissioners must expect, require and resource services to work rapidly towards compliance with the existing standards and guidance relevant to the psychological care of people with diabetes in the transition period

specifically covering the transition period (i.e. including both paediatric and adult diabetes services), are not commissioning services in such a way as to ensure that all of the necessary requirements and standards are being met.

As outlined earlier, there is growing evidence that people with diabetes experience a high prevalence of psychological difficulties. This is particularly the case for those making the transition from paediatric to adult services. It is also clear that effective service provision can reduce symptoms, improve glycaemic control, and as a consequence reduce both psychological distress and the costs of health care. Existing NICE guidance and NSF standards stipulate the necessary components of effective services for these needs, but despite this there

are remaining and important service gaps. Commissioners must expect and require services to work rapidly towards being able to demonstrate compliance with existing guidance and standards relevant to the psychological care of people with diabetes in the transition period. They must also resource those services adequately to enable the necessary service development to take place. This is clearly necessary in the region we surveyed, and the situation across the UK as a whole is highly unlikely to be any different.

Conflict of interest statement

There are no conflicts of interest.

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Appendix 1. Survey questionnaire

Psychological Support for Young People with Diabetes in the 'Transition' Stage

This survey, developed in line with both NICE guidance and NSF standards, aims to clarify what psychological support services are provided to young people with diabetes in the Yorkshire and Humber Region during the Transition period (i.e. ages 16–25). This is a period which can involve particular psychological problems, but it is believed that there are very few specific Transition services in existence and it would be helpful to clarify the current availability.

There are 10 questions in this survey. For each question stem, please simply tick/click on the box that applies to your service, remembering that *all questions apply to services for people between 16 and 25 years of age*. Thank you.

From NICE guidance:

1. Standard 1.4.2.1 states that:
'Diabetes care teams should be aware that children and young people with type 1 diabetes may develop anxiety and/or depression, particularly when difficulties in self-management arise in young people and children.'

Is this an issue that your team/service is aware of? Yes No

2. Standard 1.4.2.2 states that:
'Children and young people with type 1 diabetes who have persistently poor glycaemic control should be offered screening for anxiety and depression.'

Do you agree that this is necessary? Yes No

Is such screening being provided by your service? Yes No

If not, are steps being taken in order to provide this? Yes No

3. Standard 1.4.7.1 states that:
'Diabetes care teams should be aware that poor psychosocial support has a negative impact on a variety of outcomes of type 1 diabetes in children and young people including glycaemic control and self-esteem.'

Is this an issue that your team/service is aware of? Yes No

4. Standard 1.4.7.2 states that:
'Children and young people with type 1 diabetes, especially young people using multiple daily injection regimens, should be offered structured behavioural intervention strategies because these may improve psychological wellbeing and glycaemic control.'

Do you agree that this is necessary? Yes No

Have such strategies been implemented by your service? Yes No

If not, are steps being taken in order to provide this? Yes No

5. Standard 1.4.7.3 states that:
'Young people with type 1 diabetes should be offered specific support strategies such as mentoring and self-monitoring of blood glucose levels supported by problem solving, to improve their self-esteem and glycaemic control.'

Do you agree that this is necessary? Yes No

Does your service currently provide such support strategies? Yes No

If not, are steps being taken in order to provide this? Yes No

6. Standard 1.5.2.1 states that:
'Young people with type 1 diabetes should be encouraged to attend clinics on a regular basis (three or four times per year) because regular attendance is associated with good glycaemic control.'

Do you agree that this is necessary? Yes No

Does your service actively encourage regular attendance? Yes No

If not, are steps being taken in order to do this? Yes No

7. Standard 1.5.2.6 states that:
'Paediatric diabetes care teams should organise age-banded clinics for young people and young adults jointly with their adult specialty colleagues.'

Do you agree that this is necessary? Yes No

Does your service currently provide such clinics? Yes No

If not, are steps being taken in order to provide this? Yes No



Appendix 1. Survey questionnaire (continued)

8. Standard 1.5.2.7 states that:
'Young people with type 1 diabetes who are preparing for transition to adult services should be informed that some aspects of diabetes care will change at transition. The main changes relate to targets for short-term glycaemic control and screening for complications.'

Do you agree that this is necessary? Yes [] No []

Is this information being delivered to your service users? Yes [] No []

If not, are steps being taken in order to provide this? Yes [] No []

From the NSF for diabetes:

9. Standard 6 states that:
'All young people with diabetes will experience a smooth transition ... the transition will be organised in partnership with each individual and at an age appropriate to and agreed with them.'

Do you agree that this is necessary? Yes [] No []

Is this the case within your team/service? Yes [] No []

If not, are steps being taken in order to provide this? Yes [] No []

10. Intervention 19 states that:
'Paediatric and adult diabetes teams should liaise closely during the period leading up to and following the transfer of care. The provision of joint consultations enables the young person to be introduced to the new team that will be supporting them in the future.'

Do you agree that this is necessary? Yes [] No []

Does your service currently provide this? Yes [] No []

If not, are steps being taken in order to provide this? Yes [] No []

PLEASE COMPLETE your details:

Name.....

Title of your post.....

Hospital/centre.....

.....

THANK YOU VERY MUCH FOR YOUR HELP WITH THIS SURVEY