

Best Practice Tariff requirements for psychological care in paediatric diabetes: The approach of Leeds Teaching Hospitals NHS Trust

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Article points

1. The paediatric diabetes Best Practice Tariff offers an opportunity for practices to improve access to interventions to address psychological well-being for children and young people with diabetes.
2. The Tariff does not yet specify what to assess or how, which has led to regional variation in practice (and quality).
3. Refinement of the Tariff requirements for psychological care would further standardise practice. This will require national consensus about which aspects to assess.

Key words

- Assessment
- Best Practice Tariff
- Emotional well-being
- Psychosocial

Authors

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Children and young people with diabetes (CYPD) are more likely to achieve favourable outcomes if their care incorporates timely interventions targeting emotional well-being. The inclusion of psychological care in the Best Practice Tariff (BPT) for paediatric diabetes should theoretically ensure that, as a minimum, all CYPD have an annual psychological assessment with access to psychological support if indicated. The tariff does not yet specify what to assess and how and, contrary to a primary aim of BPTs (to standardise high quality care), this has led to variation in practice. The authors consider options for “assessment” and emphasise that, ideally, these will enhance care by focusing on improving access to targeted interventions. They also describe the attempt at Leeds Teaching Hospitals NHS Trust to embed this requirement, guided by a screening framework, and propose that national agreement on assessments would be beneficial to further standardise the tariff.

The complex and unremitting nature of diabetes management places children and young people with diabetes (CYPD) at risk of poor psychological adjustment. Despite recognised links between psychological distress and adverse health outcomes (e.g. poor glycaemic control [Johnson et al, 2012]), and national guidance stating that “attention to the mental health of the child, young person and their family should be an integral part” of paediatric services (Department of Health [DH], 2004), many interdisciplinary teams have not had input from mental health specialists. To address this shortfall, one of the care standards to attract Best Practice Tariff (BPT) funding addresses psychological well-being for CYPD by specifying an annual psychological assessment with intervention as required.

Best Practice Tariffs and psychological care in paediatric diabetes

In 2008, the DH announced the phased introduction of national BPTs to raise the minimum

level of patient care delivered by hospital service providers by specifying standards for enhanced tariff payments from local commissioners. Although “best practice” is defined as “care that is both clinical and cost effective” (DH, 2011), the details of best practice are not uniform across medical specialities and tariffs are tailored to the needs of their respective populations.

To improve UK outcomes for CYPD (which are poor relative to other European countries), a mandatory BPT was recently introduced for paediatric diabetes services (Randell, 2012a; 2012b). Adherence to the 13 standards (≥90% required) is monitored using the National Paediatric Diabetes Audit (NPDA; Royal College of Paediatrics and Child Health), and a National Peer Review Programme (NPRP; NHS Improving Quality) enables services to share good practice.

The International Society for Paediatric and Adolescent Diabetes (ISPAD, 2000) identifies psychosocial factors as “the most important influences affecting the care and management of

diabetes”. In line with their recommendations (*Box 1*) and NICE guidance CG15 that CYPD should be offered timely and ongoing access to mental health professionals (NICE, 2004), one standard states that “each patient should have an annual assessment by their MDT as to whether input to their care by a clinical psychologist is needed, and access to psychological support as appropriate” (NHS Diabetes, 2012). Although formulated as a single standard, to make this initiative both clinically and cost effective, in practice there are two requirements: the accurate identification of those struggling to cope psychologically, and ensuring that appropriate interventions are offered to those needing support.

Options for psychological assessment

The Tariff does not yet suggest which aspects of psychological functioning should be assessed or what level of assessment should be carried out (i.e. should standardised psychometric measures be administered and, if so, which ones?). This has allowed flexibility across services, which has been necessary during initial implementation due to resource limitations. Potential approaches include administration of: non-validated or validated self-report measures of psychological distress or disturbance; performance-related outcome measures (PROMS) addressing health-related quality of life (HRQOL); clinician-led semi-structured interviews; and informal or brief approaches (e.g. asking “how do you feel?”). Despite variable validity in detecting

signs of difficulty coping, all approaches are currently acceptable in their contribution towards receipt of enhanced payments.

In paediatric medicine, it is key to facilitate early support for those showing signs and symptoms of distress and mental health problems (DH, 2004). Arguably, this necessitates accurate detection, which may be optimally achieved under a screening framework. The National Screening Committee (NSC, 2004) provides useful criteria stating that screening pathways should ensure that: (i) the prevalence rate in the population justifies a screening programme, (ii) appropriate treatment options are available for identified cases, (iii) screening measures are both sensitive (i.e. unlikely to miss “true positives”) and specific (i.e. unlikely to identify “false positives”), and (iv) the screening programme is effective and acceptable to patients. While these criteria offer a reminder of ethical and practical considerations, screening for psychological distress differs from medical screening in at least two important ways: false positives are less likely to occur during psychological screening if responses are used collaboratively to agree care plans in partnership with families; and the cost of false positives is considerably lower than during medical screening programmes (where patients may be referred for unnecessary tests) and likely outweighs the burden of completing questionnaires.

While the notion of psychological screening for CYPD is not novel and is recommended internationally (ISPAD, 2000; Cameron et al, 2007), limited access to mental health specialists has made it difficult for teams to embed this recommendation. The observed absence of an agreed “gold standard” for assessment in this population (Barnard et al, 2012) has likely arisen from a lack of consensus about what to assess – an essential starting point when determining outcome sets (Williamson et al, 2012). Generally speaking, BPT infers that we should assess for indicators that CYPD are not coping with diabetes.

Leeds Paediatric Diabetes Unit (PDU)

The PDU at the Leeds Teaching Hospitals NHS Trust provides care for approximately 410 CYPD. In addition to support from the wider MDT to promote well-being, we are two clinical psychologists (positioned in Leeds Children’s

Page points

1. Children and young people with diabetes should be offered timely and ongoing access to mental health professionals.
2. The Department of Health states that it is key, in paediatric medicine, to facilitate early support for those showing signs and symptoms of distress and mental health problems.
3. The National Screening Committee states that screening pathways should use assessment tools that are both sensitive and specific for accurate detection.

Box 1. Recommendations for psychosocial care from the International Society for Pediatric and Adolescent Diabetes consensus guidelines (2000).

- Social workers and psychologists should be part of the interdisciplinary healthcare team
- Overt psychological problems in young persons or family members should receive support from the diabetes care team and expert attention from mental health professionals
- The diabetes care team should receive training in the recognition, identification and provision of information and counselling on psychosocial problems related to diabetes

“Common psychological difficulties in children and young people with diabetes include: depression and low mood; anxiety and fear of hypoglycaemia; disordered eating behaviour; behavioural problems; and ‘burnout.’”

Hospital) who offer specialist mental health input (1.0 whole time equivalent). Guided by the NSC criteria, we developed a brief annual screening strategy to identify those who are not coping psychologically with diabetes, and to offer appropriate support. We implemented this by considering four areas: 1) deciding what to assess; 2) selecting appropriate measures; 3) planning and coordinating interventions; and 4) auditing effectiveness and acceptability.

1. Deciding what to assess

In deciding what to assess, we looked at available literature to understand how psychological distress typically manifests in CYPD. Common difficulties include: depression and low mood; anxiety and fear of hypoglycaemia; disordered eating behaviour; behavioural problems; and “burnout” (i.e. diabetes-related stress caused by ongoing attempts at “controlling the uncontrollable, and coping with the incurable” [Hoover, 1983]). Although discrepancy exists about the prevalence of depression in CYPD (Johnson et al, 2012), screening for depressive symptoms may nonetheless be warranted due to robust links with adverse health outcomes (reduced glycaemic control and repeated diabetic ketoacidosis). Despite a lack of systematic reviews relating diabetes to other psychological difficulties, the links between diabetes-related distress and burnout with glycaemic control and HRQOL indicate that it is helpful to look at condition-specific adjustment.

Childhood diabetes impacts on the emotional well-being of immediate family members – especially parents. The condition increases practical dependence and reliance on parents who may be involved with: monitoring food intake and exercise; testing blood sugar; calculating insulin doses; giving injections; and inserting cannulas. Parental mental health and adjustment may contribute to positive outcomes for CYPD, or conversely, increase the likelihood of poor outcomes (Alderfer and Stanley, 2012), making it an important contextual factor. Unfortunately, parents of CYPD are at increased risk of depression, which is associated with inconsistent discipline (in general parenting) and family conflict, as well as relating directly to psychosocial adjustment for CYPD (Whittemore et al, 2012). In accordance with the increasing

recognition of the impact on the parents of caring for a child with a chronic illness, together with a bi-directional relationship between parental and CYP mental health (NICE, 2005) and recommendations from ISPAD (2000), we decided to assess parenting stress and mood.

2. Selecting appropriate measures

Selecting measures that are validated (and sensitive and specific) maximises the likelihood of detecting signs or symptoms of distress. In a document accompanying the tariff (NHS Diabetes, 2012), the HEADSS semi-structured psychosocial interview for adolescents (Goldenring and Cohen, 1988) is presented as one suitable measure. However, this elicits a psychosocial history rather than providing an assessment of psychological coping or distress *per se*. While this is a valid option, it may prove time consuming without actually achieving successful detection. One alternative that may be preferable (for both patients and clinicians) is a one-item or brief approach. Although appealing because of time constraints, single-item measures do not yet satisfactorily identify those struggling to cope: in one study, nearly half of CYPD with clinically significant levels of psychological distress were not detected (sensitivity for internalising distress=51% and depression=58%: Maas-van Schaijk et al, 2010). The PedsQL™ (Varni et al, 1999), a measure of HRQOL is also being used. However, the generic version shows similar HRQOL results for CYPD and their healthy peers, which may indicate that it is not suitable for identifying CYPD who are struggling (Laffel et al, 2003). We recognise that other validated measures may be useful and direct the reader to useful overviews elsewhere (Cameron et al, 2007; Hood et al, 2012).

In the absence of a “gold standard”, we selected questionnaires by drawing on national guidance and available evidence. To screen for signs of depression, we followed the NICE guidance CG28 (NICE, 2005), recommending the use of the Mood and Feelings Questionnaire-Short Version (MFQ-S; Angold et al, 1995). To elicit condition-specific distress and early indicators of difficulties, we included the Problem Areas In Diabetes–Teen Version (PAID-T: Polonsky et al, 1995; Weissberg-Benchell and Antisdell-Lomaglio, 2011), which provides a brief assessment of psychosocial

adjustment in diabetes. Practice-based feedback from the team has been positive about the PAID, which can also form the basis of early nurse-led interventions to prevent deterioration. As noted by NICE, further research is needed to confirm whether the use of questionnaires to identify mood difficulties in children under 11 years of age is a reliable and valid approach: we screened only those aged 11 years and upwards. CYPD are given the option to opt-in to the psychology service or to raise other concerns. For parents, we used the Perceived Stress Scale (PSS; Cohen et al, 1983), adapted to focus specifically on parenting a child with a chronic medical condition, and the two-item Patient Health Questionnaire (PHQ-2; Kroenke et al, 2003), as a brief mood screen.

3. Planning and coordinating interventions

National and international guidance emphasises that the MDT should understand how to assess and address the emotional well-being of children, identify significant mental health problems, and be trained in the provision of information and counselling on psychosocial aspects of diabetes (ISPAD, 2000; DH, 2004).

Accordingly, the children’s diabetes nurse specialists are currently administering the screens. In line with The King’s Fund report (Coulter et al, 2013) emphasising shared decision-making in

partnership with people with chronic medical conditions, we intended the assessments to facilitate a collaborative process for developing care plans with families that include emotional well-being. Instead of using cut-off points to refer to other professionals, we promoted a stepped-care response that includes interventions led by other clinicians (Table 1). We are fortunate that we can offer specialist psychological interventions within the team; elsewhere, services have gained psychology input by agreeing pathways with local Child and Adolescent Mental Health Services (e.g. Barnard et al, 2012).

4. Demonstrating effectiveness and acceptability

We registered a local audit to ensure that our screening process is effective in identifying CYPD who would benefit from additional support and that we have a robust strategy for responding. We will also gain feedback from families about the screen and establish the levels of unmet need for psychological care within the service – which could justify an increased return from the enhanced tariff payment.

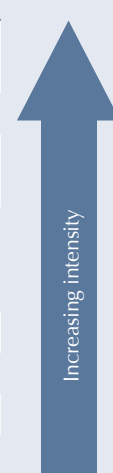
Conclusions and future directions

The cost of failing to identify, and intervene with, children and families who are struggling to cope with diabetes may be high for physical and mental health. Undoubtedly, BPT has provided

“The cost of failing to identify, and intervene with, children and families who are struggling to cope with diabetes may be high for physical and mental health.”

Table 1. A stepped-care approach to interventions following emotional well-being screening.

| Children and young people | Parents |
|---|--|
| Referral to CAMHS or liaison psychiatry | Referral to CMHT or liaison psychiatry Consider referral to social care |
| Referral to diabetes clinical psychology service | |
| Other (e.g. Initiate CAF) | Notify GP and ask them to review mood/medication/risk assessment |
| Referral to community-based services or tier 2 support | Advise parent to visit GP |
| Intervention with external agency (e.g. school) | |
| Nurse-led intervention/referral to other MDT members (if indicated by the PAID) | |
| Watchful waiting and agreed further contact (max. 4 weeks) | |
| Unclear – discussion at MDT with psychologist | |
| No action | |



CAMHS=child and adolescent mental health services; CAF=Common Assessment Framework; CMHT=community mental health team; MDT=multidisciplinary team; PAID=problem areas in diabetes

“Best Practice Tariff standards may need to be revised and expanded if the ultimate aim of improved outcomes is to be achieved. As well as maximising the likelihood of detecting those requiring additional support, further standardisation will protect patients from ineffective assessments.”

an opportunity to raise the minimum level of psychological care and embed psychologists into services. Although the current standard has allowed flexibility in the implementation of assessment and intervention pathways, it is concerning that some pathways have not been informed by evidence (and guidelines) and “assessments” could be introduced merely to “tick the box” for the NPDA.

Standards may need to be revised and expanded if the ultimate aim of improved outcomes is to be achieved. As well as maximising the likelihood of detecting those requiring additional support, further standardisation will protect patients from ineffective (and onerous) assessments. One difficulty for tariff setters in refining this standard concerns the lack of agreement about what to assess; before measures can be recommended, it is necessary to achieve consensus about what aspects of psychological functioning warrant annual assessment and how often this should take place. National agreement may be facilitated by participation in the NPRP and development of professional forums to discuss this.

It may also be necessary for contextual factors to be included in the BPT recommendations for outcomes to improve significantly. As recognised by national and international guidance, familial adjustment and parental mental health are important determinants of health outcomes for CYPD. Further, it is unlikely that outcomes will improve without addressing the social aspects of “psychosocial” care: high deprivation is associated with poorer glucose control (NHS Information Centre, 2011) and poorer mental health for CYP (Office for National Statistics, 2004). Inclusion of social aspects of care in BPT would assist the process of embedding medical social workers into teams. ■

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