RUNNING HEAD: MENTAL HELATH MEASURES IN PAEDIATRICS

Children and young people's mental health outcome measures in paediatrics

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Abstract

Paediatricians are increasingly likely to encounter children and young people with mental health difficulties, either as primary presentations or as comorbidities linked with chronic illnesses. However, paediatricians may have limited training or experience regarding the tools available to identify mental health needs and how to use them. The current paper aims to provide a go-to guide for paediatricians when considering the use of mental health and wellbeing outcome measures, including how to select, administer, and interpret measures effectively. It also provides practical guidance on the most common mental health outcome measures used in children and young people's mental health services across the UK and elsewhere, which paediatricians are likely to encounter in their practice. Paediatricians may also find these measures useful in their own practice to screen for potential mental health difficulties, monitor the impact of chronic health conditions on a young person's mental health and wellbeing, or to provide evidence when referring young people to mental health services.

Introduction

Paediatricians are increasingly likely to encounter children and young people with mental health difficulties. There has been a rapid increase in the number of children and young people experiencing mental health difficulties as primary presentations[1]. Levels of mental health difficulties are rising, as are levels of concern about the widening gap between the system's ability to meet need [2]. Extensive research demonstrates that children and young people with chronic physical illness such as asthma or diabetes are more likely to experience comorbid mental health difficulties such as depression and anxiety[3, 4]. Recent guidance encourages paediatricians to consider their role in supporting the mental health of the young people with whom they work, and in particular suggests the use of mental health measures to screen for potential difficulties[5].

The use of patient-reported outcome measures (PROMs) has increased across Child and Adolescent Mental Health Services (CAMHS)[6]. PROMs are questionnaires completed by a child, young person, or their parent or carer accessing mental health services used to measure changes in symptoms or functioning over time. Information gathered using PROMs may help monitor the impact of an intervention to inform clinical practice. Paediatricians are increasingly likely to encounter these measures when engaging with mental health professionals and may find them useful in their practice for screening or monitoring or to provide evidence in referrals to CAMHS. Mental health services research identifies many potential benefits of routinely using outcome measures in practice. These benefits include enhanced shared decision making and amplifying the voice of the child or young person[7]. It has been shown to provide information that may otherwise have been missed[8] including improving the clinician's ability to detect worsening symptoms[9].

The aim of the current paper is to provide paediatricians with a go-to guide on how to select, administer, and interpret some of the common measures used in CAMHS across the UK to assess and monitor depression, anxiety, externalising problems, and eating disorders. Although we focus on standardised PROMs of mental health symptoms and functioning, a wide range of measures exist for

other domains including other mental health difficulties, quality of life, or goals (see also [10] in this special issue).

Outcome measures in practice

This section provides a short overview of considerations paediatricians may wish to reflect on when selecting, administering, and interpreting outcome measures (for more detailed guidance, please see [11]).

Box 1. Key steps when using outcome measures in practice

- Choose the best tool for the intended purpose
- Understand and familiarise yourself with the questionnaire
- Engage in a shared decision discussions with the child, young person, and their family about using the measure, by preparing to introduce what it is, why it is being used, and how the information will be used
- Use it to explore and to understand
- Prepare to give feedback - discuss responses and scores
- Plan ahead to ensure adequate preparation for the above

Selecting the measure

It is essential to select a questionnaire that is suited to the intended purpose and designed to measure the issue or difficulties under consideration. For example, PROMs presented in the current paper are designed to monitor symptoms of specific difficulties, such as anxiety or eating disorders. In paediatric settings, quality of life is most commonly tracked[12], but there may be times when it is important to consider what other mental health measures could be meaningfully used to track outcomes of importance to the young person and their family. Thus, the use of measures that are specific to particular mental health difficulties, as discussed in this paper, may be appropriate.

Finally, some young people and their parents or carers may find a solution-focused approach helpful and so setting and monitoring individual goals could be appropriate[11].

It is important to use questionnaires that have been researched and psychometrically tested, to ensure they provide a valid and reliable assessment of the mental health difficulties examined. It is also important to ensure the tool is appropriate for the age of the child and accessible to the respondent.

We focus on measures of common mental health difficulties and those paediatricians may encounter or find helpful: the Revised Children's Anxiety and Depression Scale (RCADS)[13], Patient Health Questionnaire 9 (PHQ-9)[14], Generalized Anxiety Disorder 7 (GAD-7)[15], Youth Self Report[16], and the Eating Disorder Examination Questionnaire (EDE-Q)[17] (information on the Strengths and Difficulties Questionnaire (SDQ)[18] is also included in the Supplementary Material).

The measures are completed by the young person and do not require specialist training to administer, but guidance on scoring and interpreting responses is required. More detailed information about each measure (e.g., scoring, interpretation, and psychometric properties) can be found in the Supplementary Table. Most take 5-15 minutes to complete but the full Youth Self Report is longer.

Most tools presented below are not suitable for completion by children younger than 11, or with moderate learning difficulties; it may also be helpful to consider how to capture the different perspectives provided by the child and others around them, for example a parent or carer or the child's teacher. These views will often differ[19] but each offers observation and understanding of how the child behaves or feels in different environments and circumstances.

Administering the measure

Before using any measure, it is vital to be familiar with it. We recommend a professional complete the measure themselves initially, holding in mind the intended audience to identify any challenges they may encounter responding to the questions. This informs preparation for introducing the measure. Paediatricians should also be mindful that, for some measures, they may need to access relevant training before using them, to ensure they can be administered and interpreted effectively.

Ethically, and to encourage an honest response, it is essential that the respondent understands why they are being asked to complete the questionnaire and how the information will be used and by whom. For example, introducing mental health outcome measures may create concerns for young people with chronic health conditions and their families if they worry that "emotional issues raised by [measures] may detract from physical healthcare", as reported by Wolpert and colleagues[20]. Considerations should also be made regarding the best timing to introduce questionnaires to a child or young person. When using a measure in practice, it should be done in the spirit of investigation and curiosity. It is a tool for finding out more about the child or young person's mental state. It is important that this is communicated to the respondent. If a measure is perceived to be merely an administrative requirement, then meaningful engagement is less likely and the information gathered might be less useful.

Interpreting responses

Once a measure has been completed, individual scores could be compared against published clinical thresholds to determine the presence and/or severity of symptoms. These comparisons however should be done carefully, taking into account potential factors that may impact on the scores of the child and specific characteristics of any comparator samples. For example, it is important to reflect on how individual chronic health conditions may impact on the scores provided by the child or young person, in particular for items that focus on somatic symptoms (see [21] for a more detailed

discussion). Paediatricians or other practitioners without mental health expertise should also avoid drawing conclusions regarding a specific diagnosis based on data obtained using outcome measures.

Young people and families are generally keen to have feedback on the results of their questionnaires and want to be involved in interpreting and understanding their data[11]. It is therefore important to share the results with the young person and provide the opportunity to explore and understand what the questionnaire reflects.

Next steps

Information from PROMs should be used as a piece of information in conjunction with other clinical and lived experience information to inform discussions with the young person and parent/carer or other practitioners. Initial data may be useful to assess the severity or nature of difficulties and to inform decisions about treatment or support plans. Initial scores also offer a baseline from which to monitor progress and review the efficacy of any support put in place. In this situation, briefer questionnaires or more specific subscales may be helpful for use on a regular basis to track difficulties. The data may also be helpful when making referrals or discussing a case with a mental health practitioner or other professional such as a social worker or school staff.

Mental health outcome measures in CAMHS

Revised Children's Anxiety and Depression Scales

The RCADS is used to assess symptoms of depression and anxiety for children and young people aged 8 to 18[13]. The tool can be self-administered or completed by parents or carers and contains 47 items. Each item asks how often a thought or behaviour occurs, such as "I worry that something bad will happen to me".

Six subscales (separation anxiety disorder, social phobia, generalized anxiety disorder, panic disorder, obsessive compulsive disorder, and low mood) can be obtained by summing the relevant

items. It also yields a Total Anxiety Scale and a Total Internalizing. Scores need to be converted before comparison with clinical thresholds (see Supplementary Table), which currently are available for populations in the US[22], Australia[23] and Denmark[24].

Evidence currently available indicate that the RCADS is a valid and reliable measure of anxiety and depression in children and young people. The measure is particularly helpful to monitor distinct types of anxiety disorders that may not be captured by more general anxiety measures such as GAD-7. To our knowledge, only a limited number of studies have used the RCADS in populations of children and young people with chronic illness[25 26].

Generalized Anxiety Disorder Assessment – 7

The GAD-7 is a 7-item questionnaire used to measure the severity of generalised anxiety disorders (GAD) in young people aged 13 and above[14]. The questionnaire is self-administered. Each item asks the individual to rate the severity of anxiety symptoms, such as “Feeling nervous, anxious or on edge”, over the past two weeks.

All items can be summed to calculate a total score providing a measure of GAD. Total scores of 5, 10, and 15 represent cut-off points for mild, moderate, and severe generalized anxiety, respectively[14]. Clinical thresholds are available for German children and young people only[27].

Current evidence indicates the tool is a valid and reliable measure of anxiety in adolescents. The GAD-7 has been used as a measure of anxiety in a range of paediatrics-related research, including anxiety in transgender and gender non-conforming children and young people[28], children with Williams Syndrome[29] and in adolescents after receiving a concussion[30].

Patient Health Questionnaire - 9

The PHQ-9 is a self-administered 9-item questionnaire used to screen for the presence and severity of depression in adolescents aged 13 and above[15]. Respondents indicate how much each problem

(such as “Feeling down, depressed, or hopeless”) have been bothering them over the past two weeks.

A total score is obtained by summing responses to the 9 items and range from 0 to 27, with higher scores indicating higher depressive symptoms. In adolescents, scores of 5, 11, 15, and 20 represent cut-off points for mild, moderate, moderately severe, and severe depression, respectively[31]. Clinical cut offs are available for 14 to 24-year olds in Germany[32].

The PHQ-9 is a short, well-established assessment tool for depression and the available evidence indicates it is a valid and reliable tool to measure the presence and severity of depression in adolescents[33]. The tool has also been used extensively in populations with chronic health conditions, both in children and adolescents[34 35] and in adults[36].

Youth Self-Report

The Youth Self Report (YSR) measures emotional and behavioural problems in young people aged 11 to 18 years old, although previous research has demonstrated its validity with children as young as 7[16]. The YSR is the self-report of the Achenbach System of Empirically Based Assessment, which also includes a parent/carer-report version (Child Behaviour Checklist) and teacher-report version (Teacher’s Report Form); a multi-informant approach is often encouraged[37]. The 112-item measure can be grouped into internalising and externalising scales, with externalising behaviour measured with the subscales rule-breaking behaviour and aggressive behaviour. Items have also been organised into DSM-oriented scales consistent with diagnoses, including conduct disorder or oppositional defiant disorder. Respondents rate the frequency of each symptom/behaviour (such as “I threaten to hurt people”) in the last six months with a three-point scale (0=absent, 1=occurs sometimes, 2=occurs often).

The whole measure divides symptoms into eight subscales: withdrawn, somatic complaints, anxiety and depression, social problems, thought problems, attention problems, rule-breaking behaviour, and aggressive behaviour. Scores can be transformed into t-scores, which can then be compared to clinical cut offs for non-clinical, borderline, and clinical bands. Extensive clinical thresholds are available, including for populations in the US, Australia, China, and Turkey[38].

The YSR is widely used and has been extensively studied, like for example, in a generalisability study involving 23 societies[39]. It is available in over 110 languages and has indicated good validity and reliability in young people. Studies have used the YSR in various clinical and non-clinical populations[40], including young people with gender dysphoria in the UK[41], and in settings such as residential care and juvenile justice[42,43].

Eating Disorders Examination Questionnaire

The EDE-Q is a brief self-reported questionnaire measuring eating disorder behaviours and attitudes[17] in adolescents aged 14 and beyond. It comprises 28 items that are used to measure eating disorders symptoms experienced over the past four weeks, such as “On how many of the past 28 days... Have you had a definite desire to have an empty stomach with the aim of influencing your shape or weight?”.

Four subscales and one total score can be calculated to assess specific concerns, with higher scores denoting more problematic eating behaviours and attitudes (see supplementary material for more information). It is worth noting that the EDE-Q is not a diagnostic measure, and although cut-off scores have been suggested to determine the presence of an eating disorder, these may only be appropriate for the specific population the sample was drawn from[44]. Community cut-offs have been published for female adolescents[45] and young adults in the UK[46] as well as in Australia[47], in the US[48, 49] and elsewhere.

The EDE-Q has previously been used with young people and adults with chronic health conditions[4], indicating the validity of the measure in paediatric settings. Evidence suggests that the EDE-Q is a reliable and well-established measurement tool used in research and clinical settings to measure eating disorder symptoms. However, more research is required to validate the factor structure of the tool and subscales should be used with caution.

Although we focus on standardised PROMs in the present article, we note that the Goals Based Outcome Tool[11] is a widely used measure in CYPMS. Clinicians, young people, and parents/carer can collaboratively set up to three mutually agreed goals. They can then rate progress towards achieving each goal on a 0-10 scale. The Goal Based Outcome Tool may also be relevant for use in paediatric settings for goals about physical and mental health; e.g., "I want to worry less about my asthma".

Discussion

This paper provides an overview of considerations to reflect on when using mental health outcome measures in paediatric settings. We presented some measures of common mental health difficulties and those paediatricians may encounter or find helpful. Evidence currently available highlights that these measures are on the whole valid and reliable tools that can be used to measure common mental health difficulties including anxiety, depression, behavioural difficulties, and eating disorders. Most measures have been used with children and young people with chronic illnesses, indicating their potential benefits to the paediatric community.

Although a wide range of measures are currently available, they all assess specific mental health difficulties and all may not be relevant to an individual depending on their current needs or context. Carefully selecting a measure based on the difficulties characteristics of the individual young person will be essential to ensure it provides meaningful information. It is therefore important to discuss outcome measurement with the child, young person and their family as relevant, to determine the

type of need and the mental health outcomes that are meaningful to them, keeping in mind that outcomes that are perceived to be important to the practitioner may not be the key areas for the child or young person.

Both the approach overall and individual measures also have limitations. They do not provide the same type of information as more physical elements of symptom tracking. The wider context of the child should be considered when interpreting results, for example reflecting on how co-morbid conditions may impact on the child's responses. Current outcome measures are not able to capture subtle differences in the ways mental health difficulties present in children and young people with or without chronic illnesses; they may also overlook difficulties that are more specific to children with chronic illnesses[50]. It should be acknowledged that more evidence is needed to be confident that existing measures reliably assess severity, and capture change over time, for young people and different groups of young people in routine practice[51]. When using measures to assess a child's mental health, it will therefore be particularly important to triangulate information from different sources, perspectives, and measurement types to ensure the interpretation accurately reflects their needs. As discussed elsewhere in this special issue[10] it is important to consider personalised measures in addition to standardised measures as presented in this paper, to help paediatricians deliver care personalised to the needs and preferences of children, young people, and their families.

Although evidence is growing regarding the psychometric properties of the measures presented here, limitations remain. For example, the validity of certain subscales or the use of outcome measures across diverse groups of children and young people, especially as most measures have been validated in the Global North with majority White samples. Nevertheless, we encourage paediatricians to consider using outcome measures such as those presented. More information about these and other measures can be found at https://www.corc.uk.net/.

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