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Childhood unusual experiences in community Child and Adolescent Mental Health Services in South East London: prevalence and impact.

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Abstract

Background: Distressing 'psychotic-like' experiences signify increased mental health risk in the general population, including greater likelihood and severity of co-occurring non-psychotic mental health problems, and, from fourteen years of age, increased risk of a future psychotic illness. Healthcare guidelines for under eighteens recommend psychological intervention for UEDs, to reduce current distress and adverse functional impact, and, potentially, future mental health risk. Children tend not to report UEDs unless directly asked, indicating a need for routine screening. We report on the feasibility of a routine screening methodology, and screening outcomes, in Child and Adolescent Mental Health Services (CAMHS) in South East London, United Kingdom

Method: Four general community CAMHS teams were invited to screen, by adding a nine-item self-report UED measure to their routine assessment battery. Screening data were collected over 18 months from 02/2015 to 07/2016.

Results: All but one team agreed to screen. Each team saw around 300 accepted referrals during the audit period (total: 900); 768 of these (85%) were successfully screened; of those screened, 68% (n=524) self-reported UEs, 60% (n=461) with associated distress/adverse functional impact. Screening was acceptable to clinicians, children and families.

Conclusions: Assessing UEDs routinely in CAMHS is feasible, and suggests that around two thirds of assessed referrals could potentially benefit from interventions targeting UEDs. Additional training may be required for the CAMHS workforce to address this need.

Key words: Psychotic-like experiences, PLEs; screening; emotional symptoms; childhood psychopathology; paediatric

1. Introduction

Unusual, or 'psychotic-like', experiences are perceptions or beliefs that seem unreal or unfounded to others. Our consultation with young people and their families has indicated a preference for the term 'unusual' over 'psychotic-like' and we therefore now employ this terminology.

Unusual experiences (UEs) are relatively common in the general adult population (8% average prevalence, range 2% to 40%) and much more common in childhood (15% average prevalence, range 5% to 95%) (Linscott & van Os, 2012; Kelleher et al, 2012). Rates tend to be higher when self-reported on questionnaires compared to elicited by interview, but assessment by a short, diagnostically-based self-report screening measure has been shown to be valid and reliable in predicting future impact of childhood (11 to 13 years) UEs compared to clinical interview (Kelleher et al., 2011). Around a quarter of young people aged 9 to 12 years with self-reported UEs in the general population experience associated distress or adverse functional impact (UEDs, Laurens et al., 2010). Most studies show that while the likelihood of experiencing UEs decreases with age, the likelihood of UEs being associated with distress/adverse functional impact increases (Kelleher et al., 2012; 2015; Pontillo et al., 2016).

Childhood UEs in general population samples are reliably associated with a range of current and future mental health difficulties and functional impairments (Kelleher et al., 2013; 2015; Downs et al., 2013; Fisher et al., 2013). Although UEs are not considered to represent a specific psychosis risk in younger adolescence (under 14 years), United Kingdom National Institute for Health and Care Excellence (NICE, 2013) and European Psychiatric Association (EPA, 2015) guidance nevertheless recommend psychological therapy for younger children self-reporting problematic UEs, as part of an overall care package, aiming to reduce current distress and adverse functional impact, and potentially to reduce future mental health problems. From fourteen years, assessment within specialist services to identify at-risk mental state presentations, and, for those at clinical high risk, specific intervention to prevent transition to psychosis, is additionally recommended for help-seeking young people (Kendall et al., 2013; Stafford et al., 2013; Schmidt et al., 2015; Schimmelman et al., 2015).

Pathways from CAMHS to specialist early intervention and clinical high risk psychosis (EIP and CHR) services are often problematic, with a lack of psychosis expertise in generic CAMHS, and of developmental expertise in psychosis services with poorer outcomes reported for younger referrals (Tiffin & Welsh, 2013; Haddock et al., 2006; Staine et al., 2016). Despite the broad treatment recommendations for UEDs, current guidance is unclear on the assessment of UEs outside EIP and CHR services (Kline and Schiffman, 2014; Pontillo et al.,

Studies show that young people do not usually report even to their parents, unless directly asked, and young people are often referred for help by parents, schools, or family doctors, rather than seeking help themselves (Laurens et al., 2011; Ames et al., 2014). Researchers have therefore called for routine screening for UEDs in Child and Adolescent Mental Health Services (CAMHS), to facilitate appropriate intervention, rather than expecting young people to identify and request help for UEDs themselves (Laurens et al., 2012).

Recent studies have assessed UEs in three general CAMHS settings, using different methodologies. Kelleher et al. (2014) reported UE rates of 46% (n=50/108) in an Irish CAMHS sample aged 12-16 years with a comorbid psychiatric diagnosis. UEs were elicited using a diagnostic interview schedule, and were associated with multimorbidity, suicidality, and, poorer observer-rated functioning. Similar findings were reported in 8 to 17 year olds (n=106) in an Italian CAMHS clinic, using a standardised psychosis risk interview (Pontillo et al., 2016). Across six similar Italian CAMHS clinic settings, 167/171 participants aged 11 to 18 years reported UEs using a 92-item questionnaire assessment including schizotypal experiences (Brandizzi et al., 2014). In South East London CAMHS, we have employed a short, diagnostically-based self-report measure (Laurens et al., 2012; Ames et al., 2014), arguably better suited to routine screening, and found that 82% (n=55/67) of 8-14 year olds referred for emotional and behavioural problems reported UEs, with 76% of these (n=42) rating associated distress and/or adverse functional impact (Noone et al., 2015).

All of these samples represent only a small proportion of presentations to the respective services, recruited for separate research purposes. None therefore provides adequate data on the feasibility of screening, or the expected rate of presentation of UEs with distress and/or adverse functional impact, in routine CAMHS.

Our aim in the present study was to assess the feasibility of routine screening for UEDs in community CAMHS in South East London, and to report the outcomes of screening. We employed the short diagnostically-based self-report assessment of UEDs developed for use with children in our local community and CAMHS services, which includes self-ratings of distress and adverse functional impact for each item (Laurens et al., 2012; Ames et al., 2015). As previous general population-based studies suggest independence of distress and functional impact (Kelleher et al., 2015), we considered a UED to be present if either distress ('upset you') or adverse functional impact ('made things hard at school or home') were rated >0 (on a scale from 0 'not at all' to 3 'a great deal'). While severity of distress is a poor indicator of subsequent transition to psychosis in clinical high risk youth (Power et al., 2014), it is an indicator of clinical high risk status in youth referred for specialist assessment (Kline et al., 2013), and is also a key target, along with adverse functional impact, for recommended psychological intervention, and therefore of the proportion of young people with UEs for whom psychological intervention may be indicated.

1. The screening outcomes of interest were; The prevalence of UEs and UEDs in young people referred to CAMHS community adolescent teams; and
2. The association between UEs, UEDs and clinically significant distress/emotional symptoms, identified using an established measure.

2. Method

2.1. Service setting

Four community CAMHS teams in two inner and two outer London boroughs, representing those served by the South London & Maudsley National Health Service Foundation Trust (SLaM), were approached. Teams were the first point of entry to specialist mental health care for 12 to 18 year olds (and occasionally younger children), receiving referrals from family doctors, emergency clinics,

and schools. Each team assessed around 200 referrals/year, using a CAMHS assessment battery. Routine screening required adding a brief questionnaire measure of UEs to this battery. Three teams agreed to routine screening; the fourth decided a priori to assess UEDs as indicated by clinical impression rather than for all assessments, so were not included in the audit.

2.2. Measures

2.2.1 Unusual experiences questionnaire (UEQ, Laurens et al. 2007; 2010; 2012; Ames et al., 2014)

This nine item self-report questionnaire assessed current unusual experiences, including five items adapted from the Diagnostic Interview Schedule for Children (Costello et al., 1982). Young people first rated each item on a Conviction scale from 0 (not true), 1 (somewhat true), to 2 (certainly true). Frequency, distress, and adverse functional impact over the preceding two weeks were then rated on a four-point severity scale from 0 to 3 for each item. Items rated >0 on conviction and frequency were classed as UEs; items also rated >0 on distress and/or adverse functional impact were classed as UEDs. Participants were dichotomized according to presence of a UE, and, of those reporting one or more UEs, presence of a UED.

2.2 The Strengths and Difficulties Questionnaire, Emotional Symptoms subscale (SDQ-ESS, Goodman et al., 1997; 2001; 2010, Muris et al, 2004)

The SDQ is a 25-item self-report screening measure of general childhood psychopathology suitable for children aged from 11 to 18 years, and was already in routine use in the targeted services. The Emotional Symptoms Subscale (SDQ-ESS) was used as a standardised indication of clinical severity of distress/emotional symptoms. Five items assessing childhood anxiety and low mood are rated: 0=not true; 1=somewhat true; or 2=certainly true. Scores ≥ 7 indicate clinical levels of difficulty; 6 indicates borderline clinical severity.

2.3. Procedure

The UEQ and SDQ-ESS were completed routinely for all referrals from 02/2015. Data for the current report was collected in 07/2016 (18 months). Young people attending the service gave consent (or assent to the consent of a parental responsibility holder if under 16 years) routinely for their responses to be used to evaluate the service. Audit approval was granted by the SLaM CAMHS Clinical Academic Group audit and evaluation lead.

3. Results

3.1. Acceptability and completion

All three teams attempting to screen were able to implement this without difficulty. No adverse reports were received from young people or their families. Staff commented on the usefulness of screening to guide assessments, formulation and intervention offers. Young people noted the normalising effect of experiences being included in a formal measure. Routine audit data indicated a total of 900 assessed referrals over 18 months: 85% of these (n=768) completed the UEQ and SDQ-ESS. Demographic characteristics of completers are shown in Table 1. Services reported practical

reasons for the 15% for whom screens were not completed, e.g. using an old assessment pack without a UEQ, or being unable to find copies of the UEQ at the time of assessment.

3.2 Prevalence of unusual experiences and distress/impact

As shown in Table 1, of the 68% (n=524) of young people with a UE, 88% (n=461) reported associated distress or adverse functional impact (i.e. a UED).

3.3 Association with clinically significant distress/emotional symptoms

Table 2 shows the rates of UEs and UEDs according to the presence of clinically significant distress/emotional symptoms on the SDQ-ESS. While the majority of young people with UEDs also met screening criteria for emotional symptoms at a clinical or borderline level (73%, n=335/461), just under a third did not, and a small number of young people met clinical/borderline criteria for emotional problems with a UE that they did not rate as distressing/adversely impacting (6%, n=29, of 490 with a UED, or UE and emotional symptoms).

Discussion

We set out to investigate the feasibility and acceptability of a routine screening methodology to identify UEDs in community CAMHS services in South East London, and to report on screening outcomes regarding the prevalence of UEs, UEDs and clinical significance of distress/emotional symptoms. We considered screening to be indicated given: i) the reported tendency of children not to report UEs unless directly asked; ii) the substantial evidence for the adverse impact of UEs on general mental wellbeing and functioning, in addition to potentially increased psychosis risk; iii) research reports of elevated UE prevalence and adverse impact in CAMHS compared to general population settings; and iv) recent recommendations for psychological interventions to reduce distress and improve functioning for young people with problematic UEs. We employed a brief, diagnostically-based self-report measure of UEs, rated for associated distress and adverse functional impact, as these are the targets of psychological intervention. We found screening to be feasible, with three of four teams agreeing to screen, no adverse reports of screening, and 85% of assessed referrals over 18 months successfully screened (768/900). Screening outcomes suggest that around two thirds of CAMHS referrals experience UEs with distress and/or adverse functional impact, and may potentially benefit from referral on to EIP or CHR services, and/or the inclusion in their overall care of psychological interventions addressing UEDs, to improve wellbeing and functioning.

Our report extends previous CAMHS clinic-based findings, by including a high proportion of routinely assessed cases. Our findings suggest higher prevalence of UEDs than interview assessments (Kelleher et al., 2014; Pontillo et al., 2016), but fewer than those found by longer, psychometrically derived assessment (Brandizzi et al., 2014), and fewer than in a small research-selected sample using the same screening measure, in similar services for younger children (Noone et al., 2015). Similar diagnostically-based screens have been shown to be reliable compared to interview assessment of UEs (Kelleher et al., 2011), and prevalence rates may be genuinely elevated in our London setting (Greater London Authority, 2014; Newbury et al., 2016). Future research should assess prevalence in CAMHS across settings employing a common methodology.

Very few children with UEs accompanied by borderline/clinically significant emotional symptoms were not identified by self-report (n=29), suggesting sensitivity of the method, whereas a third of self-reported UEDs were not accompanied by such symptoms, potentially suggesting problematic discrimination of clinical significance and selection for intervention. To satisfactorily determine this, however, further longitudinal follow-up of the sub-groups is required, combined with evaluation to address the impact of additional targeted interventions, compared to routine care.

Feasibility of the chosen method was good: it is notable that the fourth team decided at the outset not to screen routinely, rather than trying to screen and finding it hard to implement. Assessing UEDs according to clinician-judged relevance, rather than for all referrals, resulted in very much lower rates of UEQ completion (around 12% of the rate in the screening teams), but, again, no adverse report of screening. The main reported obstacle to screening in the fourth team was concern about the broad acceptability of the UE measure to young people; sharing successful implementation stories across teams may facilitate implementation. It should, however, be borne in mind that screening may not be initially appealing to all teams.

Several limitations of this audit should be acknowledged. UEDs were assessed cross-sectionally, by self-report, uncorroborated by interview, so prevalence estimates may be subject to bias (Podsakoff, 2003, Pontillo et al., 2016). Younger or less able participants especially may have misinterpreted questions. Studies of criterion and convergent validity, particularly for self-rated distress and adverse functional impact, are needed. We did not include any assessment of comorbidity, except the SDQ-ESS, or of outcomes over time. Judgements regarding the clinical significance of ratings therefore rely on previous research findings of the adverse impact of UEDs. We did not collect information on subsequent referral to EIP or CHR services, and facilitating appropriate use of these pathways, to improve clinical and economic outcomes, would be an important function of CAMHS screening (Valmaggia et al., 2012; McCrone et al., 2013).

Children and young people living in urban areas are 80% more likely to experience psychotic symptoms than their nonurban counterparts (Newbury 2016), and our services may not be representative of CAMHS assessments across the UK or internationally.

Finally, while a high proportion of assessments included the UED screen (85%), it is possible that clinicians still exercised (unreported) selection in determining whether it was included, that may bias estimates. Once routine completion is fully established, with the same logistical issues as for existing routine measures, a comparison of rates of apparently inadvertent non-completion across measures could be informative.

Despite these limitations, findings raise potentially significant service implications. UEDs are common in young people routinely referred to CAMHS, corroborating findings in smaller, research-selected samples. Routinely screened rates are much higher than when assessed by clinician judgement, suggesting that any associated clinical need will be largely unrecognised without screening. Based on previous findings of the adverse mental health and functional impact of UEDs and both UK and European treatment guidance, targeted care may be indicated, both as part of the wider care package, and by facilitating referral on to clinical high risk services. Further research to establish longer term outcomes of CAMHS samples and the influence of intervention will clarify estimates of workforce development need. Given the global societal burden of mental ill health, international health and economic implications are potentially substantial (World Health Organization 2013).

Conflicts of interest: None.

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Table 1: Demographic and clinical characteristics of young people (n=768) routinely assessed in Child and Adolescent Community Mental Health Services.

		n	% of total
Age (mean, SD)	14.6 years (1.79, range 8-18 years)		
Gender	Male	249	32%
	Female	519	68%
UE		524	68%
Distress	UED	461	60%
	UE & SDQ-ESS ≥ 7	24	3%
	UE & SDQ-ESS =6	5	<1%

KEY: UE: Unusual Experience; UED: Unusual Experience with Distress; SDQ-ESS: Strengths and Difficulties Questionnaire, Emotional Symptoms Subscale (≥ 7 : clinical range); SD: Standard Deviation.

Table 2: Unusual experiences and associated distress/adverse impact and emotional symptoms in young people aged 12 to 18 years routinely assessed in Child and Adolescent Mental Health Services.

SDQ-ESS category	No UE	n (% in SDQ-ESS category)		Total n (% of total)
		UE, no distress	UED	
Non-clinical (0-5)	142 (47%)	34 (11%)	126 (42%)	302 (39%)
Borderline clinical (6)	25 (28%)	5 (6%)	59 (66%)	89 (12%)
Clinical (7-10)	77 (20%)	24 (6%)	276 (73%)	377 (49%)
		n (% of total)		
Total	244 (32%)	63 (8%)	461 (60%)	768

KEY: UE: Unusual Experience; UED: Unusual Experience with Distress; SDQ-ESS: Strengths and Difficulties Questionnaire, Emotional Symptoms Subscale