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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' or unusual experiences (UEDs) 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.

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#### 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 and Van Os, 2012; Kelleher et al., 2012a). 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

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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., 2012b, 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 selfreporting 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

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to prevent transition to psychosis, is additionally recommended for help-seeking young people (Kendall et al., 2013; Stafford 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 and Welsh, 2013; Haddock et al., 2006; Stain 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., 2016).

Studies show that young people do not usually report UEDs 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., 2012; 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 selfratings of distress and adverse functional impact for each item (Laurens et al., 2012; Ames et al., 2014). 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., 2016), it is an indicator of clinical high risk status in youth referred for specialist assessment (Kline et al., 2014), 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.

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.

2.2.2. The Strengths and Difficulties Questionnaire, Emotional Symptoms Subscale (SDQ-ESS, Goodman, 1997, 2001, 2010; Muris et al., 2003)

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  $\geq 7$  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

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