Parental help-seeking in primary care for child and adolescent mental health concerns: qualitative study
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Background
Child and adolescent mental health problems are common in primary care. However, few parents of children with mental health problems express concerns about these problems during consultations.

Aims
To explore the factors influencing parental help-seeking for children with emotional or behavioural difficulties.

Method
Focus group discussions with 34 parents from non-specialist community settings who had concerns about their child’s mental health. All groups were followed by validation groups or semi-structured interviews.

Results
Most children had clinically significant mental health symptoms or associated impairment in function. Appointment systems were a key barrier, as many parents felt that short appointments did not allow sufficient time to address their child’s difficulties. Continuity of care and trusting relationships with general practitioners (GPs) who validated their concerns were perceived to facilitate help-seeking. Parents valued GPs who showed an interest in their child and family situation. Barriers to seeking help included embarrassment, stigma of mental health problems, and concerns about being labelled or receiving a diagnosis. Some parents were concerned about being judged a poor parent and their child being removed from the family should they seek help.

Conclusions
Primary healthcare is a key resource for children and young people with emotional and behavioural difficulties and their families. Primary care services should be able to provide ready access to health professionals with an interest in children and families and appointments of sufficient length so that parents feel able to discuss their mental health concerns.

Declaration of interest
None.

At least 10% of children and adolescents have a mental health disorder and many more have significant symptoms or related impairment that do not reach diagnostic criteria.1 The rates of and risk factors for these problems tend to be greater in socio-economically deprived areas such as inner cities.1 These difficulties often persist over time and present risks for later development and impaired functioning in adulthood.2,3 Only a minority of children with mental health problems access specialist mental health services.4,5 However, most children attend primary healthcare services, providing a potential opportunity for parents to raise concerns about their child’s emotional health or behaviour. Up to a quarter of children attending primary care have mental health problems and although these children are regular attendees in primary care, they mainly present with physical rather than mental health symptoms.6,7 This results in barriers to their recognition and referral.

Children are dependent on adults to recognise their problems, determine whether they require services, and seek help on their behalf. Although parental perception of problems plays a key role in determining service use, few parents express their concerns in primary care consultations.8,9 Hence, these problems are under-recognised. Detailed reviews of the international literature on help-seeking in primary care for child and adolescent mental health confirm that barriers exist at the level of parental expression of concerns and recognition by primary healthcare professionals.9,10 An improved understanding of factors contributing to parental patterns of presentation and parental views about primary care services may help to reduce current barriers to care.

There has been relatively little qualitative research examining parental attitudes influencing help-seeking in primary care for child and adolescent mental health problems.11 Such work has an important role in improving our knowledge about help-seeking and barriers to care. The clarification of factors that systematically inhibit or facilitate the use of services can inform service development and clinical practice interventions that aim to increase access to services. Improving access to care is crucial for prevention endeavours; outcomes for children with high levels of risk or recent onset of mental health problems may be improved through early identification and access to interventions.12,13 There are public health implications in terms of the provision of health services as well as parental and/or professional education. We aimed to elicit and describe parental views about perceived barriers and facilitators to accessing primary healthcare for child and adolescent mental health problems.

Method

Sample and procedure
We conducted eight focus group discussions with parents. Parents were eligible for the study if they had concerns about their child’s emotional health or behaviour, the index child was aged 2–17 years, and they were not currently under the care of specialist child and adolescent mental health services (CAMHS). Ethical approval was given by the local National Health Service research ethics committee. We used a variety of methods to recruit participants.
that aimed to reflect a wide range of child ages and routes of initial presentation to primary care. Although the sample was recruited from a variety of sources, all the children had previously attended primary healthcare services. Parents were recruited from a range of community-based organisations working with families across the London boroughs of Lambeth and Southwark. These relatively deprived inner-city areas have higher proportions than the national average of unemployment, overcrowded accommodation, and children eligible for free school meals. Posters and flyers were placed in general practice surgeries, community organisations such as Sure Start, and child health and youth group centres. Staff in these organisations also gave information to eligible parents. Teachers (special educational needs coordinators) at primary and secondary schools gave information to eligible parents. Researchers also recruited parents directly in general practice surgery waiting areas (n = 6) and through the Institute of Psychiatry research volunteer database. In all cases, parents were invited to contact the researchers or gave permission to be contacted by the researchers for further information.

Focus groups

Following recruitment, eight focus groups were set up, each including four to eight parents who had agreed to participate. To facilitate attendance, focus groups were held at the location where parents were recruited or at a local community centre where possible. A topic guide was developed guided by the research where parents were recruited or at a local community centre where possible. The group discussions focused on parents’ concerns about their child’s emotional health or behaviour and their views and experiences about the process of seeking help, specifically through primary care as well as through friends, family and the community (including non-medical services such as schools). Each focus group discussion was facilitated by one researcher, while another researcher took field notes. The facilitator probed for possible reasons where help had not been sought for specific concerns. Suggestions about improvements to services and ideal services were also discussed. After each focus group, parents were given an information sheet signposting them to sources of further help and advice (e.g. Parentline and Young Minds). We aimed to repeat each focus group to ensure validation of findings (see below).14

Other measures

Parent and child demographic details and parent-completed Strengths and Difficulties Questionnaires (SDQ)15,16 provided descriptive data about the children represented in the groups. The SDQ is a widely used measure of the mental health of 4- to 16-year-olds, which has been validated in large community samples.17 Ratings were not collected on 2- and 3-year-olds, as this version of the SDQ has not been validated for this age group. After each focus group discussion, teacher-completed SDQs were obtained via post with parental consent. The SDQ has five items each on hyperactivity/inattention, conduct problems, emotional symptoms, peer relationships and prosocial behaviour. A ‘total difficulties’ score is based on the first four subscales and can be used to identify likely ‘cases’ with psychiatric disorders. Each scale has validated cut-offs reflecting 10% of children in community samples (www.sdqinfo.com) and scores in this ‘abnormal range’ are strongly associated with increased probabilities of having a psychiatric disorder.17 The SDQ has an impairment scale which enquires about distress, home life, friendships, classroom learning and leisure activities.16 As well as describing where children scored above cut-offs, to illustrate clinical significance, we report the proportion of children that met both symptom and impairment ‘caseness’ criteria. This is associated with an over 20-fold increase in risk of having a psychiatric disorder.17 We also used parent SDQ cut-offs to assess psychological adjustment, defining well-adjusted children on the basis of having scores within the normal range for all of the SDQ subscales.18

Analysis and participant validation

All focus group discussions were audio-recorded and transcribed verbatim. Each transcript was read by two researchers (C.C. and S.R). Initial level line-by-line coding was carried out in keeping with a grounded theory approach and descriptive codes were identified.17 Parents were asked to reconvene for a second focus group discussion, which was held within 6 weeks of the initial meeting of each group. During the intervening period, the researchers transcribed and familiarised themselves with the focus group data verbatim. Constant comparative analysis was used to compare codes, interrogate data and develop emergent categories.20 These were discussed and used to develop a second focus group discussion guide/individual interview topic guide that presented categories (themes) back to parents for further comments. In this way, the data collection and analysis took place simultaneously as recommended for a grounded theory approach.19 Where the majority of the group were able to attend again, a second discussion group was held. If the parents were unable to attend, individual semi-structured interviews were conducted over the telephone as soon as possible after the first group discussion. The validation groups and interviews were also audio-recorded and transcribed for analysis. The validation groups and interviews had two main purposes. First, they enabled the researchers to reflect on the narratives, investigate their understanding and interpretation, and feed back to participants about insights gained from the first round. This provided an opportunity to obtain additional information for the themes and to enquire further where information was unclear or contradictory. Second, information was gathered about components of an ideal service to improve access to and standards of care for child and adolescent mental health (these findings are not reported in this paper).

Deviance of views within the sample was actively sought out and accounted for; these were used to modify emergent categories. The completion of eight focus groups achieved adequacy – that is, sufficient data were collected for saturation to occur and the variation in the data was both accounted for and understood.21 We used NVivo (version 7 for Windows) to organise the transcribed data and assist with the data analysis. Two researchers (C.C. and S.R) jointly coded three focus group transcripts at different stages of the initial level coding process and separately coded the other transcripts. The two researchers worked in a similar way to develop a coding framework. This was used to develop a theory of the barriers and facilitators to help-seeking.

All participating parents gave consent to the publication of their (anonymised) comments.

Results

In total, 34 parents (one parent for each of the 34 children) participated in the focus group discussions and 22 (65%) in validation groups or interviews (Table 1). Most (88%) participants were women. Where details were given, 69% (22/32) of participants were aged over 35 years, 52% (16/31) were from a Black or minority ethnic background, and 59% (19/32) were single, divorced or separated. Each parent focused on the child (age range 2–15 years) that they were most concerned about. Of
the 34 children, 4 (12%) were aged under 4 years, 19 (56%) were aged 4–10, and 11 (32%) were 11–15 years. Just over half (n = 20; 59%) of the children were male.

Child SDQ details are given in Table 2. Teacher SDQs were obtained for 67% (20/30) of the 4- to 15-year-old children and response was not associated with child age or parent SDQ scores. The majority of children had behavioural (conduct and hyperactivity) problems and functional impairment according to parents and teachers. In terms of having scores within the normal range for all of the parent SDQ subscales, only four (14%) children were well adjusted. Three of these four children had teacher SDQs available and were not well adjusted according to the teacher. In the discussion groups, parents described a wide range of often long-standing concerns. These concerns fell into three main domains, although there was often overlap: (a) behavioural difficulties, including defiance, aggression, disruptive behaviour, temper tantrums, poor concentration, bullying and alcohol misuse; (b) emotional difficulties, including anxiety, clinginess, depression, poor self-esteem, obsessions, eating problems, suicidal thoughts and self-harm; and (c) learning and developmental difficulties. Through group discussions, we established that most previous primary healthcare attendance was for non-mental health reasons and a total of three children had had previous contact with CAMHS professionals. Parents also talked about the psychological impact of their child’s difficulties on them, including distress, exhaustion and low mood.

Four primary categories emerged from the analysis: parental perceptions and knowledge; appointment systems; attitude, communication and pre-existing relationships; and consequences of help-seeking.

**Parental perceptions and knowledge**

Parental perceptions determined whether their concerns about child and adolescent mental health problems were presented in and considered relevant to primary care (Appendix 1). Some parents agreed that it was appropriate to seek help for child emotional or behavioural difficulties from the general practitioner (GP); others did not think it was the GP’s role and saw GP surgeries as ‘medical’ places. Parents who felt that their child’s emotional or behavioural problems were not due to a health condition said that they did not feel it was necessary to take their child to see the GP. Parents’ ability to cope with their child’s difficulties and their awareness and knowledge about services and child mental health problems were identified as important in seeking help. In particular, parents who were concerned about their first child recalled not knowing where to go for help or whether any help was available. One parent explained that she had not realised that her child’s behaviour may not be normal until her child exhibited this behaviour during an appointment with the health visitor (primary healthcare child specialist nurse) who noticed the problem. Parents of teenage children were also mindful of the shift in the responsibility for initiating help-seeking from themselves to their child. Other parents felt that it was difficult to discuss emotional or behavioural issues with healthcare professionals because of embarrassment or cultural factors influencing whether this was perceived as being appropriate.

**Appointment systems**

Appointment systems represented a key barrier to help-seeking for many participants (Appendix 2). If parents made a decision to consult the GP, reported barriers included difficulties in getting an appointment and the short duration of appointments. National policy initiatives such as enhancing access to same-day appointments had a paradoxical effect, reducing the availability of pre-bookable appointments and giving parents little opportunity to arrange time off from work or school. Some parents had attempted to discuss their feelings of stress or depression resulting from their child’s behaviour but felt that the short duration of appointments acted as a barrier to presenting issues they described as ‘needing to talk about’. Parents also felt that short appointment times were not conducive to the GP observing the behaviours that they were concerned about and that this also acted as a barrier to their child receiving help. Parents also mentioned facilitators to help-seeking such as being able to get appointments easily, being asked about their children when seeing the GP about their own health and being given time to talk about emotional issues.

**Attitude, communication and pre-existing relationships**

Parents reported experiences of raising their concerns about their child and feeling that the problem was not taken seriously or that the GP or health visitor did not appear to listen or be interested in their problems (Appendix 3). One parent reported being described as an ‘over-anxious parent’ by her GP. This led her to avoiding that particular GP and reconsidering whether to take her child to the GP in future. In contrast, other GPs and health visitors were described as showing concern and being helpful and sympathetic. Parents described experiences of primary healthcare staff helping with filling out forms and dealing with a child’s bullying at school. They also praised GPs who appeared passionate about their work, particularly relating to children...
and families; this had a positive impact on parents' help-seeking. Positive experiences were usually related to good relationships with members of the primary healthcare team. Building a relationship with their GP was important to parents and some preferred to see the same doctor each time. Some parents reported trusting their GP as they had made good decisions about care in the past and hence felt that they were competent. In particular, parents felt more comfortable contacting primary healthcare staff who had known them through significant life events such as pregnancy and childbirth, knew their history and enquired about their own well-being.

Consequences of help-seeking

Participants were concerned that they were not 'good enough' parents if they resorted to seeking help (Appendix 4). Some described worries that this may begin a process whereby their child could be taken away from them. Some had based this view on the experiences of friends or relatives, or they felt that their own poor health would be judged as limiting their ability to take care of their child. Parents talked emphatically about the potential impact of stigma and labelling on their child, which prevented them from seeking professional help. One parent stated that she was reluctant to have contact with services because she felt they would be quick to label her child purely on the basis of ethnic origin. Another parent felt her child would be labelled because she lived in a certain area. Once a child was labelled, parents felt the child would carry the label throughout their school years and beyond. They suggested that this was not in the best interest of the child and may jeopardise the child's future. Widespread negative experiences that deterred future help-seeking included being 'bounced' from one service to another and not knowing where to go next.

The receipt of delayed, ineffective or inappropriate help also contributed to parents saying that they had given up seeking help. The possibility of receiving a diagnosis acted as a barrier to help-seeking and parents talked about GPs either not making a diagnosis because their child did not meet all the diagnostic criteria or being too quick to make a diagnosis, in particular in relation to attention-deficit hyperactivity disorder. They were concerned that professionals might focus on diagnosing the child's problems without exploring what the parent wanted for their child. Other parents experienced the receipt of a diagnosis as having a positive impact on receiving appropriate help, particularly at school.

Discussion

This study elicited a number of barriers and facilitators to help-seeking from parents who had concerns about their child's emotional health or behaviour. The scores on the parent and teacher SDQs confirmed that our sample reflected severely affected children who had functional impairments associated with their difficulties. Despite this, parents varied considerably in their attitudes towards the use of primary healthcare services to address their concerns. This was particularly the case if they did not regard these difficulties as a health problem or within the remit of the GP role. Help-seeking was also influenced by parental perception of the problems, their perceived ability to cope, and parental knowledge of child mental health problems and availability of services. Other barriers included feelings of embarrassment in relation to presenting these problems and, particularly, concerns about possible consequences of help-seeking. Perceived consequences included feeling blamed, perceptions of stigma associated with these difficulties, concerns about them or their child being labelled, possible adverse consequences of the child receiving a diagnosis and, most extremely, the possibility of their child being removed from the family.

Parents also described a number of facilitators to help-seeking, including parents perceiving the GP as being interested in the child and the family and previous experiences of good communication with the GP. Continuity of care came out as a major facilitator and this reflected components such as positive and long-term relationships with specific GPs and trusting their GP.21 However, major structural barriers were identified, including booking appointments or perceived short duration of appointments. Difficulties with booking planned appointments had a major impact on continuity of care and ability to express concerns. Changes in primary care policies in the UK in recent years, which aimed to improve timely access ('Advanced Access'), might have inadvertently increased barriers for particular groups such as people with mental health difficulties or their carers.24 Mechanisms by which such barriers may have increased include reduced opportunities for continuity of care with the same GP, less choice about appointment times, and insufficient notice to arrange time off work or school. Findings from countries which have different healthcare structures also suggest that continuity of care and primary care physician behaviour are particularly important in facilitating disclosure of concerns.25,26

Methodological considerations

Our findings reflect the views of parents who have concerns about their child's mental health but who are not under the care of specialist health services. The findings are of international relevance, particularly for countries with similar healthcare systems involving GPs with gate-keeping roles.9,10,27 Furthermore, although the main findings reflect the role of GPs within primary healthcare, the role of health visitors was also salient for children aged 5 years and under. Most children and adolescents with mental health disorders have not been seen by specialist services although the main findings reflect the role of GPs within primary care. The findings are of international relevance, particularly for countries with similar healthcare systems involving GPs with gate-keeping roles.9,10,27 Further research is needed to investigate whether parents whose children receive specialist CAMHS have different perceptions of primary care. These might reflect the ease with which a referral was obtained to secondary care and the child's outcomes following referral.

Strengths and limitations

Our sample reflects an important group, as epidemiological research suggests that parental concern about a child's mental health is associated with childhood psychiatric disorder or substantial psychopathology.29 By focusing on a wide range of parental concerns, the findings improve our understanding about reasons why parents do not express these concerns in primary care. Other strengths of our study include the ethnically diverse sample and the inner-city setting reflecting higher prevalence of disorders (especially behavioural disorders). The focus group methodology facilitated the generation of experiential data related to a sensitive topic20 and promoted 'theoretical' generalisability – that is, findings of relevance to populations with similar characteristics.31 It incorporated participant validation with follow-up groups and interviews, and involved two researchers using consensus approaches to coding and analysing data.

In terms of limitations, sample attrition meant that two of the focus groups had fewer than four participants and validation took place with two-thirds of the sample. The use of focus-group methodology might have limited the number of participants and may have precluded less confident or articulate parents from

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participating. However, as well as repeat validation groups, a number of individual validation interviews were carried out. Future research might consider alternative approaches such as online focus groups to improve participation.\textsuperscript{32} It is possible that the inner-city sample might have introduced bias as this population may have different expectations of help-seeking and services. Although few parents were recruited from GP surgeries, their views were in keeping with other parents. As all children had previously attended primary healthcare, the sample is fairly homogeneous with regard to primary healthcare attendance and hence consistent with the main findings.

We did not elicit views from the perspective of the older children, GPs or other healthcare staff and these might differ considerably from those of parents. Although our study aimed to focus on and better understand the role of primary healthcare for these difficulties, future research should investigate how self-help approaches and support from professionals based in education services can best help parents.\textsuperscript{33} In the UK, from a policy perspective, other front-line (Tier 1) services for children such as schools are being encouraged to take on a greater remit for mental health.\textsuperscript{34}

Practice and research implications

A better understanding of parents’ views is important as attendance and the presentation of emotional and behavioural problems within primary care is an opportunity for their early detection. The limited recognition of childhood mental health difficulties can have a long-term impact, with persistence of psychopathology into adulthood.\textsuperscript{35} Additionally, children of adults with mental health problems are at increased risk of emotional and behavioural problems and may not be appropriately recognised. Our findings have implications for parental awareness of available help and GP training. Parents place a high value on GP interest in the child and family situation and GP behaviour demonstrating that they listen to and take their concerns seriously, rather than on the need for specific expertise in the area of child and adolescent mental health. An implication of this is that most GPs should be able to assist parents who have concerns about their child’s mental health rather than this work being confined to a small number of GPs with a special interest in this area. This might be achieved through generic skills training to enable family-oriented approaches during consultations and giving more prominence to children’s mental health training within postgraduate education. Clinicians should also be sensitive to cultural factors in better understanding why there might be differences in parental propensity to present concerns during consultations.

Barriers to maintaining continuity of care act to inhibit care for child and adolescent mental health problems. Improvements in access that allow for relationship continuity are needed if primary care is to enhance its role in recognising and managing these problems. At a policy level, incentives through GP funding mechanisms that promote continuity of care might be considered.\textsuperscript{36} To achieve this, some modification of the Advanced Access policy, allowing for more pre-bookable or planned longer appointments might be helpful. Information for parents about which GPs have a particular interest in child and family health could be contained in leaflets which all practices are required to produce, or on posters or websites. In related work, the views expressed by the parents are being used to develop potential quality standards for primary care mental health. Building on our findings, further empirical work is also required to obtain children’s views about accessing mental healthcare.
"She wants to see how I'm doing and how things are with me and all the rest of it. And I think that's just as important. (regarding health visitor; F.06, boy, age 4; high parent-rated hyperactivity, conduct problems, and impairment; no teacher ratings)

'We have a good relationship with the doctors and the nurse and [my daughter] feels that she can talk to her.' (F.05, girl, age 14; high parent-rated impairment; no teacher ratings)

'I'm lucky in that I've got a very good family doctor . . . I would feel personally fairly happy to go with my son to him because I've got the trust in my GP – maybe I'm just fortunate perhaps.' (F.08, boy, age 10; high parent-rated conduct problems; teacher ratings in normal range)

'I have a fantastic GP. And she knows all of us . . . we've been with her for 11 years. And I think that's the best person who would have an overview . . . if there were any medical problems or mental health problems.' (F.03, boy, age 7; high parent-rated hyperactivity, conduct and emotional problems, and impairment; no teacher ratings)

Appendix 4

Consequences of help-seeking

'We try our best but you've got another system out there that says your best isn't good enough . . . . The minute you get caught up in that system, you are finished and your child is finished, 'cos your child's got a label stuck on his forehead. He might as well walk around saying I am a nutters.' (F.07, boy, age 12; high teacher-rated hyperactivity, conduct and peer problems, and impairment; parent ratings in normal range)

'I'm frightened to bring anyone else in because they will look at her and start saying 'I'm frightened to bring anyone else in because they will look at her and start saying that might not be the case. But it seems to be that a lot of kids are getting labelled then you're fine . . . If your child's got any type of behavioural problem or they're conduct and emotional problems, and impairment)

'So that's helped a lot there and it's given a reason for it.' (F.03, boy, age 7; high parent-rated hyperactivity, conduct and emotional problems, and impairment)

'Some people are scared that [the GP] thinks you're not a good parent and [could] take your kids from you. That's why a lot of people say nothing . . . They just think that Social Services gonna come and take their kids. And that's how I felt for a while: they're gonna come and take your kids. That's why a lot of people say nothing . . . They just think that Social Services gonna come and take their kids. And that's how I felt for a while: I thought they would just take my kids from me. So that's why I don't go [to the GP] for a long time.' (F.04, girl, age 4, high parent-rated hyperactivity, conduct and emotional problems, and impairment)

'They expect everybody to be textbook. If you don't fit into the criteria that they have, then you're fine . . . If your child's got any type of behavioural problem or they're disrupting things and stuff, they'll be quick to say 'oh your child's got ADHD', when that might not be the case. But it seems to be that a lot of kids are getting labelled with that and it might be something totally different.' (F.06, boy, age 4, high parent-rated hyperactivity, conduct problems, and impairment; no teacher ratings)

'He was then diagnosed as dyslexic and that's changed the way they then taught him. So that's helped a lot there and it's given a reason for it.' (F.03, boy, age 7; high parent-rated conduct problems and impairment, and teacher-rated hyperactivity)