Experiences of a child and adolescent mental health service

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Abstract

Aim To explore the experiences of children, young people and their families attending their first appointments in a child mental health service.

Method Semi-structured interviews were conducted with a sample of 17 family groups who attended an outpatient clinic.

Findings Four themes were identified: telling traumatic events, feeling the stigma associated with mental ill health, experience of being in unfamiliar territory and having a therapeutic connection.

Conclusion Families attribute significant meaning to their first engagement with child and adolescent mental health services. Practitioners need to be cognisant of the importance of this first encounter for families and offer clear information for children and young people before their first appointments.

It is important for a person with mental health issues to be able to access appropriate care in a timely manner to help relieve distress. The additional complication for children and young people with mental health issues is that while they are distressed they fall behind in developmental tasks, such as maintaining progress in their education, developing and maintaining social relationships with peers, and achieving psychological developmental norms. If appropriate assessments of mental health needs are not sufficiently timely, appropriate interventions for children's or young people's mental health needs can be delayed. The situation is complicated further if children or young people are distressed, and precluded from the normal educational, psychological and social development enjoyed by their 'healthy' peers.

Literature review

Biering (2010) found there were no published studies exploring how children younger than 13 experience mental healthcare. He also found that most studies in the literature report **[Q1: please note small edit]** satisfaction with services, and suggests that research is needed to build on the small but existing body of knowledge. Coyne et al (2015) conducted a qualitative descriptive study involving focus group and interviews to explore the views of adolescents, and carers of child and adolescent mental health services (CAMHS). The study was prompted by a suggestion that satisfaction with services correlates with functional improvements and symptom reduction in the child or young person (Garland et al 2007, Ronzoni and Dogra 2012). Coyne et al (2015) found that accessing services in a timely manner is important, that families need to have a 'voice' and be heard by the healthcare professional, the therapeutic alliance is critical to the process, and families are sensitised to their children being stigmatised by CAMHS referrals.

Studies by Barber et al (2006) and Tas et al (2010) sought to standardise service-user feedback by using questionnaire formats, but one of the limitations of using standardised questionnaires is that they do not offer open questions or opportunities for children, young people and their families to discuss their experience of CAMHS beyond expressing their levels of satisfaction **[Q2: please note small edit]**. There is nothing in the literature about how families conceptualise their engagement with child mental health services and this study aims to address that gap.

Aim

The aim of this research was to explore the experience of children, young people and their families attending their first appointments in child mental health services.

Method

CAMHS in the UK comprise a range of inpatient and outpatient secondary care services for children and young people up to age 18. The innovation in this study was to focus on a triage clinic, which had reduced its waiting list. **[Q3: please note small edit]** A survey of families referred to the clinic was conducted using semi-structured interviews to generate data as part of an action research project reported in Evans (2014).

Initially, an interview schedule was devised to organise the structure of the family interviews, but was found to restrict the participants, possibly because of the nature of the closed questions. A change in emphasis, including more open questions such as 'what have I not asked that you expected me to?' prompted more interesting feedback.

Participating families who had been seen for their first triage assessment appointments during a three-month period were sampled. These families were sent flyers advertising the research project as well as adult and child versions of a participant information sheet. In addition, a poster advertising the study and inviting participation was displayed in the reception area of the CAMHS clinic. Families who expressed an interest in taking part in the study

were sent a full information pack, contact sheet and consent form. Consent was obtained verbally and in writing using specifically designed age-appropriate information sheets and consent forms.

The term 'families' is used here to describe children, young people and their caregivers or families who attended the CAMHS clinic. Children and young people who were being looked after by the local authority were excluded from this evaluation because, to secure consent to take part in the study, both parents and the local authority would have needed to agree given their shared parental responsibility for a child on a care order.

On triage assessment clinic days, the researcher was available in the waiting room to discuss and answer questions about the study with interested families. Of the 49 families invited to participate, 17 family groups who met the inclusion criteria for the study agreed to be interviewed (34%). The families were self-selecting, and the sample was drawn from children and young people referred to CAMHS. Mothers were present at 16 interviews, fathers at two **[Q4: the table shows mothers at 15 interviews and fathers at one]** . In one family, the child lived with grandparents and both were present (see Table 1). Each of the children and young people who took part in the interviews were given a certificate thanking them for their contribution.

Table 1. Interview participants [Q5: Please add ages for F7, F8 and F12, if available]			
Code	Present	Gender	Age (years)
F1	Mother	Male	Ten
F2	Mother	Female	16
F3	Boyfriend	Female	16
F4	Mother	Female	13
F5	Grandmother and grandfather joined later	Female	13
F6	Mother. Sister joined later	Female	16
F7	Mother	Female	Middle school
F8	Mother	Female	Teenage
F9	Mother and father	Female	13
F10	Mother and brother	Male	Eight
F11	Mother	Male	15
F12	Mother	Male	Teenage
F13	Mother	Female	12
F14	Mother	Female	Seven
F15	Mother	Female	15
F16	Mother	Male	18

F17	Mother		Female	Five

Data collection

All families were interviewed in their own homes at times convenient to them. The duration of the interviews was 40-90 minutes. For each family, the assent of the child or young person was sought in addition to parental consent. All interviews were digitally recorded and transcribed verbatim.

Data analysis

A three-stage approach was adopted to thematically analyse the data (Miles and Huberman 1994): data reduction, effective data display, and conclusion drawing and verification. The qualitative data-analysis software Atlas.ti (Scientific Software Development/Scolari 1997) was used to store, manage and visually display the data. A single, hermeneutic unit for collating the data was created in Atlas.ti. After sorting and sifting, the data codes were assigned, and 'families' were created where connections between coded data were evident.

Ethical considerations

Approval for this study was obtained from the local research ethics committee. **[Q6: Please add statement about how confidentiality was assured?]**

Findings

Four themes were identified: telling traumatic events, feeling the stigma associated with mental ill health, experience of being in unfamiliar territory and having a therapeutic connection.

Telling traumatic events

Families reported how they relayed stories of traumatic events at their initial appointments with CAMHS. It was unclear whether they told them to emphasise or justify their need to access therapeutic support, or whether it was a relief to be able to share the trauma they were experiencing with a professional. One participant related a distressing event that happened to the child preceding the referral to CAMHS and explained their need to access the service:

'One of his friends from school had died and I think we had a quick referral perhaps because of that' (participant F1).

For this family, the death provided a clear justification for their referral to a specialised service. It provided the family with a legitimate story to tell others, such as friends and school, and meant they could be open with their reasoning for accessing services.

Another participant explained the significantly distressing events that led her to seek help for her daughter, which were traumatic for both the child and mother:

'Because of the circumstances I said, you know, I'm willing for any help because of what we've gone through... she had her bruises and they had to come from somewhere... He – the child's father – has been cautioned by the police because I asked my solicitor for a child protection policy' (participant 17).

Another participant described their distress and in relating the story of their traumatic situation was almost pleading for a service, creating a rationale for why the family needed help:

'My son Joshua started being very violent towards me and I need help with it... I was being abused, physically, and that was the whole point of me going to the doctors in the first place' (participant F11).

In all three cases there had been triggering events that prompted referral to CAMHS services. In two of the cases violence had been involved. It appeared that the storytelling of the traumatic events offered a cathartic process for the mothers in a supportive and non-judgemental environment.

Feeling the stigma

Some family members thought there was a degree of stigma associated with seeking help for their children from a mental health service and the clinical appointments were concealed in some way. Participant F1, for example, did not mention the appointment to the younger sibling, giving no detailed explanation about why the action had been taken. Mother: 'Because we didn't tell Tom, did we? He knows that we've been but he doesn't know why.' Researcher: 'Oh. Okay. And that's private from him, is it?' Mother: 'Yeah, well we think it's better for us just to keep it between ourselves, really, don't we, Sam?' Child: 'You told me not to.' Mother: 'Well, yeah, because I didn't want him worrying about the fact that Tom would say something to somebody else. I thought it was better we kept it to ourselves.'

In the following extract there is a wider family context of people experiencing mental health problems and how that information is managed in the family. It hints at a family rule about not discussing mental health problems in public and a belief that such information is private family business.

'I've got an obsessive-compulsive disorder (OCD) and my sister has got extreme OCD. Very extreme, and my sister doesn't want everybody knowing the details of it... I wouldn't let the children out of my sight or out the door, even to my parents, oh it was horrendous... It just really does become a problem and for people to make me do things that at the time were debilitating me, they were preventing my children having a life' (participant F13).

National campaigns have been launched to end the stigma and discrimination faced by people with mental health problems, such as Time to Change (2017), which is designed to make accessing mental healthcare less discriminatory. Nevertheless, **[Q7: please note small edit]** for the families in this study there was an overriding need to keep information about mental health issues guarded and knowledge about the involvement of mental health services restricted to specific family members.

Moses (2011) looked at stigma experienced by families whose children access mental health services and found that about one-third of parents interviewed avoided use of the diagnostic label. They described their child's experiences as responses to environmental vagaries or were uncertain about the definitive cause of their children's problems, hinting at an avoidance of using stigmatising diagnostic labels.

Unfamiliar territory

This theme relates to feeling stigmatised because some families who were seen in the CAMHS clinic had felt they did not belong there, as though the people already in the reception area were in some ways different from them.

'We felt we were sitting in the wrong place, because the people there obviously had mega problems. We were a bit upset because we had to wait so long and there was a young boy sitting across from us [who] was obviously troubled' (participant F15).

Other participants found using the waiting room disconcerting because of privacy issues or because they were distracted by the presence of other children and families.

'I didn't expect to have those forms. They were, I don't know, probing personal questions, really. Not too personal, but personal enough' (participant F9).

Bone et al (2015) highlight that young people in CAMHS clinics **[Q8: please note additional text]** are anxious about what questions they may be asked or what tests they may need to take. This suggests CAMHS should think more creatively about what information to make available for children and young people ahead of their first appointments.

Some families raised what they called 'unexpected issues', or issues the families had not anticipated and that left them feeling uncomfortable. One family reported their discomfort at being dealt with by a CAMHS practitioner from a social work background, rather than a nursing or psychiatric one.

In this case the service was in a district general hospital, so the family may have assumed there would be a nursing-medical mix in the staff group. The family talked about being put on the back foot and being a little startled by the introduction of a practitioner who was a social worker. This led to the young person worrying whether they would be taken into care.

Another parent had found the experience of seeing a CAMHS service emotionally draining and upsetting. They had been embarrassed that they themselves had become distressed during the clinical interview in front of their 16-year-old daughter, and felt this was not helpful, believing their crying had increased their daughter's emotional distress.

Therapeutic connection

Two mothers said the CAMHS practitioner could connect with their daughters to such a degree that the nature of the psychological distress was elicited effectively, which they found reassuring.

'The initial referral was querying Asperger's syndrome, but during the triage appointment the therapist picked up on [the child's)] low mood and explained that depression was present and quite significant. The outcome of that was that the therapist felt that the depression actually took priority' (participant F8).

The therapeutic connection between the child or young person was commented on by several parents. Even though their CAMHS appointments lasted only 20 minutes, the time appeared to be sufficient for the beginning of a therapeutic relationship to be formed:

'This lady we're seeing, she's absolutely fabulous. I notice [my daughter] says a lot more than she would normally say. She could get her to say things – just come out with things naturally' (participant F7).

This challenges the findings of Bone et al (2015), who found parents were critical of some of the processes in CAMHS, such as repetitive information giving, that unduly limit the potential development of therapeutic relationships between their children and CAMHS practitioners.

Discussion

Conducting any research with children and young people should be timely, preferably contemporaneous. In this study, some younger children struggled to recall their visit to CAMHS because of their developmental age or the lack of significance of that appointment. Adolescents could recall general impressions, but their memories of subsequent appointments affected their recall of the details of their first appointments.

There are several tested methods of eliciting children's views and feelings (Davies et al 2009). Children can be asked about the thoughts and feelings of characters in pictures or, using a partially completed cartoon strip in which there is a blank box of a child with an empty thought bubble arriving at or leaving the clinic, asked to complete the thought bubble to reveal what they expect the cartoon child may experience. These methods allow for a less direct way of engaging with children and young people, and inviting them to discuss their ideas without feeling under pressure because the discussion is about them. **[Q9: please note small edit]**

The overriding message from families interviewed in the study was that the initial appointments were of significance to them because it indicated the acknowledgement of trauma or highlighted the stigmatising effect of mental ill health.

Some families reflected on the trigger that brought them to the services. This appeared to have a cathartic effect, which itself can be helpful to families if facilitated effectively by practitioners. This reiterates the findings of Stafford et al (2016), who emphasise that the quality of the therapeutic relationship created during a first appointment affects the direction of the therapeutic work.

There appeared to be some relief among the parents that CAMHS practitioners had identified the reason for their children's psychological distress and that the appointments had provided them with opportunities to discover the

nature of their children's problems. Provision of advance information that explains in accessible language what can be expected from a first appointment may help families cope with being in an unfamiliar place.

Strengths and limitations

Most of the feedback was generated from the parents and carers, which is one of the limitations found by other researchers in the field (Stafford et al 2016). Hearing more of the views of the children and young people themselves by interviewing them immediately after their initial appointment, or within a few days of it, may have increased the likelihood that they would remember their experiences in detail. Alternative methods of data generation, such as inviting younger participants to draw what the appointments 'felt like' to them, may have led to richer data, although the interpretation of such data would have been subjective. **[Q10: please note small edits]**

In this study, the brevity of the appointment did not seem to limit the opportunities for families to experience catharsis following disclosure of traumatic or troubling events. The families reported that they had been heard and understood, and could discern the nature of their difficulties even in short clinical interviews.

Conclusion

The initial engagement of children, young people and their families with mental health services is significant. There appears to be a need to justify their referrals through the experience of traumatic events. Families feel they do not belong but despite being in unfamiliar territory, they sense the beginning of a therapeutic connection. In this research, most of the data were generated by mothers and so further studies inviting feedback specifically from fathers and other caregivers, as well as the children and young people themselves, would be useful.

Implications for practice

- The quality of the therapeutic relationships created during first appointments affects the direction of the therapeutic work.
- CAMHS should provide information to families about what to expect from first appointments.
- Further research should invite feedback from fathers, caregivers, and the children and young people themselves.

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