


Attention-deficit/hyperactivity disorder: parent/carer perceptions of barriers to healthcare access

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ABSTRACT

Background Children and young people (CYP) with attention-deficit/hyperactivity disorder (ADHD) face delays in diagnosis and barriers to accessing appropriate interventions. Evidence is limited on how these barriers are perceived by their parents and carers.

Methods Focus group in South London with parents/carers of CYP with ADHD. Data were thematically analysed using an inductive/deductive hybrid approach.

Results Participants (n=8) described the challenge of accessing services within a disjointed, multiagency system for their CYP's ADHD and broader health needs. They described feeling judged and overlooked by healthcare professionals, which could negatively impact the health, relationships and educational progress of their children. Pragmatic solutions were proposed, including providing parents with information on navigating services at an early stage of ADHD symptom recognition.

Conclusions Parents/carers sought improved continuity of care within and between services. They are a key group for consultation on the development of interventions to improve access for CYP with ADHD.

BACKGROUND

Attention-deficit/hyperactivity disorder (ADHD) is a neurodevelopmental disorder with a prevalence of 3%–5% among children and young people (CYP).¹ Accessing care for CYP with ADHD can involve a network of actors, including parents; paediatricians; psychologists; teachers and general practitioners (GPs). Barriers to access range from a lack of awareness of available services, limited awareness of symptoms by teachers and limited resources within health and social care services.² Many studies have investigated CYP's experiences of their ADHD,³ but evidence is lacking on parent/carer perspectives. We conducted a focus group study within a support group of parents/carers of CYP with ADHD, exploring perspectives on barriers to accessing general practice or specialist services for their CYP for ADHD and broader health reasons and strategies for improvement.

METHODS

An audio-recorded focus group was facilitated by an academic GP (VP) and researcher (ER-P) in a South London community centre in February 2019. Members of a support group for parents/carers of CYP with ADHD were invited to participate and sent the participant information sheet in advance. Participants were informed that their anonymity

would be protected, they could withdraw at any time and asked to provide written consent. A semi-structured topic guide prompted an open, exploratory discussion which took just under 2 hours (table 1).

ANALYSIS

The recording transcript was thematically analysed using an inductive/deductive hybrid approach.⁴ Coding was first performed using a deductive coding framework, derived from themes in the literature,² with miscellaneous responses interpreted inductively into new codes. Transcripts were independently coded by ER-P and VP then finalised with all coauthors.

RESULTS

There were eight (P1–P8), female participants aged 25–44 years; 50% self-identified as being of white ethnicity, 40% of black ethnicity and 10% as mixed, white and black African.

Central challenges

Parents/carers had to express the needs of their CYP who could struggle to convey the impact of their impairments to healthcare professionals by themselves. This involved in-depth understanding of their children's experiences at home and school. This quotation relates to a parent and child attending appointments with psychiatrists and GPs:

...he was saying 'it's all right, it's not too bad' and then...when you put him in a class of 30...how miserable he's feeling after being excluded... for the eighth time and he doesn't know why...then I have to ring up...and say 'actually, he'd like to go back on medication'. (P2)

They discussed the challenge of effectively communicating with healthcare professionals for their needs to be 'taken seriously'; requiring knowledge of a complex web of services and medical terminology, described as needing an 'ADHD vocabulary':

Parents are fighting and...under tremendous mental distress...yet we're expected to advocate... to be experts... to know how all the systems work and we are left to try and manage our children when they are in school and we can't even be there... (P4)

Impact on parent–child relationships

Barriers were faced repeatedly from early recognition of symptoms through to CYP's transition into adulthood. Participants explained the negative



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Table 1 Focus group topic guide

Introduction:	Researchers introduce themselves and the purposes of the research and ensure all participants have signed a consent form before the recording begins.
Framework for researchers:	Broadly discussion should be aimed at exploring the pathway from symptoms (or onset of problems with the child) to seeking help and obtaining specialist help (eg, in hospital or a specialist clinic). Explore healthcare access in relation to CYP's ADHD specifically, but also broader access for other physical and mental healthcare needs.
Prompt questions:	<ol style="list-style-type: none"> 1. Can you talk about your experiences of accessing healthcare for your child? 2. What has been good about accessing healthcare for your child? 3. What has been bad about accessing healthcare for your child? 4. What should be changed about the healthcare services? 5. How has accessing healthcare for mental health compared with accessing it for physical health? 6. What would you like GPs to learn about your experiences? 7. What would you like other health providers to learn about your experiences? 8. How do the health services make you feel?

ADHD, attention-deficit/hyperactivity disorder; CYP, children and young people; GPs, general practitioners.

impact that frequent discussion of symptoms had on CYP's self-esteem:

...going through their difficulties again and again...it's not good for their self-esteem... (P1)

...if you have to go to the GP with your child and sit right there, saying it all again, it's just going to give them really bad anxiety. (P3)

They discussed experiences of healthcare professionals contesting the legitimacy of an ADHD diagnosis and/or pharmacological treatment and instead feeling judged to be a 'bad parent'. This could instil feelings of shame and powerlessness when children were not receiving the appropriate care:

...we can only watch helplessly from the side lines as our children are spiralling out of control. (P4)

A disjointed, multiagency system

Participants positioned healthcare services within a broader framework of agencies. They desired integrated care, highlighting the absence of communication between schools, the GP and specialists. They offered various explanations, from ignorance to the deliberate protection of resources:

...there's no communication between the GP, the specialist services...the schools and... other services, so it's all disjointed and... there's ignorance...also an incentive for them to pretend it's not happening because it would then mean they'd have to allocate resources. (P4)

Barriers and facilitators to accessing healthcare services

Participants discussed barriers to accessing general practice including difficulties with getting appointments, appointment times which conflicted with school and that were inconveniently located. Difficulties were compounded by an already busy family life:

... you have to have quite a lot of spare time available to you to actually get through to the [GP] surgery in the first place, which a lot of parents in complex situations don't. (P1)

Participants expressed distrust of their GP and preferences to see only specialists for their CYP's ADHD treatment:

P1: I just didn't bother with the GP then, I'd just go to [Child and Adolescent Mental Health Services] CAMHS...

P2: I do try and avoid the GP actually...

P3: No, I don't go there with my boys... They've never been to... my GP about ADHD. They've gone from school referral to CAMHS...

Where GPs were discussed positively it was to emphasise familiarity with a family's situation and healthcare over the life course with ease of communication between practice staff and pharmacists:

...most of the doctors... know my situation and they immediately respond to me with anything to do with [my youngest child] and anything to do with myself or anything to do with...my older child. (P5)

Some participants had children with additional health conditions. One parent discussed her child's diabetes and emphasised that healthcare visits improved once the team who managed his care understood her child and how his ADHD impacted him.

...he's more comfortable now that they've got his diabetes and he knows the team. (P8)

Another participant discussed her difficulties with getting an appropriate referral from CAMHS for her child's self-harm behaviours. She felt that accessing mental healthcare was immensely challenging unless at a very severe stage, despite the common coexistence of ADHD and other mental healthcare needs.

I would ring up CAMHS, I'd get through on their emergency number and I would speak to somebody... and they would fob me off. (P4)

Proposed solutions

Participants suggested solutions to overcome the barriers that had been raised (table 2).

DISCUSSION

Parents/carers conveyed the frustration of repeatedly dealing with barriers to healthcare access and the impact of these on parent-child relationships. They positioned healthcare within a broader framework of services which they experienced as challenging to navigate. They wished to be understood and listened to by healthcare professionals, especially their GPs. They stressed the value of efficient referral systems for CYP with additional mental health needs and the importance of recognition of the coexisting ADHD diagnosis when attending appointments for other conditions.

Participants proposed solutions for improvement, several of which are already in the National Institute for Health and Care Excellence guidance on ADHD diagnosis and management.^{6,5} However, guidance is lacking on the impact of ADHD on accessing care for other health conditions. We recommend

Table 2 Solutions to overcome barriers to healthcare access with quotations from participants and level of intervention required to implement change

Solution	Quotations	Level of intervention
Listening and mutual respect between healthcare professionals within services and between the patient and healthcare professionals	'...listen to each other because even within the surgery the GP hasn't necessarily spoken to the nurse or, you know, there's so many different practitioners, you end up having to repeat yourself a lot ... that's quite frustrating.' (P1) '...a little bit of respect for the person who's on the other side of the chair...who also has a lot on their plate...instead of that...sort of dismissive attitude to your time and your opinion and your knowledge.' (P1)	Individual
Redress the balance of power between the parent/carer and the professionals through comprehensible and empathetic communication	VP: 'Do you have any tips for those healthcare professionals?' P2: 'They could listen actually.' P4: 'Yeah, listening is good.' '...a mechanism for us to be informed so that we're able then to work in partnership with the professionals? At the moment, it's the professionals who know everything and we don't. It's like a parent/child situation and actually it should be two adults.' (P4) 'The letters have medical terms in them, the way you're spoken to is medical. It's all medicalised, it's all on the assumption that you understand exactly what they're talking about... I think it's not putting themselves in the parents' shoes and thinking how can I present this in a way that they can understand it and access it?' (P4)	Individual/organisational
Special consideration of the requirements of CYP with ADHD when attending healthcare services for non-ADHD reasons	'...kids with ADHD, their aggression is not understood with professionals... having to hold down my son for tests is an excruciating pain when you're the parent. And then all you're getting is looks, 'well what's wrong with them? Why do you have to do that?'" (P7) 'I think they should ask you, 'are there other neurological conditions?', so when you say ADHD... they should immediately...refer you to somebody in there who's an expert, like a CAMHS person.' (P4)	Organisational
Consistent professional support for improved continuity of care	'...it would be really helpful if a parent actually automatically had access to someone who could... advocate on their behalf who could actually give them all the information that they could then have that person with them through their journey... You need somebody there that you can access...before it gets to a crisis.' (P4)	Organisational
Support with intra-agency information sharing and organisation of notes and records	'It would be good to have like a kind of passport thing to keep a track of all those early warning signs that seem to get a bit lost... You know when you're pregnant and you get your medical notes and you take them around with you.' (P1)	Organisational
The availability of written information in schools and health services at an early stage of symptom recognition and for groups suspected to be at high risk	'...it needs to be started from primary nursery where they acknowledge all these problems and give out all these leaflets so that people and parents are aware.' (P5) '...for GPs to actually have little booklets to say OK, your child is having challenging behaviour, it's a direct look into, here's an information pack on the services that you need.' (P8) 'I've got depression and anxiety and my daughter feeds from me so they could have given me the information from day one with me.' (P5)	Organisational/societal
Recognition of the impact of ADHD diagnosis on the parent/carer and support for their emotional and mental health needs	'...if you have a child that has all of those issues, it is going to have an emotional and mental impact on you as a parent and for that then to be automatically recognised and that support to be put in place in tandem would be really good.' (P4)	Organisational/societal
Training days for general practitioners and school staff	'they probably should have a workshop for SENCO for all schools.' (P5) '...a day's training to primary school staff and a day's training for universal services.' (P4) '...given the very long waiting lists for CAMHS...you will be seeing your GP about your son's diabetes and about the ADHD, so they are crucial and they're...the weakest link in some ways because it's not their fault. How can they have the information?' (P2)	Organisational/societal
Help earlier in the pathway rather than at crisis point	P7: '...hitting where we're not at crisis but we're heading that way and we have that chance to get in there before the crisis actually happens.' P5: 'Yeah, that's a good one. Getting the children where you do know your child has a problem, you mention it to the school and the school then can probably do a referral.' 'It is well known with neurological conditions like that, that anxiety, depression, suicidal ideation, not coping with school, bullying, all of those things are so common. It's unusual for a child who has that diagnosis not to be experiencing that. The only way you can access help is if they're actually trying to kill themselves.' (P4)	Organisational/societal

Continued

Table 2 Continued

Solution	Quotations	Level of intervention
Flow diagrams showing the pathways between different services	'I'd like to see pathways, going to the GP so you understand... a clear pathway that I can hand out to parents and say 'this is how you go to CAMHS, this is how you are referred'... also an understanding of second language and also people may have processing problems with written word. So at least a flow diagram kind of gives you a fighting chance to understand.' (P2)	Organisational/societal

ADHD, attention-deficit/hyperactivity disorder; CAMHS, Child and Adolescent Mental Health Services; CYP, children and young people; GP, general practitioner; SENCO, special education needs coordinator.

further research with parents/carers of CYP with ADHD, ensuring representation of salient characteristics, such as gender, to enhance the implementation of existing guidelines and develop strategies for improvement.

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