Parent and sibling perspectives on ADHD: A cross-cultural study in Kenya and the UK

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Abstract

This qualitative study explored the impact of ADHD on parents and siblings in two different cultural contexts: the UK and Kenya. Although the prevalence and characteristics of ADHD appear to be similar across cultures, the lived experience may vary as a result of different social attitudes, and approaches to diagnosis and treatment. However, most research has focused on WEIRD (Western, Educated, Industrialized, Rich, and Democratic) samples, and it is important to broaden the evidence base to different cultural settings. We carried out semi-structured interviews with parents and adult siblings of individuals diagnosed with ADHD. Using Interpretive Phenomenological Analysis (IPA), we identified five superordinate themes: 1) Lack of accurate information, 2) Family Experience, 3) Access to support, 4) Healthcare System and 5) Education System, reflecting 12 subthemes. There were striking similarities in the descriptions of personal experiences across cultures, both in terms of family dynamics, and in relation to a lack of support outside the family. Differences in experience across countries reflected structural differences in the educational and health systems of the UK and Kenya. While in Kenya the challenge faced by families was in the lack of formal support structures, families in the UK reported that despite formal recognition and support for ADHD, there was a frustrating failure of effective implementation. These findings highlight the interface between the lived experience at the personal level and the social and national structures that help to shape that experience, and underscore the importance of considering this in a broader range of cultural contexts.

Keywords: ADHD, Cross-cultural, Family Dynamics, Sibling, Parent, Education, Healthcare

1.Introduction

ADHD is one of the most common neurodevelopmental disorders of childhood, often persisting into adult life. The core characteristics of ADHD are difficulties in regulating attention and/or impulsive behaviour and hyperactivity, and they have broad and profound impacts on children's academic experiences and outcomes, peer relationships, and of particular interest to the current study, family dynamics (American Psychiatric Association, 2022). Moreover, although the presentation and prevalence of ADHD appears to be similar across cultures (Rohde et al., 2005; Bauermeister et al., 2010; Song et al., 2021), societal attitudes, diagnosis and treatment approaches can vary widely (Hinshaw et al., 2011). The lived experience of ADHD may therefore be very different for individuals and families in different cultural contexts. However, as is increasingly recognised for psychological research more generally, most studies in this area have focused on Western, Educated, Industrialized, Rich, and Democratic (WEIRD) samples, with very limited research carried out in the global south. For example, in a recent review of qualitative studies of adults with ADHD, almost no studies were identified with participants from South America, Oceania or Africa (Ginapp et al., 2022). In the current qualitative study, we aim to explore the lived experience of parents and siblings of individuals with ADHD in two very different cultural contexts: the UK and Kenya.

Families which include a child with ADHD often experience heightened levels of stress: Alongside the richly rewarding aspects of raising a family, parenting also presents ongoing challenges, particularly around managing children's behaviour. These challenges are often amplified for the parents of a child with ADHD, as evidenced by a substantial literature which draws on both quantitative and qualitative methods. A recent meta-analysis reported higher levels of parenting stress in families with a child with ADHD than in those with typically developing children (Theule et al., 2013), or with clinical conditions which are not strongly associated with behavioural difficulties (Larkin et al., 2021). Qualitative studies add depth to the description of the lived experience of parents, with a recent large-scale meta-synthesis identifying several common themes across multiple studies. Parents reported struggling with exhaustion, and intense, negative emotions as a consequence of constantly managing their child's behaviour, maintaining household routines, and dealing with high levels of chaos and conflict in the home. Particular frustrations and feelings of failure arose in relation to their own parenting skills, as they struggled to find effective ways to manage their child's behaviour; these were exacerbated in some cases by feeling judged by others as being ‘bad parents’ (Corcoran et al., 2017a). These stresses often spill over into broader aspects of life, beyond the parenting role: physical and mental health can both be adversely affected, as can the marital relationship (Bull & Whelan, 2006; Peters & Jackson, 2009).

Many of the stresses described above are not confined to parents; the disruptive behaviours associated with ADHD also have direct and indirect effects on other relationships, including peers and siblings. The relatively small number of studies focusing on the sibling experience document this impact: in a large-scale survey of families in the UK, siblings reported significantly lower levels of happiness, both with their families and with life overall (Peasgood et al., 2021). Qualitative analyses highlight sibling conflict, as well as neurotypical siblings feeling neglected by their parents and having the perception of taking a back-seat role in the family, with their own needs unmet. Additionally, neurotypical siblings reported an expectation that they would take on parent-like responsibilities for their sibling with ADHD (Kendall, 1999; King et al., 2016). Importantly, however, much of the negativity associated with having a sibling with ADHD appears to be specific to experiences of aggressive behaviour. In a quantitative analysis drawing on multi-informant data (self, parent and sibling-report), ADHD was associated with increased sibling conflict and decreased relationship warmth, consistent with previous studies; however, when comorbid externalizing symptoms were accounted for in the model, ADHD status itself was no longer predictive of these negative outcomes (Mikami & Pfiffner, 2008). It is worth noting that these studies have focused exclusively on sibling relationships during childhood and adolescence; we are not aware of previous studies examining the perspective of adult siblings in families with ADHD.

Family experiences, although intrinsically personal, are also powerfully influenced by external factors. School is one of the most salient external factors in family life, and often poses particular challenges for children with neurodevelopmental conditions, including ADHD, which is strongly associated with both academic difficulties and problems with peer relationships. The importance of academic success for children's experience and future life outcomes means that advocating for their child with respect to school, and finding appropriate support within the school system, is a major concern for many parents of school-aged children with ADHD; a lack of support from teachers and the school community is a theme that has emerged from previous studies of the parental experience of ADHD (Mofokeng and van der Whath, 2017; Leitch et al., 2019). An additional source of stress specifically cited by many parents is the pressure to conform to school-related routines and expectations, such as getting ready in time for school in the morning and keeping on top of homework in the evenings (Corcoran et al., 2017). Similarly, part of the 'caretaking stress' described by the siblings in Kendall et al., (1999) related specifically to being tasked with helping their brother with ADHD with homework and academic skills. Conversely, school can also be a source of support, providing structure, routine and expertise that benefits the child with ADHD as well as 'breathing space' during school-hours for their parents and siblings.

In the current study our focus is on how parents and adult siblings describe their family experiences of ADHD, in two very different cultural contexts: Kenya and the UK. The formal educational and healthcare structures in these two countries differ in key ways which are relevant to individuals with ADHD and their families. The UK National Health Service (NHS) provides universal coverage, free at the point of use, which has included mental health care since the 1960s. However, the NHS is currently facing severe staffing shortages, including in psychiatry and mental health provision more generally (Rimmer, 2021). The consequences for the diagnosis and treatment of ADHD have included long delays for diagnosis and treatment provision (Young et al., 2021). In Kenya, mental health has only very recently been included in the National Health Insurance Fund (NHIF), with the passing of the Mental Health Bill Amendment in 2022 (Mental Health Act, Cap 248). Thus, in contrast to the families in the UK, the families we interviewed in Kenya would not have had the option of state-funded support for ADHD diagnosis or treatment. Furthermore, under the Special Educational Needs & Disabilities legal framework in the UK, schools are required to provide support and accommodations for children with ADHD (SEND Code of Practice, 2015). In Kenya, although ADHD is formally recognised as a disability, it is not included in SEN provision (KICD 2019); consequently schools are not under any legal obligation to provide specialist support for this group of children.

With this context in mind, we carried out semi-structured interviews with parents and adult siblings of individuals with ADHD, with the aim of exploring their lived experiences and the impact of ADHD on family dynamics. We were particularly interested in potential similarities and differences in families' descriptions of their experiences in Kenya and the UK, in light of the differences in the healthcare and education systems, as well as the broader cultural environment.

2. Method

2.1 Ethical Approval

The study was reviewed and granted ethical approval by the Ethics Committee at the Department of Psychology, University of York in May 2022. Participants provided written consent before participation, and further oral consent at the start of the interview. They were fully informed about the aims and procedures of the study, as well as their right to withdraw from the study without needing to provide a reason; this included the period of time following the interview but before the date by which final data analysis would be completed. There were sufficient opportunities for questions and clarification before the interviews. Participation was voluntary, and was not rewarded or remunerated. Participants were thanked and sent a debriefing letter following the interview.

2.2 Participants

Participants were recruited via social media ADHD support groups, and via one of the researcher's links to a large healthcare setting in Kenya where study information was shared with healthcare staff. Inclusion criteria for participation were: 1) parent or sibling of an individual diagnosed with ADHD, 2) over the age of 18 years; 3) English or Swahili speaking; 4) access to a computer with an internet connection. In total, six British and six Kenyan participants took part in the study, of whom eight were parents and four were siblings. All participants were female, apart from one sibling from the UK. Of the 12 participating families, one included 2 children with ADHD, which meant that 13 individuals with ADHD were considered in the study, four of whom were female, and nine male. The ages of the individuals with ADHD at the time of interview were between 8 and 33. A range of comorbidities for 7 of the individuals with ADHD were reported, including anxiety, autism, eating disorder and substance abuse. Table 1 summarizes participant demographics.

2.3 Methodological approach

This was a qualitative study using semi-structured interviews to gain insight into the lived experience of families with ADHD, from the perspective of parents and adult siblings. Questions were developed following a pilot interview with an expert by experience, who assisted the research team in refining a set of 12 open-ended questions (listed in Appendix A); these allowed participants to interpret and answer the questions in their own way. The same set of 12 questions was asked in the same order in each interview, with occasional follow-up questions that varied slightly from interview to interview.

Interviews were carried out remotely, using online video conferencing software such as Zoom, and lasted approximately half an hour (ranging from 16 minutes 53 seconds to 51 minutes 6 seconds, with an average length of 29 minutes 48 seconds). Interviews were recorded (either video or audio-only according to participant preference), and were stored securely on University of York servers, with access limited to the research team. Interviews were transcribed verbatim off-line, and the original recordings were then deleted. The transcripts were anonymised using pseudonyms to preserve confidentiality as per the ethical approval. All participants were English-speaking and the interviews were carried out in English. A small number of responses in the Kenyan sample included words or phrases in Swahili (usually to emphasise a comment already made in English); these were translated into English for the transcripts by the lead author, who is a bilingual Swahili-English speaker.

The anonymised transcripts were analysed using Interpretative Phenomenological Analysis (IPA, Smith, Flowers & Larkin, 2009). IPA is an inductive method which allows participants to identify and describe the experiences they deem relevant; interpretation is then based on this rather than relying on pre-existing hypotheses. Following the IPA framework, the lived experience of the participants was the objective of the study (phenomenology), participants provided specific events and reflections to describe their experience (ideography), and the commonalities across these descriptions were interpreted (hermeneutics). The transcripts were analysed using the 6 stages of IPA: 1) data immersion, 2) initial noting of themes, 3) development of emergent themes, 4) synthesis of emergent themes into super-ordinate themes, 5) repeat for each transcript, 6) identify patterns across transcripts (Smith et al., 2009). Additionally, IPA involves a 'double hermeneutic' approach, in which the researcher makes their own interpretation of the participants' interpretation of their experiences. In order to aid this process, the researchers kept a 'reflective journal' in order to acknowledge and address their own biases and expectations (Ortlipp, 2008). As such, different coders are likely to derive similar but not identical themes from a set of interview responses. The current study is based on analysis carried out by the lead author; however, a parallel set of analyses were carried out by a second member of the research team, and cross-validation was carried out on one transcript, to help identify potential biases. The cross-validation yielded agreement on the majority (80%) of themes, and differences were discussed and incorporated into the final set of themes.

In order to evaluate the thematic saturation of the data a post-hoc analysis of the themes was conducted using the methodology described by Guest, Namey and Chen (2020), which is appropriate for thematic saturation analysis either during data collection or as a post-hoc analysis. The UK sample and the Kenyan sample were analysed separately: a full thematic saturation across both locations was not appropriate in this case, as the aim of the study was to contrast themes across countries. The UK sample had a total number of themes of 10 and the Kenyan sample had 11 themes. Analyses were conducted with a base of four records and a run of two records in each case. In both the UK and Kenyan samples full thematic saturation was achieved with no new themes being present in any of the records following the base run in either sample.

Table 1: Participant information

Country	Participant Code	Participant Sex	Relationship to Family member with ADHD	Sex of Family member with ADHD (Age)	Co-occuring conditions of person with ADHD (according to respondent)
UK	UKP 01	Female	Parent	Female (8)	"Anxiety", "ODD", "Depression", "Bipolar tendencies", "Mild autism"
	UKP 02	Female	Parent	Male (9)	"Autism", "Anxiety", "Vocal and motor tics", "Brain injury from birth", "Sensory"
	UKP 03	Female	Parent	Male (12)	None reported
	UKS 04	Female	Sibling	Male (22)	"Borderline Asperger's"
	UKP 05	Female	Parent	Male (14)	"Undiagnosed eating disorder (AFRID)"
	UKS 06	Male	Sibling	Female (32)	None reported

Kenya	KS 07	Female	Parent	Male 20<n>30	“Mildly Autistic”
	KP 08	Female	Parent	Female (12)	None reported
	KP 09	Female	Sibling	Male (22)	None reported
	KS 10	Female	Parent	Male (33)	“Substance Abuse”
	KP 11	Female	Parent	Male (17)	“Autism”, “Suicidal Ideation”
	KP 12	Female	Parent	Male & Female (18)	None reported

Note: Co-occurring conditions are presented as reported by interviewees (no independent confirmation of clinical diagnosis). Key: ODD – Oppositional Defiance Disorder, AFRID - Avoidant restrictive food intake disorder

3. Results

The interviews revealed clear similarities as well as some specific differences in family experiences of ADHD between Kenya and the UK   The commonalities across interviews yielded twelve Emergent Themes, which mapped onto five Super-ordinate Themes: 1) Lack of accurate information, 2) Family Experience, 3) Access to support, 4) Healthcare System and 5) Education System. Table 2 presents the allocation of themes to super-ordinate themes, as well as the proportion of participants endorsing each theme in the UK and Kenya. Themes will be discussed further below, using additional illustrative quotes to help convey essential aspects of participants’ experiences.

Table 2: Themes and their endorsement in the UK and Kenya.

Super-ordinate Themes	**Emergent Themes**	**Illustrative Quotes**	**UK**	**Kenya**
Lack of accurate information	Stigma in society	*“...there's a lot of stigma ooh there is too much stigma around it…” (KS 07)*	100%	83%
	Research and	*“….so before his diagnosis I did*	66%	100%

	educating yourself	*a lot of research into ADHD and how to parent…" (UKP 02)*		
Family experience	Understanding their behaviour	*"And we as parents came to understand them, the siblings came to understand them." (KP 12)*	100%	100%
	Expectation of more sibling responsibility	*"...then he's on this medication, which we are to ensure he takes it so that was made my responsibility." (KS 07)*	50%	100%
	Family stress	*"I get looked at and talked to as if I'm this mean, mean monster" (UKP 02)*	83%	100%
Access to support	Parenting Challenges	*"....because it's not like parenting a neurotypical child… you can't discipline them the same way you can't expect the same things, there is a lot of forgiveness needed a lot of patience and you need to work on yourself first, you need to model healthy reactions." (UKP 02)*	100%	50%
	Advocacy	*"...getting (high school) placements is not easy, you have to fight your way in if you have to." (KP 11)*	83%	100%
	Informal Support	*"Join a support group and try and strike up the dates with other parents in the same position as they get it." (UKP 01)*	100%	100%
Health care	Diagnostic	*'...And so, initially, she has a*	100%	0%

system	process	*diagnosis of ADHD at the age of three but by the time she reached the age of six or seven she has a diagnosis of autism, ODD, ADHD and anxiety." (UKP 01)*		
	Financial strain	*"...So you see a lot, especially in Africa, a lot of the people with mental health issues are on the streets cause this stuff is expensive it is." (KS 07)*	16%	83%
Education System	Rigid education systems	*'It makes me feel like the other the system (IGCSE) is more prepared for such children and our system (8-4-4) is not." (KP 12)*	0%	100%
	Lack of support from the school	*"…they back each other up, right, and I feel like half the time I'm fighting the school and half the time I'm fighting the local authority…." (UKP 01)*	100%	100%

Key: *KS - Kenya sibling, KP – Kenyan parent, UKP – UK parent, UKS – UK sibling*

3.1 Lack of accurate information.

Most participants across both the UK and Kenya reported having very limited awareness or knowledge of ADHD, prior to their family member's diagnosis. The two exceptions were both Kenyan siblings, one of whom had ADHD themselves, and the other of whom was a practicing psychologist. *'No, I didn't really know anything about it, but from my son starting to toddle I knew there was something different about them.' (UKP 05)*

3.1.1 Stigma in Society:

Participants from both the UK and Kenya agreed that stigma was something they have experienced or seen their family member with ADHD experience. Some families put strategies in place to deal with social stigma; for example, shopping online instead of at the supermarket, to avoid having to engage with other people. *'...your child gets stigmatised you know not invited to parties all that sort of stuff.' (UKP 05)*

3.1.2 Research and Educating yourself:

Almost all participants reported having to actively educate themselves about ADHD, following their child/sibling's diagnosis. Although 30% of parents said that their health practitioners had provided helpful information, the majority felt that they received little or no helpful advice from the formal healthcare system, and therefore had to seek out alternative sources of information. Particularly in Kenya, siblings affirmed that they had done a lot of reading to better understand their siblings with ADHD.

3.2 Family Experiences

A majority of participants described feeling emotionally closer as a nuclear family unit, following the ADHD diagnosis; in these families getting the diagnosis was viewed positively. However, this did not necessarily extend to the wider family or social networks: specifically in Kenya, none of our participating families shared the ADHD diagnosis outside the nuclear family and key stakeholders (particularly school). In a minority of the families we interviewed, relationships were described as being negatively impacted: some parents described not being supported by their partners, and are currently separated; one sibling (in Kenya) described a lack of understanding and trust between parents and siblings in the family.

3.2.1 Understanding of ADHD:

The confirmation of an ADHD diagnosis was described as serving a useful purpose in that it allowed parents and siblings to better understand their family member with ADHD and their behaviour. For some of the siblings, this process occurred in adulthood, rather than while growing up in the same household as their sibling. In turn, this enhanced understanding also modified their expectations, and improved the quality of family relationships*: 'I think. they [other siblings] were not as affected and if there were any effects, it must have been positive, to help them understand why, like probably some of the children don't do as well as the others in school.' (KP 12)*

The majority of participants, including all of the siblings, were optimistic about the future of their relationship with their family member with ADHD, and felt it had a good prognosis. The exceptions were parents of children with ADHD approaching the teenage years, who expressed anxiety about this phase of family life. *’Our relationship is really good at the moment; it has been about the whole year’ (UKS 04)*

3.2.2 Expectation of more sibling responsibility:

All siblings felt a sense of responsibility for their sibling with ADHD. In two families, the parents gave siblings clear responsibilities to support the additional needs of their family member with ADHD, for example helping with medication. Two other siblings, who were both adults in their 30s at the time of interview, had taken the initiative to support their siblings who were both diagnosed in adulthood (at 30 and 35 years old); they had taken an active role in educating themselves, and supporting and advocating for their sibling with ADHD.

Parents with more than one child described feeling that they had neglected their other children due to the time taken by the child with ADHD. They reported feeling guilt and concern over their experiences and would like to see support for siblings, as well as support for how to parent when you have children with and without neurodevelopmental conditions.

3.2.3 Family stress.

Family stress, including conflict, was reported by most participants, across both countries. Arguments and disagreements were described as being stressful for the parties involved and the rest of the family. Conflict between parents and children with ADHD tended to arise from ADHD symptomatology and was exacerbated by parents trying to set boundaries and systems. *“So our relationship is on-off. Today, she will remember something that happened to her a long time ago - ‘Remember mama you pitched me on them, in 2010 Saturday in the morning, at, it was the 13th, you pinched.’ You know. So yeah, and sometimes she's like ‘oh mama you’re the best mama in the world.’ (KP 08)*

Sibling conflict was also highlighted and again, it was noted that disagreements were often exacerbated by ADHD symptoms: *‘…they squabble a lot, they fight, they argue, it's a constant, like it does in my head in the amount of arguing they have. Because he winds her up. He wants to play with her, but he doesn't have this set of skills to join in and play so winds her up instead” (UKP 02).*

Negotiating these family stresses was described as emotionally very draining for parents, with consequences for their own mental health and wellbeing: *“I find it really hard, and I find it hard to regulate myself never mind regulate her because it's so distressing to see her in so much distress. (UKP 01).* Also *“It was quite overwhelming and um the road looked* *very far and like are we going to make it? You know, it's actually psychological it was really, really tense. It did look very dark ahead." (KP 08).*

3.3 Access to Support

A key concern reported almost universally was a perceived lack of support. Parents reported feeling overwhelmed, frustrated and alone with no guidance. However, an interesting cultural difference emerged in that parents in the UK had a clear expectation of external support, whereas parents in Kenya did not have such expectations. Thus, the frustration for the parents in the UK was directed at a perceived failure of the existing systems of support, while parents in Kenya pointed to the absence of formal support. *'They don't want to do anything so yeah me, schools and SENCOs don't get on at all and I would say, their support is not even minimal.' (UKP 02)*

3.3.1 Parenting challenges

Parents described being blamed for bad parenting that led to their children having ADHD. While parents in the UK mentioned receiving parenting advice from other family members, this was not necessarily helpful; in two cases, they were told they needed to be stricter with their children in order to make them behave. Parents in Kenya seemed to refrain from seeking parenting advice from other family members, and looked to specialists and teachers for advice instead. Specific challenges were raised around the different parenting approaches needed for the child with ADHD and their neurotypical siblings.

Families with younger children with ADHD were apprehensive about navigating the teenage years, while those with children in early adulthood voiced concerns about university, work and future romantic relationships. *'Also don't know your space as a mother, in her life, you know you really have to be the one to even pray about it and, hope God I am a role model for her to have because the mood swings sometimes come in and out and again because she's a teenager as well.' (KP 08)*

3.3.2 Advocacy

Parents and siblings in both countries described themselves as advocates for their family member with ADHD. Parents reported having to defend and explain their children's behaviour to family and school, and to 'fight' to have their children's needs met. *'You've got a long battle on your hands, there's very little support out there…a lot of these issues are brushed under the carpet, especially at school….' (UKP 03)*

3.3.3 Informal Support

Informal support networks were described as being important, with all parents reporting having access to some form of online support group (typically Facebook in the UK, WhatsApp in Kenya). These communities provided parents with an opportunity to share resources and experiences, as well as a space to air their grievances. *'Our school is trying to pull a lot of moms who have different special needs children and in that forum we have one or two moms who are there(have experience), who you can ask a question or two, so we also have those kinds of informal conversations.' (KP 08)*

3.4 Health care system

As described earlier, the healthcare system and provision for ADHD is very different in the UK and Kenya, and these differences directly impact the nature of families' experiences. While participants in the UK expressed frustration over long waiting times for diagnosis, participants in Kenya highlighted an even broader challenge, in the general lack of support for mental health within the healthcare system and beyond. *'The mental health space lemme tell you in Africa is very lonely. Is a very lonely space and very ostracised and very like… we have like..what is it… like we have leprosy.' (KS 07)*

3.4.1 Diagnostic process and what to do next

The diagnosis itself was described as a positive, validating experience: *"Um, how I felt after the diagnosis... um, relief. Because I wasn't going mad, 'cause I was honestly made to feel like I was going mad.' (UKP 02).*

The UK has a clear diagnostic process based on evidence-based national guidelines, and which is closely regulated (NICE, 2019). All of the UK parents we interviewed reported that their children received a diagnosis before the age of 11, but that the waiting times within the National Health Service were frustratingly long. Even more distressing was the realization that the diagnosis did not lead to further guidance and support, as they had expected. *'I think the lack of provision in school, it compacted the issue and the fact that she's a girl and autism and ADHD show up differently in girls and boys, so the teachers were fighting me saying she didn't have it.' (UKP 01).*

In Kenya, there was no state-funded provision for mental healthcare, including ADHD diagnoses, until 2022. Consequently, all the diagnoses in the Kenyan sample were carried out privately, and they did not experience delays. Two referrals were made through school, and two others by health practitioners. One parent voiced concern that their own lack of knowledge about ADHD meant they had been taken advantage of by different practitioners offering different treatment plans. Parents described being heavily reliant on the advice given to them by private practitioners, as well as school, on how best to support their children.

3.4.2 Financial Strain

All Kenyan participants, both parents and siblings, discussed the financial impact of managing ADHD. Both diagnosis and treatment had to be paid for privately; while private medical insurance could be helpful, it was expensive, and mental health (including ADHD) was not covered by all insurance plans.Our study was carried out shortly after the COVID-19 pandemic, and a number of participants raised the financial impact that job losses during the pandemic had on their family members with ADHD; as well as the impact on wellbeing, it exacerbated the financial strain of having to pay for treatment.

In the UK, financial strain was a much less salient theme, and when mentioned was specific to the two participants who opted to go through the private sector.

3.5 Education

Education and schooling were a major theme discussed by all parents, in both the UK and Kenya; they viewed education as an important stepping-stone into the future, and ensuring a good education for their child was a high priority. However, across both countries this was challenging to achieve. In the UK parents reported being in constant conflict with their children's schools; they felt that their children's needs were not understood and that schools were not making enough effort to provide appropriate support. Similarly, Kenyan parents described having to explain their children's ADHD to the school, and push for accommodations to be made. However, as in healthcare, there are substantial differences in the education systems in the two countries which shape families' experiences in relation to school.

3.5.1 Rigid education System in Kenya

Parents in Kenya all highlighted the rigidity of the traditional '8-4-4' education system, which is described as inflexible and not accommodating of students who struggle with concentration, memory, and academic pressure, and is thus 'not ready' for students with ADHD. This was contrasted with the British school system; as well as being the standard system in the UK, the iGCSE has also been adopted by some schools internationally, including in Kenya. This system was perceived as being more flexible and accommodating in terms of both the curriculum and instructional approach, and was described as being a better fit for children with ADHD.

3.5.2 Lack of support from the school

Parents in the UK were universally dissatisfied with the quality of support their children received at school, describing it as 'rubbish' and 'a complete joke'. One parent felt that 'backward thinking' about ADHD was widely prevalent in schools.

In Kenya, parents described better support in the British iGCSE school system, but little or no support in '8-4-4' schools. Parents were active in seeking solutions within these constraints, such as opting for private schools with smaller class sizes to ensure more teacher-student contact time. They also described intensively advocating for their children with the school, and having to push teachers to support their child. *'My kid is like 'this', kindly accommodate him and it is like begging the education system…' (KP 11)*

4. Discussion

Across two very different societies, the impact of ADHD on parents and siblings was described in similar ways, with common themes emerging around family dynamics, the need to advocate for the family member with ADHD beyond the family sphere, and the sources of support - or lack thereof - to be found in the wider social network, schools and healthcare systems. Although there were inter-cultural nuances in the specificities of the lived experiences described by our participants, the biggest differences across UK vs Kenyan families related to structural differences in the national education and healthcare systems. One area in which the commonalities across cultures emerged clearly had to do with personal and broader societal awareness of ADHD, including misperceptions about the nature and causes of ADHD. In the UK, despite a generally high level of awareness of ADHD some of our participants reported that the information they had prior to their family member's diagnosis was actually misinformation. They also reported a high level of stigma around ADHD, with a common description participants used being 'the naughty child'. Furthermore, among the UK parents many mentioned that they had been told that bad parenting is the cause of ADHD and that their children's behaviour would improve if they changed their parenting style. In Kenya, societal awareness of ADHD has been low, but is now increasing. This lack of background knowledge and awareness was a theme that emerged clearly in the interviews with our Kenyan participants. Prior to receiving the diagnosis for their child or sibling, none of our Kenyan participants had heard of ADHD. Most parents struggled to explain it to other family members and teachers, while siblings mentioned that the general perception is that ADHD is something that you can control but choose not to. Kenyan parents also described keeping management of ADHD within the nuclear family, and were reluctant to seek parenting advice from their extended families, instead turning to educational and healthcare professionals for support, as well as informal parent networks through social media.

Access to support was another theme that emerged very clearly across interviews, but there were some notable differences between UK and Kenyan participant experiences. In the UK, all participants reported that their child received a diagnosis of ADHD before the age of 11, although this process was often slow. Following diagnosis, however, parents found the subsequent lack of support extremely frustrating, both from healthcare professionals, and within the school system. Parents were angered by the lack of collaboration between teachers, SENCos (Special Educational Needs Co-ordinators) and themselves. They felt they had to constantly fight for their children to receive the educational support they needed, and struggled to understand why schools were seemingly unable to provide this, although some parents attributed it to stigma and a lack of understanding among teachers. This perception coheres with teachers’ own reports of feeling under-prepared and under-supported for managing and supporting children with ADHD in their classrooms (COMRES Teacher survey, 2017).

In Kenya, the challenges around accessing support were different. As mental health was not included in the National Health Insurance Scheme until 2022, and even private health insurance schemes do not necessarily cover ADHD, all participants had to pay privately for diagnosis and long-term medication. For these families, the difficulties were not around delays or inadequacies in state-funded provision, but rather the ongoing financial strain of managing ADHD privately. They also faced difficulties with support from school, but tended to attribute this to the rote-learning-based school system - known as the 8-4-4 system - which has been described as ‘cutthroat’ and rigid (Amutabi 2019), and which parents consider to place unduly high pressure and unrealistic academic expectations on students, particularly but not only those with SEN. (It is worth noting that the Kenyan educational system is currently undergoing substantial changes, due to be implemented in 2027). Like the parents in the UK, parents in Kenya reported having to advocate for their children, and described pleading personally with teachers to provide support for their children through extra classes, printing notes and keeping an eye on them. Whether or not teachers were able to accommodate these requests for personalized assistance varied widely, and depended on the school and individual teachers' workloads (a typical classroom in Nairobi has 40-60 students, compared to 20-30 in the UK).

Healthcare and education systems are both formal support structures, and the differences between the UK and Kenya in these systems had a clear and direct influence on family experiences of ADHD. However, all participants across both countries also emphasized the key role of informal support, and the importance of having a network of other families who were facing similar challenges. Online platforms provided a practical way of connecting with other parents, sometimes locally (e.g. within the same school) and sometimes more geographically dispersed. Within the descriptions of informal support, there were some interesting nuances that differed across the two countries. Some of the Kenyan participants referred to religious beliefs as a source of personal support, and described an acceptance of the challenges posed by ADHD as part of 'God's plan.' In contrast, none of the UK participants mentioned religion or spirituality. This coheres with the broader cultural context, whereby 85% of the Kenyan population self-identify as Christian, while 52% of the UK population does not identify with any religion (Office of International Religious Freedom, 2021; British Social Attitudes Survey, 2018).

Turning to the experiences of parents and siblings within the family unit, it is important to note that all but one of our participants (a UK sibling) were female: the perspective we have in both the UK and Kenya is that of mothers and sisters. One theme that emerged clearly in both cultures was that all siblings felt a sense of responsibility for their family member with ADHD. In some cases, the older sibling had been allocated clear additional responsibilities in the household while still a child - for example, ensuring their younger sibling with ADHD took their medication, completed school assignments, and attended therapy, as well as sometimes being asked to take care of other siblings in the family. In other families, siblings reported taking on an active supporting role later in life, when their sibling with ADHD was an adult. The theme of the 'parentified child' is consistent with previous reports of the experiences of siblings in families with ADHD (Kendall, 1999; King et al., 2016), but this was not necessarily seen as a positive or negative experience by our participants. Particularly in Kenya, this may be related to cultural norms whereby first-born children are often considered to be the third parent in the home, and the additional responsibility is expected rather than being considered an unusual burden. All siblings we interviewed were also positive about the outlook for their relationship with their sibling with ADHD; despite the added responsibilities they felt their relationship was going to get even better, they spoke fondly of them, and were protective of them.

Parents also spoke positively about family relationships, although alongside this there were also common experiences of family conflict which were at least partly attributed to behaviours related to ADHD. The challenges and emotional strain associated with caring for a child with ADHD were described by some parents (and also siblings) as having a substantial impact on their mental health. In addition, those whose child with ADHD was approaching adolescence expressed specific concerns around navigating the teenage years, and supporting their child into adulthood while also allowing them to be independent. Overall, across families, it was clear that - despite a clear acknowledgement of the personal and family challenges involved - the experience of ADHD for parents and siblings involved a life-long commitment to supporting their child/sibling with ADHD.

In interpreting these findings, it is important to bear some specific features and limitations of the study in mind, particularly around the nature of our sample. The themes were derived from the specific experiences of the particular people we interviewed. We aimed to recruit a reasonably homogeneous sample within each country, and through IPA identified commonalities in their experiences: the thematic saturation analysis suggested that within those samples, we were able to capture some key aspects of common experience. However, we cannot generalise beyond the small number of people we interviewed within Kenya or the UK, particularly as recruitment was carried out either through a hospital clinic, or social media, and so participants are unlikely to represent the full range of families with ADHD in either country. There are also some differences in the characteristics of the individuals with ADHD in the two countries: in the UK they were younger than those in Kenya, and had a greater number of co-morbid conditions according to the parent/sibling we interviewed (although it is not possible to confirm the extent to which this reflects individuals' clinical profiles, or other factors that may differ across countries, such as diagnostic practices). On the other hand, we suggest that the cross-cultural comparison yielded themes which perhaps could be generalised with more confidence: common themes emerging in both Kenya and the UK are likely apply more broadly, if not universally. Conversely, key differences in experience across the two countries – particularly those relating to structural differences in health and education systems – are likely to apply to many other families with ADHD within each country. Finally, our sample comprised both parents and adult siblings of individuals with ADHD (3 parents and 3 siblings in Kenya; 4 parents and 2 siblings in the UK). Ideally, we would have been able to recruit a sufficiently large number of each, to allow a direct comparison of the experiences of parents and siblings, which likely would have highlighted interesting differences as well as similarities. Instead, what we have captured is the experiences within the family unit as a whole, and are unable to differentiate between what might be systematically different perspectives.

In conclusion, families' lived experience of ADHD was strikingly similar in two very different cultural settings: the UK and Kenya. Parents and adult siblings in both countries described challenges in terms of dynamics within the family (e.g. sibling conflict), but also in most cases a sense of closeness and unity within the nuclear family. An almost universal theme was in relation to the world beyond the immediate family: a lack of understanding and support in broader society, within school settings, and even the extended family. Families had to educate themselves and be very proactive in seeking support and advocating for their child or sibling with ADHD; some of the best support was to be found in informal networks, and particularly other families with children with ADHD. Although there were some nuanced cross-cultural differences in personal experience - such as the expectation of sibling responsibility that was especially marked in Kenya, or the reference to religion as a source of support - by far the biggest differences across countries related to the impact of structural differences in national health and education systems. In both countries families described a serious lack of support, but for different reasons. While in Kenya the education system was perceived as structurally too rigid to accommodate learning differences of any kind, families in the UK were frustrated by a system that in principle could provide the necessary support, but - in their experience - consistently failed to. Similarly, in Kenya the healthcare system simply did not include provision for mental health at the time these families were raising their children, and private diagnosis and treatment caused ongoing financial strain. In contrast, the UK health system, which is free at the point of access, has clear guidelines for ADHD diagnosis which are adhered to nationally - but as a consequence of an overburdened health service, families expressed frustration at lengthy delays for an ADHD diagnosis, and a disappointing lack of follow-up support. These findings highlight inter-cultural commonalities at the personal level and within the family system, of raising or growing up with a child with ADHD, as well as how the lived experience is shaped by structural factors at the societal and national level.

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