Title:

Barriers to accessing pediatric healthcare: A focus on health equity in the UK

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Abbreviations:

NHS – National Health Service

ED – Emergency Department

LGBTQ+ - Lesbian, Gay, Bisexual, Transgender, Queer

RAP – Rapid assessment procedures

RREAL – Rapid research evaluation and appraisal lab

UK – United Kingdom

US – United States

WHO – World Health Organization

Article summary:

This study uses findings from UK qualitative research to draw parallels with the US and provide recommendations on improving equity in access to pediatric healthcare.

Contributors Statements:

Dr Louise Brennan wrote the first draft of the manuscript and was involved in study design, data collection and initial and subsequent data analysis.

Drs Liz Brewster and Judith Lunn critically reviewed and revised the manuscript and were involved in study design, data collection and initial data analysis.

Professor Rachel Isba was the study chief investigator, acquired funding, had primary responsibility for the study design and was involved in data analysis and revision of the final manuscript.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Abstract (178/200)

Introduction: To achieve health equity we must first understand health inequities. This article focuses on socioeconomic deprivation and associated barriers to accessing healthcare for children and their families in the UK, where, despite care being free at the point of delivery, economic barriers to healthcare access remain.

Methods: Thematic analysis of findings from a large qualitative study with providers of secondary and tertiary pediatric care in the UK. Rapid research evaluation and appraisal lab (RREAL) methodology was utilised to analyse data and identify themes.

Results: A total of 217 staff were consulted at all levels within nine pediatric healthcare providers. Barriers to healthcare access were categorised under two intersectional themes: economic barriers and system accessibility. Examples of approaches to address barriers are presented and discussed.

Conclusion: Decision makers, clinicians and staff at all levels are encouraged to consider the accessibility of their services against the key themes identified in this study. To fully address equity, national policy is required to address system sensitivities and avoid unregulated approaches for certain groups/ specialties widening the inequities they aim to address.

INTRODUCTION:

Health inequities are defined as unfair and avoidable systematic differences in health between people (1), although there are differences in nomenclature used across the Atlantic that need to be briefly noted. In the UK the term 'inequality' is used to describe unjust and avoidable differences in health. In North America the term inequalities refers to all known differences between groups whereas the term 'inequity' is reserved only for differences considered unjust (2). Socioeconomic deprivation, a term originating in the 1980s (3), is a multidimensional concept referring to the relative disadvantage experienced when living with reduced resources, including income and social assets such as education, employment and social position (4). The links between socioeconomic deprivation and health inequities are evident in pediatric health outcomes worldwide, e.g. disparities in infant birth weight by country and ethnicity (5), and infant mortality by ethnicity and level of education(6).

However, inequities are not just measured in health outcomes. Children and their families' access to care is also socioeconomically patterned (7). In the UK, healthcare is predominantly delivered by the National Health Service (NHS), a government-funded, free at the point of access, universal medical and healthcare service (8). Despite the seemingly equitable system, UK research has demonstrated disparities in access to care such as children from the least deprived group having 11% less emergency admissions to hospital (9), and being more likely to attend primary and secondary care appointments than the most deprived (10). These findings suggest that inequities in how families access care are more than just monetary, mirroring findings from the US (11).

Previous studies have investigated the barriers to healthcare utilisation. Despite early work recommending the need for child centric health systems and research (12), more recent review studies have focussed on urban adult populations (13), adults with mental health challenges (14) and adults with disabilities (15, 16). A systematic review of barriers and facilitators to healthcare access for children with autism in the UK found seven overarching themes around barriers, including lack of person-centred care, communication issues and culture, however recommendations are specific to autistic children and their families, rather than the pediatric population as a whole (17).

In the UK, NHS healthcare providers have a statutory duty to consider inequities in care (18). International human rights treaties also obligate World Health Organization (WHO) Member States to provide equitable healthcare to all (19). It is therefore vitally important that we are aware of the barriers that exist to accessing services, in order to address them (20).

This article explores the findings from a large qualitative study investigating health inequities within children's hospitals in the UK. Two main themes are discussed. Firstly, economic barriers, highlighting both the immediate and concomitant costs of attending hospital, typically described by health economists as direct, indirect or opportunity costs.

Secondly, system accessibility barriers including language, literacy and disability are explored. In discussing the intersectionality of the aforementioned barriers an additional theme relating to sensitivity of the healthcare system is highlighted, specifically applicable to children with neurodiversity, cultural differences or multiple conditions.

Whilst these findings are from the UK, parallels are drawn with the US and further recommendations on steps to achieving health equity can be made that are transferable to international contexts, including the US.

METHODS

Ten hospital organisations, responsible for delivering pediatric healthcare were invited to take part in a qualitative focus group and interview study in 2023, focussed on how staff in children's hospitals in England viewed their responsibility to reduce health inequities for the children and young people they serve. In the UK, pediatric healthcare is for patients aged up to approximately 16 years old. This project was part of a wider programme of research; a more detailed description of the aims and objectives and research methods are described elsewhere (21).

Ethics

Ethical approval was granted by FHM Research Ethics Committee Lancaster University on 16 June 2022 (ref: FHM-2022-0844-RECR-3). Health Research Authority approval was granted on 24 August 2022 (ref: IRAS315113 and 22/HRA/3123) and capacity and capability to participate were confirmed by each organisation.

Recruitment

Nine hospitals chose to take part in the study. Participants were staff represented at all levels within the organization, recruited via a hospital identified 'key contact' with an interest in equity within each organisation. Participants were given standard information distributed by email and asked to complete and return a consent form prior to taking part.

Data collection

One to one interviews with individual leaders and clinicians were conducted over Microsoft Teams, following a structured topic guide, which provided initial focus with flexibility to explore emergent topics/ areas of interest. Focus groups were held on site and composed of staff from similar categories e.g. 'clinical' (e.g. doctors and nurses) and 'professional and support staff' (e.g. administration and porters) to ensure that staff felt comfortable to contribute. Focus groups lasted approximately 60 minutes and followed a similar topic guide. All interviews and focus groups were audio recorded. Thirdly, *ad-hoc* informal conversations with clinical, professional and support staff who were not able to attend a focus group were conducted. Written notes and debrief audio recordings were collected and analysed along with focus group and interview transcripts.

Data analysis

Data analysis followed the rapid research evaluation and appraisal lab (RREAL) methodology for rapid assessment procedures (RAP). Recognised for being team based and iterative in its approach, amongst the benefits of the RAP process is the ability to conduct rigorous and robust data analysis in a short amount of time (22).

Following initial data collection (conducting interviews and focus groups), RAP sheets were generated for each data collection event. This was done by at least two researchers and involved listening to the audio recording and completing a pre-designed ‘RAP sheet’ (21). Once RAP sheets were completed for all interviews, focus groups and informal discussions, two members of the team generated site-specific RAP sheets (condensing findings into an overview of themes for each site). Team members then read all 171 RAP sheets, generating their own themes. Suggested themes were then discussed as whole team events at several day long de-briefing sessions which ultimately led to agreement on key themes and recommendations as detailed elsewhere (21). For this subsequent study all RAP sheets were re-interrogated and transcripts revisited as necessary to further develop and evidence the themes relating to the barriers discussed hereon.

RESULTS

In total, 217 members of staff were spoken to across nine hospitals. Staff were represented from all groups including senior executives, managers, doctors, nurses, administrative staff, catering staff, porters and volunteers. Sixty-one interviews were completed and recorded via Microsoft Teams. The number of interviews per organisation ranged from 4 to 11. One to two focus groups were conducted in each organisation, with participation ranging from three to 10 members. Across the nine sites, 39 focus group and informal discussions were completed. A total of 171 RAP sheets were generated from 100 data collection events.

Two initial key themes emerged from analysis of the qualitative data. Firstly, ‘economic barriers’ in relation to the out of pocket and opportunity costs of attending appointments or hospital stays was discussed. Secondly, ‘system accessibility’ arose, covering language and communication including digital technology, as well as cultural differences.

Economic barriers

When asked for examples of their experience of health inequities, staff talked openly about the barriers that patients and their families were facing when accessing care in their hospitals. The most common, or easily cited, barrier was in relation to poverty, or the immediate costs of having to attend a hospital appointment, whether it was routine or emergency. During analysis, these barriers were grouped with the subsequent costs associated with a child’s ill health and/ or treatment and the concomitant costs, such as time off work for carers.

Transport to hospital and parking:

Whilst most hospitals had a mechanism to support families with the costs of travel and parking, this was most frequently via retrospective reimbursement, and families were therefore required to have the funds available to pay upfront for transport and/ or parking.

In addition, this offer of support was not always advertised or accessible. For families accessing hospital care outside of their local area the cost of travel, parking and accommodation could become too much to manage. One doctor described the family of a child in intensive care who could only afford to visit their child once a month.

"We have a family where the parents are located in a different city… and now they don't even have the money to come and see their child in ICU, so they come and see their child probably once a month now, or less which is really really a difficult thing for the family to cope with" Clinician

Whilst staff across all hospitals discussed the disproportionate costs of parking and travel, very few hospitals had taken meaningful action to address this. One hospital was in discussions with local transport providers to arrange subsidised travel for patients, and had increased parking charges for more senior members of staff to pass on reductions to others. A pilot project offering free transport to families at risk of non-attendance was found to be successful, but had not been funded long-term. Other hospitals had the facility to book transport and parking for families when required, but this was not universal, and often at the discretion of senior nursing staff in their own service, and they often seemed reluctant to admit their use of this:

"We often… even if we should or shouldn't… if it means that they could get their treatment then we would try to help with a taxi home" Clinician

Food:

Disparities in the offer of food was evident within and between hospitals. Whilst all inpatients were offered food, provision for outpatients, caregivers and visitors was fragmented, often not advertised, and guidelines unclear for staff to follow. The lack of central and local policy on food provision led to staff and patients being creative to feed families:

"Families have identified that they have been sitting on a ward for 2 days and not eating" Clinician

"We saw families who are sharing their patient food as well. So, like halving their meals. So you have a very sick child and they're giving food to their mum as well because they haven't seen them eating and things like that" Clinician

Staff across hospitals admitted to 'breaking the rules' to ensure that families ate, offering left over food on trollies, bringing in food from home or going to retail outlets within the hospital to put together food parcels.

Even in hospitals where the cost of food had been considered, this was poorly advertised to patients and communicated with staff ineffectively. In one hospital where a ‘pay it forward’ scheme was available, staff admitted taking part but having no idea who got the meals or how it worked. Likewise, catering staff admitted that if anyone ever asked for a free meal they wouldn’t know what to do and would need to ask a manager for authorisation.

Other unseen costs:

On top of the immediate costs of getting to, and being in, the hospital, staff talked about the further expense for the families of children with conditions requiring medical equipment and treatment. Those with community roles described adverse patient housing conditions including mould and damp, their disadvantage compounded by the costs of heating and medical equipment required for a sick child.

> *“Especially when they have multiple equipment plugged in, heating is an issue, that’s a big one at the moment, especially when they have carers in overnight they can’t sit in a cold house, but equally you can’t expect the parents to heat the house overnight when they are asleep” Clinician*

Whilst prescriptions are free for children until the age of 18 in the UK, staff talked about the hidden costs such as travel to collect medication from the hospital:

> *“There’s an expectation by NHS England that some of the specialist drugs we give have to be given out here every two weeks. They’re travelling two hours to collect them” Clinician*

The need for parents and carers to accompany children to appointments or stay with them in hospital had consequences for their income. Whilst less deprived families were described taking paid leave, or being able to work from the hospital, those most at risk from health inequities were identified as having less flexibility when it came to taking time off work:

> *“If we think about those struggling financially, we have some who are more fortunate jobwise who are flexible and can work on their laptops while in clinic, those who aren’t as well off economically have managers above them saying ‘no’, ‘you’re not going to get this 6-months full pay, and bereavement and special leave’. So the dilemmas and stress they go through to make those decisions on... and, you know it’s not just one, they have other children to think about as well.” Clinician*

The impact on other children in the household was not only referred to in terms of the opportunity cost of parents being away from home. Descriptions of multiple children accompanying their families to the hospital and the impact on their lives and schooling was also frequently described:

"That's it, a lot of other children come with them, meaning the other children and siblings they're missing school time, they're missing the early years, and socialisation. If they are just sat in clinic, could be waiting hours, then they're not having any of the experiences they should be having and their education then is getting stunted. And then we have young carers as well who attend all these clinic appointments with their families, who are pulled out of school to attend appointments, and they're say in the entrance at 7 o'clock at night you know, waiting for transport home. Its having a massive impact on the next generation." Clinician

Whilst the majority of hospitals offer charity-funded accommodation on site, this was often described as insufficient and oversubscribed, leading to families paying for nearby hotels or looking for alternative means of accommodation:

"I was talking to someone this morning who has a family who have been on the waiting list for 21 days for family accommodation. We've got Dads who are sleeping in cars again because there is nowhere for them to stay but they want to be here to be part of the conversation about their child's care, but they can't even afford the youth hostel because it's too expensive for a length of time" Professional and support staff

Accessibility barriers

When talking about what their hospital could do better to improve equity, focus often turned to groups of patients and families who struggle to navigate the system and get the same access to care as other groups of patients. Staff saw addressing accessibility as a key step to achieving equity.

Language barriers were discussed at all hospitals and the inequities in care faced by those families unable to communicate in English were striking. In all hospitals written communication, including invitations to appointments and follow up information, was provided in English by default. And whilst translator services were available in the hospital stories of insufficient, unsuitable or inadequate translation services were common.

"I've spent up to 40 minutes of my one hour consultation searching for a translation device" Clinician

Having to seek out translation provision – rather than it being available at the start of the appointment – was leading to shorter, less thorough appointments for those with English as a second language , widening the inequities that this group already faced. When asked why language was a barrier, staff responded that systems are not set up to accommodate the array of languages they encounter. Most hospitals did not routinely record language requirements in patient records, unless the child was well known to a service and a frequent attender. Even then, staff were reluctant to 'over-use' translation services for fear of scrutiny from management due to the costs:

"If you use the translators too much you get flagged" Clinician

However, language was not just a barrier to receiving information, but also to navigating the system. Non-English speakers and families new to the country were less likely to be UK health system literate and know how to navigate the system:

"Language and generally understanding how to navigate the system is harder for people not born in this country or maybe don't speak English so well… but also actually the confidence to be able to ask for things, and know what they can ask for and who to ask for it can all impact on how people access healthcare and what they get out of it ". Leadership

In addition to language and literacy barriers, cultural barriers were also evident. Staff described the NHS as a system set up to fail these families:

"There's a big assumption from the NHS that these families know how to navigate the NHS themselves… I think we confuse them". Clinician

Since the SARS-CoV-2/COVID19 pandemic, digital technology has played a large part in healthcare across English hospitals. Whilst some staff saw this as a positive, reducing the economic barriers described above, others were reluctant to see it as a solution to health equity due to digital poverty and accessibility issues, particularly for those facing language and literacy barriers.

"Digital solutions are not necessarily accessible to all. A 30-minute video consultation on your phone might not be possible for example". Leadership

Over reliance on digital technology and reduction of face to face, in person contact can also further distance those children and families having to avoid the system, for example young parents, refugees and asylum seekers, children vulnerable to exploitation and gangs and those living with domestic violence. Staff were conscious that the move to digital appointments may exacerbate the health inequalities already faced by these groups, reducing opportunities for intervention.

DISCUSSION

This paper has presented the findings relating to systemic socioeconomic bias resulting in barriers to accessing healthcare, derived from a large qualitative study with staff working at nine children's hospitals in England, UK. Two key themes arose from analysis of data collected from 217 members of staff; these are presented under the headings economic and accessibility barriers to care.

In the US, an average hospital stay for a child was estimated to cost $7,800 between 2017-2019, with families with private insurance still experiencing 'out of pocket' costs of up to $3,000 (23). In the UK, healthcare should theoretically be cost-neutral at point of care as it is paid for by general taxation. A previous study conducted in Liverpool, England showed that this was not strictly the case, as 8% of families interviewed cited costs of attending as a reason for missed appointments (24) and more recent calculations suggest out of pocket costs of hospitalizations have further increased (25). Our results show that despite healthcare in the UK being free at the point of access, there are still multiple economic barriers that impact on whether children and families can practically access care.

First, we identified the travel costs not accounted for when getting to appointments, and the costs of meeting basic needs (e.g. food and accommodation) when children have a long hospital stay. In the UK, some of these needs (e.g. accommodation) are met through philanthropic means, but many of the wider costs (e.g. food) whilst being recognized were being met informally through staff taking the initiative to intervene.

The role of philanthropy has parallels with the US system, where charitable donations are an important part of the healthcare system, yet have the potential to unwittingly exacerbate health inequities (26). In the UK, while staff in some of the organizations we worked with felt empowered to act and to intervene to support families in need, others did not have the same agency, or resources were more tightly managed and so there was less opportunity to overcome inequities to meet the basic needs of families and children. Regardless, it is worth noting that these interventions were frequently led informally by staff at ward level, rather than being an organization, or even national priority.

The agency of staff to act when they see inequities and access to resource to overcome these inequities has not been examined in a North American context despite research indicating that families require better access to support, such as financial counselling, whilst in hospital (27). This is an area for future research.

Second, financial barriers were also experienced by families in this research as opportunity costs. The longer-term impact on familial income and equity of opportunity around employment have been explored in Australian settings (28), but few studies have explored the impact on non-income based costs, such as time spent away from other caring responsibilities and the longer-term impact of a hospitalized child on their own and siblings' education and development. It is clear that both types of opportunity cost will potentially have more lasting impacts for families already experiencing socio-economic deprivation, and both require more research in this context.

Third, we identified how language and communication could be an additional barrier to accessing care. This aligned with a further issue around digital accessibility and skills, which presented a further concern around the change to online appointments and how they may retrench inequalities rather than overcoming previously identified barriers.

Language, literacy and cultural barriers are not new concepts. Healthcare systems are notoriously difficult to navigate (29). Previous studies have reported the complexity of systems for people from deprived backgrounds (20), recognising the role of a pediatrician in advocating for greater equity in access to care. Similarly, a study with children and families with autism experience also uncovered system level barriers such as lack of joined up services, language and communication issues (17). A US study also found language, culture and bureaucratic systems as reasons for frequent use of the ED over primary care. This was further pronounced in families whose first language was not English, or were not familiar with the US healthcare system (30).

Overall, our findings demonstrate a lack of ‘system sensitivity’ to manage children with different needs. Most strikingly, if children and young people have more than one need identified, hospitals are ill-equipped to manage these inequities as they accumulate. Research, including the present data, has uncovered an institutional level lack of understanding and sensitivity to children with complexities such as adverse childhood experiences, multiple conditions (31), parents with other children, cultural differences, LGBTQ+ communities, children with neurodiversity and people with mental health illness (32). This lack of sensitivity results in healthcare staff assuming personal responsibility to meet patients’ needs as they strive to maintain the professional and ethical standards of high-quality care.

Our study has identified some areas of good practice where organizations had listened to the needs of their patient groups. Examples of interventions included the ‘rainbow badge’, worn by staff to indicate their support for LGBTQ+ communities, (an initiative that started at one hospital and is now used at many hospitals in the UK), and ‘mental health passports’ in the form of ring binder containing information about a patient’s circumstances and condition so they did not have to explain this every time they see a new clinician. These examples also clearly demonstrate how organisational sensitivity can meet systemic biases without necessarily higher financial burden.

Similarly our findings agree with previous US research that systems are also not sensitive enough to coordinate care for those children with multiple conditions under the care of more than one service (33). The concept of system sensitivities can be used as a framework to help find solutions that can apply to both US and UK settings.

A limitation of the current study is that only views of hospital staff were elicited. Future studies investigating patient and caregiver perspectives on barriers to accessing care are recommended.

CONCLUSION

Whilst some of the findings of this study of children's hospitals in the UK are stark, they mirror findings from research across US settings. Successful interventions and recommendations from the English system are therefore transferrable to other health care systems.

Decision makers, clinicians and staff at all levels in both systems are urged to consider the accessibility of their services in terms of economic barriers and system accessibility recognizing that inequalities and barriers are intersectional. Hospitals should have a clear universal offer, addressing the socioeconomic determinants of heath. This should be consistent across all specialties in their hospital, with advertising to patients and staff alike.

For meaningful difference a focus on 'system sensitivities' is required to overcome health inequities. However, for real change, policy steer should come from the national level, thus eradicating place-based inequities in access to care.

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