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Obstacles to use of patient expertise to improve care: a co-produced longitudinal study of the experiences of young people with sickle cell disease in non-specialist hospital settings

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ABSTRACT

Involving young people in their own healthcare is a global priority, yet we know little about how this might work in practice. In this paper, co-produced between academic researchers and people with lived experiences of sickle cell and its treatment, we examine how young people with sickle cell disease attempt to use their expertise in their own condition during emergency hospital admissions and through encounters with healthcare workers who are not sickle cell specialists. Our qualitative longitudinal research in England examined young people's experiences of hospital encounters via repeat and one-off interviews. We show that young people's expertise is sometimes undermined, including not being taken seriously when they report pain. They face barriers to care in non-specialist wards, particularly when they are alone with nobody to advocate for them. Although healthcare services use rhetoric that encourages young people to take control of their health and act as patient experts, in practice young people's expertise is routinely ignored. To improve health service quality, and meet the needs of young people, young people's own expertise must be better supported in routine interactions with healthcare providers.

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Young people; sickle cell; co-production; patient involvement; patient-centred care

Introduction

Ensuring that patients are active parties in effective healthcare service delivery is a priority worldwide (Lavery et al., 2010; MacQueen et al., 2015; Robert & Cornwell, 2013). Yet we know surprisingly little about how such processes do or do not work in practice, particularly for young people. In this paper, we explore patient and clinician encounters in emergency healthcare settings and during unplanned admissions to non-specialist wards. The ways in which services engage with patients at the 'micro' level of the healthcare encounter can help illuminate broader aspects of patient-clinician interaction that can be applied in healthcare service improvement more generally.

Measures of patient experience are increasingly valued in policy and research (Department of Health [DoH], 2008; Institute of Medicine, 2001; World Health Organization [WHO], 2015). Patient and public involvement (PPI) initiatives often try to amplify patient voices in healthcare settings (for example in the UK, NHS Shared Decision Making, 2017; National Institute for Health and Care Excellence [NICE], 2016), including through co-production, in which patients and the public work with healthcare providers to improve services (Renedo et al., 2017). Achieving and sustaining

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healthcare co-production is of interest to healthcare policy makers, clinicians and researchers (Gruen et al., 2008; Lennox, Maher, & Reed, 2018), and has the potential to generate 'meaningful ways of shaping and taking part in health care' (Filipe et al., 2017, p. 2). This might take the form of shared decision making with patients (NHS, 2017), or developing patient-centred services in hospitals and clinics (Robert et al., 2015).

Young people with long-term health conditions in the UK and elsewhere are – nominally at least – encouraged to act as 'patient experts', utilising their patient expertise in healthcare settings, for example by involving themselves in decisions about their care and taking individual responsibility for self-management of their condition (Department of Health and Department for Education and Skills [DoH/DfE], 2006; Kane & Bibby, 2018; Sawyer et al., 2012; WHO, 2017). National and international expert bodies have argued that patients with long-term conditions who are transitioning from child to adult services are particularly likely to benefit from engaging with their own care (DoH/DfE, 2006; Royal College of Physicians of Edinburgh [RCPE], 2008) because this is a time of increased medical vulnerability (Wijlaars et al., 2018). Their participation is also important to ensure that healthcare decision-making and policies take young people's voices into account and are more responsive to the needs of young people (WHO, 2017). However, we lack understanding of how this involvement happens in practice. Our research aims to address this gap.

We conducted a qualitative research project, 'This Sickle Cell Life', to explore the experiences of young people with sickle cell disease, one of the most common severe monogenic disorders worldwide (Rees et al., 2010). Sickle cell disease is characterised by chronic pain in any part of the body, with a third of people with the condition reporting pain nearly every day and over half reporting pain for more than half of the time (Dyson et al., 2010; Smith et al., 2008). Blood vessels of individuals with sickle cell disease can become blocked, causing severe pain that can last up to seven days (NHS, 2018). When a person with sickle cell disease experiences these acute painful episodes (also known as pain crises), they must receive emergency treatment to avoid severe injury or death (NICE, 2012). During treatment, the effectiveness of their pain relief must be reassessed every 30 minutes until the patient has reported that it has worked, and for at least four hours afterwards (NICE, 2012). Careful monitoring during treatment is essential; inadequate monitoring of respiration after opioids are given for pain can lead to death, as evidenced by the 2008 Report of the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) (Lucas et al., 2008). NICE guidelines (2012) state that healthcare providers should treat patients who are having an acute pain crisis as experts in their own condition, and should take into account patients' own views and preferences. Sickle cell disease is an excellent example of a condition for which it is not only desirable but essential that patients and clinicians work together to achieve optimum health outcomes. Encouraging young people with sickle cell to become experts in self-management, however, is not enough – individuals also need an environment (including healthcare staff) that facilitates their involvement (Sickle Cell Society, 2018). This is particularly important given the labour that is often tied up in performing an expert patient identity in contexts where there are multiple barriers to having one's voice heard (Campbell et al., 2010; Greenhalgh, 2009).

Sickle cell care in the UK has historically been 'racialized' (Dyson, 1998, p. 124; see also Bediako & Moffitt, 2011; Pletcher et al., 2008), with patients – who are usually from Black and minority ethnic groups – experiencing limited health services compared with patients living with 'disorders such as cystic fibrosis, which primarily affects people of Northern European descent' (Dyson, 1998, p. 124). Research has also shown that in the US, and to an extent in the UK, sickle cell patients perceive a lack of respect on the part of health providers, which can lead to a breakdown of trust (Elander et al., 2011). In the UK, specialist sickle cell care for children and young people has improved in recent years (Chakravorty et al., 2018), with new non-emergency children's day centres, tailored care for young people moving between specialist paediatric and adult services, establishment of an NHS specialist commissioning group for sickle cell and thalassaemia, and development of NICE guidance (2018) and Sickle Cell Society standards (2018) for care. In non-specialist services such as hospital accident and emergency departments, however, there can still be a lack of understanding about sickle cell disease (Sickle Cell Society, 2018).

This paper explores how patient expertise and patient involvement in their own care works in practice for young people with sickle cell disease. We examine young people's experiences of negotiating care during emergency hospital attendance and unplanned admissions onto non-specialist wards in England. We focus on how expertise is articulated by young people with sickle cell, and the ways in which their interactions with non-specialist healthcare professionals affect how and whether their voices are heard and acted upon. This article contributes to critical public health analyses of the 'expert patient' as experienced by patients themselves.

Methods

Our research project *This Sickle Cell Life* developed from conversations that took place between researchers and sickle cell service users and carers during an earlier quality improvement project involving co-authors CA, PO and NW. Our research questions were co-produced between academic researchers and patient experts in sickle cell disease (defined as people living with or caring for others with sickle cell disease) and paediatricians and haematologists specialising in sickle cell. The study was approved by the London School of Hygiene & Tropical Medicine Observational Research Ethics Committee (Ref 10107) and NHS research ethics committee (REC 15/LO/1135).

We used a longitudinal qualitative study design. Data collection involved interviews with 48 young people with sickle cell disease: 30 young women and 18 young men, aged 13 to 21. We conducted 80 individual interviews in total, made up of 27 one-off interviews (17 with 19–21 year-olds, and 10 with 13–18 year-olds), and 53 repeated interviews, over a period of approximately 18 months. Repeat interviews were used to capture the changing nature of the illness experience and evolving nature of the sickle cell condition, and interactions with healthcare services. We recruited participants via multiple hospital trusts and from the wider community via our network of contacts with patient advocates. AR, a university researcher not employed by any health services or recruitment sites, conducted all interviews. We conducted interviews at a location of the participants' choice, most often their homes but sometimes in healthcare settings. We checked participant wellbeing throughout interviews, offering breaks and opportunities to continue the interview at a different time if they felt tired. We took a holistic approach to questioning, asking participants about their healthcare encounters as well as broader aspects of their lives including education, relationships, and life at home and work. Interviews were 60–90 minutes long and audio-recorded and then transcribed. Participants (16–21 year-olds) and parents/carers of 13–15 year-olds gave informed consent to participate, and 13–15 year-olds additionally gave their informed assent. We gave participants referral information to sickle cell patient groups and young people's services for support on issues raised, as well as high street gift vouchers to compensate them for their time. To protect anonymity, we use participant age range not exact age and identify individuals only using a number-letter organising system.

We analysed the interviews using inductive and iterative techniques, using practical steps from Grounded Theory (Charmaz, 2006). Specifically, we developed our coding frame inductively from the entire data set and refined it further alongside data collection. We refined analytical categories during repeated rounds of coding, re-coding and 'memo-writing' (Charmaz, 2006). Reflexivity was an important part of the fieldwork, and AR considered how her identity as a white, adult academic researcher without sickle cell disease influenced the interview dynamic. She explained to participants that she was a researcher independent of their healthcare services. Taking fieldnotes after interviews, and reflective analytical sessions with service user representatives involved in the project in which we critically discussed emerging themes at different stages of our analysis, helped us examine the data reflexively.

This paper emerged as a result of intensive reflective analytical discussions between academic researchers (authors AR, SM, CM), individuals who had experienced sickle cell healthcare as young people (authors CA and NW) and a carer of a young person with sickle cell (author PO). This collaborative approach aimed to minimise barriers between scientific and lay expertise (following

Dyson, 2019) and ensure research outcomes were applicable and transferable to real-life sickle cell health services. During the discussions it became clear that our process was yielding important insights and would, if we were all academic researchers, naturally end in ‘writing together’ and so we decided to work together as a group on this article. We have also involved patients in co-producing other aspects of this research project, including project conception, designing data collection tools, and translating findings into practice (see Miles et al., 2018).

Findings

Young people repeatedly described having their expertise disregarded. We present these accounts here, then explore features of healthcare interactions that exacerbated these problems.

Young people’s patient expertise: highly developed, often disregarded

Young people growing up with sickle cell disease develop in-depth, personalised knowledge about their bodies, about the limits of their bodies, and knowledge about which specific therapeutic or clinical practices and medications work for their individual bodies. For example, participants told us that they knew which pain relief medication to take – and what would be ineffective – depending on the stage of their crisis or type of pain, and about regulating how much pain relief they took to ensure stronger pain relief would work when needed. They described being aware of their bodily limits, and of practices that were good or bad for their condition. They often mentioned knowing the risks to their health, and talked about listening to their body and needing to act promptly to avoid or address a pain crisis. They articulated extensive awareness and monitoring of their own condition.

Participants described incidents of having their expertise questioned or disregarded during healthcare encounters. Participants told us that they had protested to non-specialist healthcare staff that particular medication was not effective, but that the staff had administered it, or staff had inserted cannulas in places where our participants had already tried to explain it would not work or would cause pain.

The doctors that I’ve experienced [in A&E] do not help. Because I had – it wasn’t a crisis, but I had a weird pain here, and so when we went they gave me Naproxen, which is just a different form of ibuprofen. And even though I said ibuprofen doesn’t work, that’s what they gave me, and they told us to go home. (A6, f, 16–18 years old)

If they [ward staff] were looking for a vein but they couldn’t find one and I was telling them where the veins were and they weren’t really listening [...] My veins collapse a bit and like when they look for one they can’t find one but like I know where they all are, so then I’ll be trying to tell them where it is and they weren’t really listening and they’ll just be, like, moving my arm around a lot and it would hurt. (A1, f, 13–15 years old)

Participants often reported having experienced delays in receiving urgently-needed pain relief during acute pain episodes. They told us for instance that their reports about their pain were questioned or undermined, or that they were made to wait for long periods before receiving medication.

The nurses are different on each ward. So it depends on the nurse itself, they’re gonna be mean or kind. So you just don’t know what you’re going to get when you’re on [...] Sometimes you’re just calling out in pain and you know you need your medication but no one’s coming. And it’s like your pulse is going up and no one’s here [...] sometimes they’re, they’ll take their time coming [ward nurses] to get to you[...] I feel sad ‘cause sometimes it upsets me, like I feel like I’m neglected. [O3, f, 19–21 years old]

She’s supposed to be giving me pain relief every two hours, she’s ignoring me for half the day. I keep on asking her, you know, can I have my tablets now? She’s like OK, I’m getting them, and then an hour later I still can’t find her (I6, m, 19–21 years old)

Participants reported knowing when they needed medication but feeling ‘ignored’ and judged when requesting it (O3). They told us that they anticipated these types of negative experiences, and because of that, they resisted going to hospital, trying to delay hospital admission or avoid it altogether, even when they knew they needed treatment (A5).

One of the main things is the kind of, the attitude that some of the staff have and, erm, I feel like I'm not listened to [...] And they just ignore me. And I'm not sure if it's like, if it's actually like that or if I'm kind of just imagining it but, erm, but it does affect my mood still [A5, f, 16–18]

Participants told us of times when they asked staff for assistance and were not attended in a timely way:

You'd press it, and like she wouldn't come, and like you'd always keep pressing it. You could hear it ringing in the nurses' station, but no nurse would, you know, come to, to me to see like if there's anything wrong or anything. So you know, you'd be just waiting and waiting. And at that time, I think I needed the toilet or something, because I couldn't walk, so I needed someone to take me there. But no one would come, so I had to wait for like half an hour or so to just, until they decided to come. [Z1, f, 16–18 years old]

Older participants articulated more explicitly than younger ones how they realised that they were not seen as sufficiently knowledgeable about their own condition:

They're [staff] always patronising. And they think I don't know what's best for me [...] they can't just do whatever, they have to know how I feel, about what I'm feeling [U3, m, 16–18 years old]

One participant explained how his accounts of feeling unwell and requests to stay longer in hospital were not taken seriously and he was released, only to then have to be re-admitted to hospital the next day. Another participant told us how she struggled to convince the nurse to keep her in the hospital, and finally succeeded, to discover the next day that she had a chest infection.

Invisibility limiting involvement

The invisibility of symptoms and lack of knowledge of sickle cell disease among non-specialist staff appear to have made it harder for participants to make themselves heard when they tried to negotiate good care. Participants told us they were used to being in pain, and they practised techniques such as breathing exercises to calm down and stay in control. Participants also reported keeping pain to themselves in their everyday lives, by hiding and controlling it – often to try to protect onlookers from becoming alarmed. As a result, even when they were in severe pain they said they often did not exhibit the types of signs of pain that others might typically expect. They said that they thought staff judged whether or not their complaints about pain were valid based on whether they *looked* as if they were in pain, regardless of their reports of *being* in pain.

People think that I can, if I'm laughing and I'm fine, if my [family] come to see me then I'm fine, then they'll just think, ah you're fine, and they won't give me my medication on time [...] Like the nurses, the nurses all think because I'm laughing they'll think that my pain score is like five or three [O1, f, 13–15 years old]

Some participants mentioned how staff would judge their needs based on their limited experience of a small number of previous sickle cell patients or of other conditions where pain was part of the illness experience, as opposed to listening to the individual and considering their report of pain on its own merits.

They'd [staff in the ward where she reported being ignored] only had one other sickle cell patient before me. I'm not sure how they handled her, but they didn't handle that well with me, it was very bad [...] that's what they kept referring to when they were partially ignoring me, they'd just tell me: 'we've had someone else with sickle cell before', and that was sort of the end of the discussion. Because they, whatever they did, they figured it worked with this other person, but it didn't work with me [...] it [sickle cell] varies from one person to the next. [Z2, f, 19–21 years old]

As much as I was saying that it's really hurting it's like they couldn't really see it in my face. And I don't really know why they didn't think to do the blood test earlier but when they did it, it was like my haemoglobin was so low and then like they called me back. (U9, m, 19–21 years old)

The lack of visibility of physiological indicators also acted to override participants' personal accounts. Participant I9, for example, talked about attending A&E when unwell and feeling that A&E staff were undermining her and denying her account of her own symptoms by insisting on conducting multiple tests to try to find biomedical evidence of her illness experience:

You don't want to feel like they're judging you [A&E staff] and you're kind of like overreacting and you're just being silly and you're wasting their time [...] [they] check your heart, they check your blood, they check like stuff [...] and your haemoglobin may not be low at that point, [...], they check things that don't really affect your situation. So if I'm feeling pain and my haemoglobin isn't low [...] oh you're fine, and send you home [...] it would be nicer if they, like, asked you, how are you? You know, how are you feeling? What do you think could be the cause, what's going on with you? As opposed to, yeah, your haemoglobin's fine, your heart rate's fine, your oxygen's fine, get out. You know? 'Cause then you kind of feel like you don't even know how to take care of your, yourself. You kind of go, like, you're not looking at the right signs, feel like you're wasting their time (I9, f, 19–21 years old)

Participants described how their difficulties in making their voices heard were also compounded when they felt ill, or were under the effects of medication, or when they were unaccompanied by relatives. Many emphasised the importance of having adult relatives with them to advocate for them and to give information to staff (e.g. about medication reactions or allergies).

[I had] this arterial line but it was in my groin and they attached it with stitches, but then a doctor ripped it out without cutting the stitches off and it was bleeding, it was terrible [...] He was trying to take the arterial line out and the nurse said, you need to take the stitches out. But because I was so, so disorientated I was so out of it because I was in pain, and I was sick, I didn't know what was going on. [...] it was crazy. (E1, f, 19–21 years old)

Some participants said that their specialist consultants, who knew their sickle cell history, played an important role as expert advocates. They told us how consultants had had to step in during ward visits to explain their needs to staff and demand specific care for them, even in one case insisting they were moved to another ward to receive better care.

Discussion: implications of findings and recommendations for navigating barriers to patient expertise

Many young people with sickle cell disease are able to call on their extensive expertise in their own condition and body, often bolstered by diligent self-monitoring and self-disciplining with respect to their health as they transition to adulthood (Renedo et al., 2019). As we have shown, however, their status as 'patient experts' – experts in their condition and in their bodies – may well be disregarded altogether in the non-specialist hospital setting. Young people's voices are less heard than those of adults in healthcare in general (Children and Young People's Health Outcomes Forum, 2013, 2015), and in the case of sickle cell disease there may also be a dimension of racism to their voices and experiences being dismissed (Dyson et al., 2011, p. 414; see also Bediako & Moffitt, 2011; Pletcher et al., 2008; Rouse, 2009). While UK government and NHS policy suggests that young people should act as experts in their own health care (DoH, 2011; NHS, 2017), we have shown that in practice this expertise is discounted even in the contexts where it is most essential, and that this failure of healthcare staff to work together with patients prevents young people from successfully asserting their right to quality care.

Planned hospital admissions to a blood disorders ward involve specialist staff with specific experience of treating sickle cell disease. In non-scheduled or emergency care wards, on the other hand, clinicians are rarely sickle cell specialists and may have limited or no experience of treating patients with sickle cell (see for example STCAPP, 2018). Sickle cell affects different people in different ways, and so it can be difficult for non-specialist clinicians to make generalisations about different cases. What our participants chose to tell us may have been affected by

how they perceived us due to our different backgrounds (see methods section) but participants nevertheless asserted their patient expertise in interviews, and their experiences resonated with our co-authors' experiences. Those of us with sickle cell (authors CA and NW) or with experience of caring for someone with sickle cell (author PO) have repeatedly encountered non-specialist healthcare staff who assume there is a one-size-fits-all approach to care for sickle cell crisis, sometimes seemingly overriding our experience-based expertise and instead generalising from their encounters with a small number of other sickle cell patients. Listening to the patient is essential when their history and experiences can help clinicians tailor care more effectively. The scepticism of some staff – whether communicated directly or expressed more obliquely by, for instance, delaying clinical assessment or treatment – is doubly debilitating for the young person in question already navigating their chronic health condition.

Our participants' reports of their expertise being overruled by non-specialist healthcare staff in acute care settings reflect Ciribassi and Patil (2016), who argue that sickle cell disease is a condition that is ignored or 'rendered invisible' (137) within healthcare settings disempowering patients in the process. Our findings also support the contention by Elander et al. (2011) that a lack of respect for the patient from the health provider inhibits relationships of trust. Those of us with sickle cell (CA; NW) have experienced these barriers. We are experts in our own bodies and know not only when a sickle cell crisis is imminent, but also when related health complications are developing. Having our patient expertise disregarded is a frustrating experience outside non-specialist hospital acute care. As Ciribassi and Patil (2016) have found, biomedical indicators often appear to carry more weight in the healthcare encounter than our own patient expert voice and symptom testimonials. Having to struggle to be heard removes the patient's ability to act as a 'knowledge broker' (Hargadon, 2002), with insight into their own bodies and how sickle cell affects them. Many patients in our study expressed frustration at not feeling listened to by healthcare workers.

The culture of disbelief circulating around young people presenting with sickle cell pain can extend beyond the patients to their advocates too. O'Hara et al. (2018, p. 1) argue that in emergency care, 'in the absence of access to records, *patients or their carers can become the main source of safety critical information for staff* about medical history, treatment regimens and medication' (emphasis added). Yet in reality this safety-critical information may not be requested by clinical staff, and if it is offered by a friend or family member, it is not always addressed. In other words, advocates may be heard but not listened to. O'Hara et al. (2018, p. 1) point out that in the context of healthcare quality involvement work, 'the reality of involving patients and families is that both preferences and opportunities for involvement are situated within a complex, dynamic healthcare system'. In an emergency care department, a young person admitted with an acute sickle cell crisis or pain episode may face multiple barriers to receiving good care, from ambivalence or reluctance of healthcare workers about accepting the expert status of the young patient, to delays in being seen and delays in receiving pain relief. There is a tension between being encouraged to act as an expert in one's own condition whilst simultaneously having to navigate institutional and personal barriers to care when trying to voice that expertise. It is not enough to empower young people to assert their voice if the wider environment does not enable them to do so.

Carers might find themselves struggling to be heard when they advocate for patients. For example, one of us (PO) made the conscious decision to equip his son with the skills to advocate for himself in a hospital setting, including encouraging his son to communicate with clinicians in ways that ensured he would come across as cooperative rather than adversarial, even when in extreme pain. PO had found from his own experience of advocating for his son that these types of 'diplomacy' skills were crucial in order to be heard by healthcare workers and to attempt to overcome the type of barriers that numerous participants articulated in this research project. We suggest that this diplomacy work is necessary not just for the young sickle cell patient to be heard by clinicians but also to build several sets of relationships to protect health with: (i) emergency healthcare staff; (ii) with clinicians; and (iii) an ongoing relationship.

Skills building is recognised as part of the process of transition from paediatric to adult care across different areas of health (DoH, 2006). Learning diplomatic ways to communicate is not the type of skill that is emphasised in guidelines on translation, but, rightly or wrongly, may be crucial for young people to be able to navigate healthcare systems successfully and claim their right to quality care. The healthcare scenarios described by participants in this study mirror the experience of those of us with direct experience of sickle cell: to be taken seriously it is important not to be seen as a 'difficult patient' (Bergman & Diamond, 2013), for instance learning to avoid shouting 'too much' when in pain. However, not showing physical signs of pain, as we have shown, can lead to pain not being taken seriously and also result in delays in receiving timely pain relief, which in turn exacerbates pain. Another aspect of learning how to present oneself and one's condition in an 'appropriate' way in healthcare encounters is coming to realise that introducing oneself with particular identity positions (for example, as working for the NHS) helps the patient to be taken more seriously. Young people who are unable to self-identify in this way, or who do not have the support of an advocate to guide their 'diplomacy training' through childhood, are likely to be further disadvantaged.

Patient workarounds to accommodate staff and conform to 'correct' ways of being should not ever be necessary; it is particularly alarming and disappointing that they should be required of patients who are in severe pain and their advocates in distress. Listening to young patients, particularly their reports about pain when they have a chronic condition characterised by pain crises, should be a priority for healthcare workers. More training is needed for non-specialist and emergency care staff if individuals with severe pain are to receive the care they are entitled to.

Our findings have implications for other long-term health conditions such as cancer and cystic fibrosis too. To what extent are young patients with other health conditions recognised as experts in their own health? How can young patients and staff work together for optimal care? Our findings particularly apply in scenarios where patients are less heard – because of their minority identity, their health condition (whether sickle cell or other 'invisible' (cf. Ciribassi & Patil, 2016) or marginalised conditions), their young age, or their anxiety asserting themselves in intimidating 'expert' environments or unfamiliar healthcare settings (e.g. in unscheduled hospital care).

There are also implications from this research for patient and public involvement (PPI) initiatives and the extent to which patient expertise is valued in a range of health environments where the patient ostensibly has a 'right to quality care and decisions about treatment' (NHS, 2017, n.pag). If the micro-encounters we have explored in this article disempower young people, then their participation in larger PPI practices that try to improve services will likely also be compromised. Our study highlights a clear tension between, on the one hand, referring to patients as experts and asking them to behave as such – for example, in 'top-level' healthcare policy or in the PPI strategies for a hospital trust – and on the other hand, what happens in practice when their expertise is questioned during treatment. Young people may be prevented from becoming involved at all when they encounter these barriers, compounding instances when their voices are less accessed in participatory spaces (Renedo & Marston, 2015; see also Cavet & Sloper, 2004).

Despite a stated mission to put patient expertise at the front and centre of healthcare services in the UK (NHS, 2015), routinised underestimation of patient expertise remains widespread in young people's non-specialist healthcare settings, echoing findings from sickle cell research from more than two decades ago (see for example Midence & Elander, 1994; Waters & Thomas, 1995). Whilst patient/public involvement is rarely straightforward (Cooke & Kothari, 2002; Renedo & Marston, 2015; Reynolds & Sariola, 2018), listening to the lived experiences of those who are living with a health condition can improve clinical expertise. If young people are to influence health service improvement and assert their right to quality care, patient expertise must be better recognised in healthcare environments and supported 'on the ground' in healthcare encounters. For excellent outcomes, providers must recognise patient expertise and work with patients and carers to improve care.

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References

- Bediako, S. M., & Moffitt, K. R. (2011). Race and social attitudes about sickle cell disease. *Ethnicity & Health, 16*(4–5), 423–429.
- Bergman, E. J., & Diamond, N. J. (2013). Sickle cell disease and the “difficult patient” conundrum. *The American Journal of Bioethics, 13*(4), 3–10.
- Campbell, A. D., Ross, P. T., Kumagai, A. K., Christner, J. G., & Lypson, M. L. (2010). Coming of age with sickle cell disease and the role of patient as teacher. *Journal of the National Medical Association, 102*(11), 1073–1078.
- Cavet, J., & Sloper, P. (2004). The participation of children and young people in decisions about UK service development. *Child: Care, Health & Development, 30*(6), 613–621.
- Chakravorty, S., Tallett, A., Witwicki, C., Hay, H., Mkandawire, C., Ogundipe, A., ... Warner, J. (2018). Patient-reported experience measure in sickle cell disease. *Archives of Disease in Childhood, 103*(12), 1104–1109.
- Charmaz, K. (2006). *Constructing grounded theory*. London: Sage.
- Children and Young People’s Health Outcomes Forum. (2015). Children and young people’s health outcomes forum report. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/410482/CYPHOF_Report_2014-15.pdf.
- Children and Young People’s Health Outcomes Forum: A system wide response. (2013). Department of health. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/214928/9328-TSO-2900598-DH-SystemWideResponse.pdf
- Ciribassi, R. M., & Patil, C. (2016). “We don’t wear it on our sleeve”: Sickle cell disease and the (in)visible body in parts. *Social Science and Medicine, 148*(2016), 131–138.
- Cooke, B., & Kothari, U. (2002). *Participation, the new tyranny?* London: Zed Books.
- Department of Health. (2008). High quality care for all: NHS next stage review final report. Retrieved from www.gov.uk/government/uploads/system/uploads/attachment_data/file/228836/7432.pdf.
- Department of Health. (2011). Quality criteria for young people friendly health services. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216350/dh_127632.pdf
- Department of Health and Department for Education and Skills. (2006). Transition: Getting it right for young people. Retrieved from https://webarchive.nationalarchives.gov.uk/20130123205838/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132145
- Dyson, S., Abuateya, H., Atkin, K., Culley, L., Dyson, S. E., & Rowley, D. (2010). Reported school experiences of young people living with sickle cell disorder in England. *British Educational Research Journal, 36*(1), 125–142.
- Dyson, S., Atkin, K., Culley, L., Dyson, S. E., & Evans, H. (2011). Sickle cell, habitual dys-positions and fragile dispositions: Young people with sickle cell at school. *Sociology of Health & Illness, 33*(3), 465–483.

- Dyson, S. M. (1998). 'Race', ethnicity and haemoglobin disorders. *Social Science and Medicine*, 315(37), 121–131.
- Dyson, S. M. (2019). *Sickle cell and the social sciences: Health racism and disablement*. London: Routledge.
- Elander, J., Beach, M. C., & Haywood, J. C. (2011). Respect, trust, and the management of sickle cell disease pain in hospital: Comparative analysis of concern-raising behaviors, preliminary model, and agenda for international collaborative research to inform practice. *Ethnicity & Health*, 16(4–5), 405–421.
- Filipe, A., Renedo, A., & Marston, C. (2017). The co-production of what? Knowledge, values, and social relations in health care. *PLOS Biology*, 15(5), e2001403.
- Greenhalgh, T. (2009). Patient and public involvement in chronic illness: Beyond the expert patient. *BMJ*, 338. doi:10.1136/bmj.b49
- Gruen, R. L., Elliott, J. H., Nolan, M. L., Lawton, P. D., Parkhill, A., & McLaren, C. J. (2008). Sustainability science: An integrated approach for health-programme planning. *Lancet*, 372(9649), 1579–1589.
- Hargadon, A. (2002). Brokering knowledge: Linking learning and innovation. *Research in Organizational Behaviour*, 24, 41–85.
- Institute of Medicine. 2001. *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academies Press. Retrieved from http://www.nationalacademies.org/hmd/~/_/media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf
- Kane, M., & Bibby, J. (2018). Listening to our future: Early findings from the Health Foundation's Young people's future health inquiry. Retrieved from: <https://www.health.org.uk/sites/default/files/Listening%20to%20our%20future.pdf>
- Lavery, J. V., Tinadana, P. O., Scott, T. W., Harrington, L. C., Ramsey, J. M., Ytuarte-Núñez, C., & James, A. A. (2010). Towards a framework for community engagement in global health research. *Trends in Parasitology*, 26(6), 279–283.
- Lennox, L., Maher, L., & Reed, J. (2018). Navigating the sustainability landscape: A systematic review of sustainability approaches in healthcare. *Implementation Science*, 13(27). <https://implementationscience.biomedcentral.com/articles/10.1186/s13012-017-0707-4>
- Lucas, S., Mason, D., Mason, M., & Weyman, D. (2008). *A sickle crisis? Report of the national confidential enquiry into patient outcome and death*. London: NCEPOD. Retrieved from http://www.ncepod.org.uk/2008report1/Downloads/Sickle_report.pdfMacQueen
- MacQueen, K., Bhan, A., Frohlich, J., Holzer, J., & Sugarman, J. (2015). Evaluating community engagement in global health research: The need for metrics. *BMC Medical Ethics*, 16(44), 1–9.
- Midence, K., & Elander, J. (1994). *Sickle cell disease: A psychological approach*. Oxford: Radcliff.
- Miles, S., Renedo, A., & Marston, C. (2018). 'Slow co-production' for deeper patient involvement in health care. *The Journal of Health Design*, 3(1), 57–62.
- NHS. (2017). Shared decision making. Retrieved from <https://www.england.nhs.uk/shared-decision-making/>
- NHS. (2018). Sickle cell disease. Retrieved from <https://www.nhs.uk/conditions/sickle-cell-disease/>
- NHS Five Year Forward View. (2015). NHS England. Retrieved from <https://www.england.nhs.uk/publication/nhs-five-year-forward-view/>
- NICE (National Institute for Health and Care Excellence). (2016). Transition from children's to adults' services for young people using health or social care services. Retrieved from www.nice.org.uk/guidance/ng43
- NICE (National Institute for Health and Clinical Excellence). (2012) Sickle cell disease: Managing acute painful episodes in hospital. Retrieved from <https://www.nice.org.uk/guidance/CG143>
- O'Hara, J., Aase, K., & Waring, J. (2018). Scaffolding our systems? Patients and families 'reaching in' as a source of healthcare resilience. *BMJ Quality & Safety*. doi:10.1136/bmjqs-2018-008216
- Pletcher, M. J., Kertesz, S. G., Kohn, M. A., & Gonzales, R. (2008). Trends in opioid prescribing by race/ethnicity for patients seeking care in US emergency departments. *JAMA*, 299(1), 70–78.
- RCPE (Royal College of Physicians of Edinburgh). (2008). Think transition: Developing the essential link between paediatric and adult care. Retrieved from <http://www.rcpe.ac.uk/clinical-standards/documents/transition.pdf>
- Rees, D. C., Williams, T. N., & Gladwin, M. T. (2010). Sickle-cell disease. *Lancet*, 376(9757), 2018–2031.
- Renedo, A., Komporozos-Athanasiou, A., & Marston, C. (2017). Experience as evidence: The dialogic construction of health professional knowledge through patient involvement. *Sociology*, 52(4), 778–795.
- Renedo, A., & Marston, C. (2015). Spaces for citizen involvement in healthcare: An ethnographic study. *Sociology*, 49(3), 488–504.
- Renedo, A., Miles, S., & Marston, C. (2019). 'Transitions to adulthood: Self-governance and disciplining in the making of patient citizens. *Sociology of Health and Illness*. forthcoming.
- Reynolds, L., & Sariola, S. (2018). The ethics and politics of community engagement in global health research. *Critical Public Health*, 28(3), 257–268.
- Robert, G., & Cornwell, J. (2013). Rethinking the policy approaches to measuring and improving patient experience. *Journal of Health Services Research & Policy*, 18(2), 67–69.
- Robert, G., Cornwell, J., Locock, L., Purushotham, A., Sturme, G., & Gager, M. (2015). Patients and staff as codesigners of healthcare services. *BMJ*, 350, g7714–g7714. <https://www.bmj.com/content/350/bmj.g7714>
- Rouse, C. M. (2009). *Uncertain suffering: Racial health care disparities and sickle cell disease*. Oakland, CA: University of California Press.

- Sawyer, S. M., Affi, R. A., Bearinger, L. H., Blakemore, S. J., Dick, B., Ezeh, A. C., & Patton, G. C. (2012). Adolescence: A foundation for future health. *Lancet*, 379(9826), 1630–1640.
- Sickle Cell Society. (2018). *Standards for the clinical care of adults with sickle cell disease in the UK*, 2nd ed. Retrieved from <https://www.sicklecellsociety.org/sicklecellstandards/>
- Smith, W. R., Penberthy, L. T., Bovbjerg, V. E., McClish, D. K., Roberts, J. D., Dahman, B., ... Roseff, S. D. (2008). Daily assessment of pain in adults with sickle cell disease. *Annals of Internal Medicine*, 148(2), 94–101.
- STCAPPG. (2018). I'm in crisis: Sickle cell & thalassaemia all party parliamentary group report into the education of pre-registration nurses and midwives. Sickle cell society. Retrieved from <https://www.sicklecellsociety.org/im-in-crisis/>
- Waters, J., & Thomas, V. (1995). Pain from sickle-cell crisis. *Nursing Times*, 1(16), 29–31.
- Wijlaars, L., Hardelid, P., Guttman, A., & Gilbert, R. (2018). Emergency admissions and long-term conditions during transition from paediatric to adult care: A cross-sectional study using Hospital Episode Statistics data. *BMJ Open*, 8(6), e021015.
- World Health Organization. (2015). WHO recommendations on health promotion interventions for maternal and newborn health 2015. Retrieved from http://www.who.int/maternal_child_adolescent/documents/health-promotion-interventions/en/
- World Health Organization. (2017). Global accelerated action for the health of adolescents (AA-HA!): Guidance to support country implementation. Retrieved from https://www.who.int/maternal_child_adolescent/topics/adolescence/framework-accelerated-action/en/