



# The experiences of young people with sickle cell disease transitioning from paediatric to adult care

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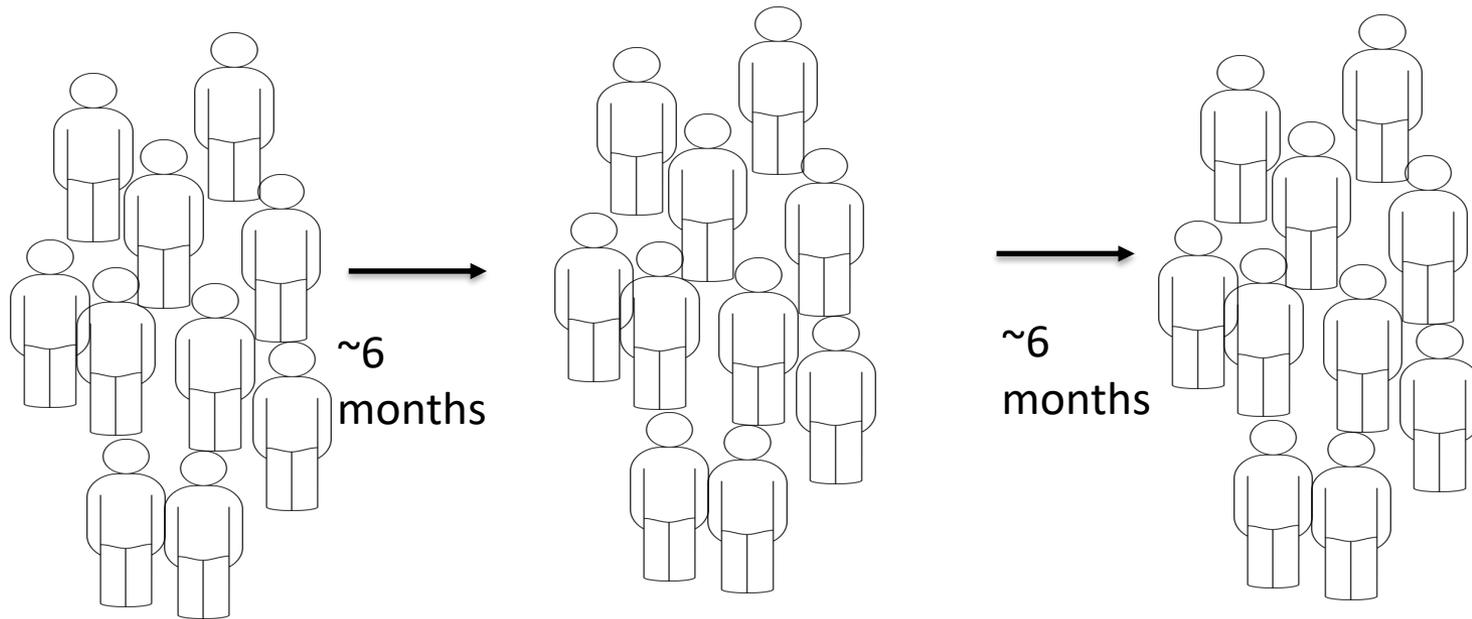
# Road map

- Research aims
- Methods
- Findings:
  1. Barriers experienced in non-specialist unscheduled hospital care
  2. Social silencing
  3. Identity development during transitions



# Repeated interviews

**Ages 13-18**

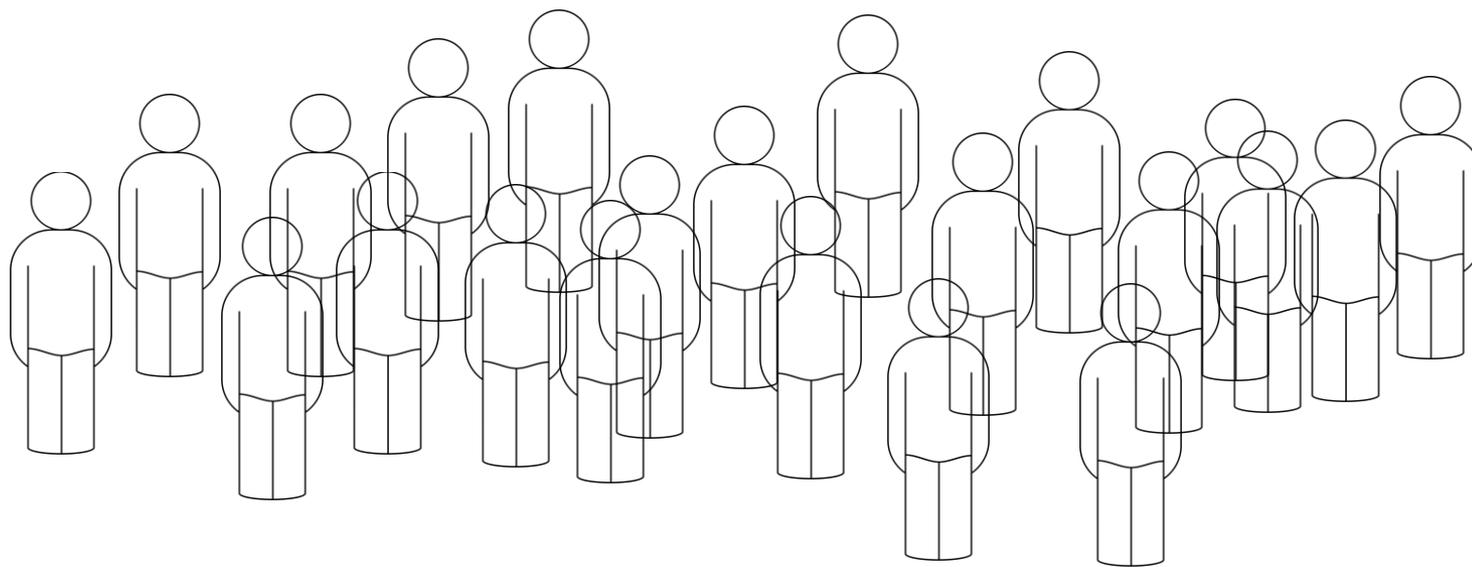


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# Single interviews

**Ages 19-21**



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# Holistic approach

- Focus on both lived experiences of transitioning between paediatric and adult healthcare services
- Broader aspects of their lives including other transitions to adulthood



# Findings

- Social aspects:
  - difficulties developing new/adult identities
  - social silencing
- Healthcare services:
  - young people did not report any issues to us about their transition from specialist paediatric to specialist adult services, but they encountered barriers in unscheduled non-specialist hospital care
  - barriers to mobilising patient expertise

# **Barriers experienced in non-specialist unscheduled hospital care**

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# Barriers to...

1. Receiving timely and adequate pain relief
  2. Having requests for basic bodily care needs met
  3. Mobilising their patient expertise
- Moving from the children to the adult ward was challenging
  - Participants wanted to avoid being admitted to hospital as much as possible

# Transitional tactic; resorting to oneself

- Transitioning involves a realisation that one cannot always count on non-specialist staff:
  - they lack knowledge of SCD
  - they do not take the young people's voice and patient expertise seriously
  - they will not always respond to my care needs, allow my involvement in decisions about my care
- The tactics used to avoid this:
  - Self-reliance
  - Accessing unscheduled care only as a last resort

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# Pain management

- Requests of pain relief were not given a sense of urgency:
  - feeling “ignored” and “abandoned”
- They felt judged and misunderstood by staff in relation to their pain experience
  - staff questioning or disregarding their claims about pain
  - not letting them be involved in decisions about how to manage pain
- They thought staff would judge their pain relief needs based on how they looked



*It was a bad experience really [being in the ward] [...] The doctors just didn't really believe, not believe but **they thought I was like faking or like doing it to get medication [analgesia] as if I like was addicted to medication and nurses, but I can be laughing but still in pain** and that's what people need to understand, like nurses and doctors and even people in general, that I can be in pain, anyone can be in pain and like still be laughing because we know how to, people, like kids or, you know, **kids know how to deal with the pain and we just try to distract ourselves** as much cos it's not the same pain as everyone gets  
(O1 13-15 years old)*

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# Pain management

- Participants explained that they did not visually present signs of pain because they had learned how to control the expression of pain in the eyes of others.

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# Body management and basic care needs

- Participants also felt not listened to and not involved in decisions about how to manage their bodies
- They shared their dissatisfaction with how cannulas were inserted in their bodies;
  - often too abruptly and with insistence/repeatedly
  - in areas they had reported they knew through past experience would not work

*At the [children ward] they put the needle erm here, then the vein collapsed and then they started going here. Erm at [adult ward] they went back to here [the one that collapsed] and the first few times **I told them that it's not gonna work** and it was like **they weren't listening** to me. But then erm it's like, I would tell them it's not going to work but they would just be, they would still try and do it, they was, oh it might work, it doesn't matter, let me try it. And erm then it would fail, so **it felt like they were putting a needle in for no reason**. But it felt like **they weren't listening at first**, and then they knew to go here cos I kept on telling them (U5 19-21 years old)*

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# Body management and basic care needs

- Being 'stabbed'
- The consequences of not being listened to and staff being too "rough";
  - scars, heavy bleeds and pain

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# Body management and basic care needs

- Barriers encountered when trying to overcome lack of bodily autonomy and mobility
  - being put on a bed far away from the toilet but being unable to walk properly
  - requests for help to go to the toilet or for a commode not being given a sense of urgency.

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*I needed that [commode] like every single because the, I had a drip. So then one of **the nurses were like, oh every time,[...]** every time you need the commode, commode, it's like, when **she was talking to the other nurse but I heard her[...]** She was saying, all the time this one needs a commode, commode.[...] **I felt really upset [...]** (U2 16-18 years old)*

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# Body management

- Being moved from ward to ward when in pain or having to wait for a hospital bed
- Often staff could not decide whether they should be in an adult or paediatric ward

*It's just sometimes, like, if I'm admitted, like, now, for, like, any reason, it's, like, a bit of a, it's like, really weird, because they're like, you should [be] on the [adult ward] because you're [16-18 years old], [...] **they're [doctors] always getting confused [...]** It's just, it's kind of **tiring**. Especially if, especially, like, if I'm, have to walk around, or, or if I had, like, if I'll be in a bed and I have to go somewhere different. So, it's just, sometimes it's just, like, a big fuss out of nothing.[...] So I've been moved from, I've been moved from a ward to another, and back again, then back to A&E, and then back to another ward, [...] Yeah, **they can't, they don't know where to, where I should be**. So, it's kind of like, here we go again.[...] And obviously I'll be, **there's no one going to be there to fight my corner**, because mum's not going to be there. And so, it'll be like explaining to them, like, no, this is what it is, this is what it is, like, honestly. Um, I guess, yeah. **So I want to try and, I want to try and stay, like, as healthy as I can**. That way I don't have to put myself in that, like, position. (E5 16-18 years old)*

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# Feeling out of place

- Participants saw the adult ward as a sick space
- Shocking first experiences in the adult ward
  - feeling “scared”
  - hearing patients scream and shout
- Feelings of loneliness and being bored

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Seeing someone which is pretty old and is just near you by a few steps and you say, “OK he has cancer so OK **it’s pretty sad this**” actually it’s really OK I don’t, I don’t find any other words, it’s pretty sad staying in the adult part because you see each people which is staying there like with er with a serious face like facing their phone or everything else for the whole [...] it’s like the **going from, from a happy and coloured [children] ward from a grey and sad ward.** [...] even if you listen to a child laughing it’s, it’s pretty good because actually you want to laugh too because it’s happy and then you’ll be, you’ll be happy as well. [...] you’re just staying in the room [in the adult ward] like in silence doing nothing and **thinking when you can go out or when you can go away from that room for yeah five minutes just to not think that the person next to you is going to die in about three days (U1 16-18 years old)**

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# Adult ward versus home space

- Home: the ideal space that would afford them the calmness needed for recovery
- A space they had more “control” over and where they felt more “independent” and “free” to manage pain
- At home they can have access to alternative pain management resources: hot water bottles, massage, hot bath
- Importance of having their family around checking up on them and just in case they needed help

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# Implications

- Their healthcare transitions involve learning to resort to themselves and individualise care to avoid unscheduled hospital care
- Resorting to oneself is labour-intensive. It requires efforts to:
  - self-manage pain crisis at home as long as they can, knowing this can pose a risk to their health
  - be vigilant of non-specialist hospital care
- Additional stress brought up by:
  - the lack of control over their treatment
  - the uncertainty of whether one's voice is going to be taken seriously

# Implications

- Participants talked about their extensive patient expertise in their own condition and body
- Yet their expertise is frequently marginalised or disregarded altogether in the non-specialist hospital setting
- It is also questioned in interaction with friends, or at school
- Our findings illustrate the barriers to developing positive patient expert identities;
  - identities that enable people to assert their right to quality care and to stake their patient expertise out



# **Social silencing**

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# Social silencing

- Not wanting to disclose and disclosing only to few close ones
  - Avoiding talking about sickle cell and management needs
  - Expectations that others will not know and will not understand what sickle cell disease is
  - Silencing also includes:
    - keeping the explanation short, asking friends to search in Google, explaining biomedical aspects but not the living experience
- Silencing has a protective function



*I feel like some **people don't even know about the condition.** They don't, they've never heard of it [...] I still have to explain it often. It kind of **gets irritating** [...] I usually would explain it, **just a quicker version** [...] I get pains quite often, and that's just a, it's just a quick way of saying it.*

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*There are times where **they [friends] don't really get it** because, when I get tired doing, well playing basketball, for example, they just think I'm really lazy but sometimes it's not that, it's just I have sickle cell [...] I often think, it's just they don't understand, erm, like **sometimes I can't be bothered to explain the whole thing.** Yeah, I've been doing a lot of explaining a lot during high school as well about my illness, **and then sometimes I can't be bothered** so I just don't tell them, **I just let them think that I'm lazy.***

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# Implications

- Social silencing can contribute to:
  - the creation of a ‘risk space’ for young people
  - portraying particular images of young people as lazy
- ‘Risk space’ :
  - a context that limits young people’s attempts to self-manage
  - where young people might not be able to talk about their needs and access help



# Identity development during transitions

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# Identity development during transitions

- Health transitions need new health knowledge and new behaviours to develop, but they also need development of self-perceptions and understandings of how a person should behave as an adult (rather than a child) patient
- Identities play an important role in shaping health practices
- Understanding identity development can help explain why some young people transition smoothly or less smoothly into healthy adulthood



# Difficulties reconciling competing adult identities

- Ideas about individual responsibility, self-management and healthy lifestyle within healthcare today act as a way to discipline young people “at a distance”, and influence their behaviour
- These healthcare self-management discourses intersect with demands from schools that are often not compatible
- These intersecting demands can translate into conflicting “self-disciplining” identities



# Conflicting self-disciplining identities

We found that transitions to adulthood involve:

- relentless self-disciplining and self-monitoring to try to be as healthy as possible
- while also aspiring to work hard so that they can develop and meet educational and career goals.

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*‘[...] usually, like I, I work **really hard** like, and I work **really fast** because a lot of the time in school I would be out for so long that I have to catch up. [...] If I like missed a few days I **don’t** want it to look like, like I'm not as useful to the team [at work].[...] it’s like the laziness thing, it’s like in my head maybe [...] sometimes I'll be **reluctant to take time off** [from work] or I'll try, or I'll just take painkillers and go rather than, erm, not going’*  
(U9, 19-21 years old )

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# Laziness

- Young people struggle to reconcile their disciplined patient self with their self-actualising/achiever self
- The tensions between both identities are played out in young people characterising themselves as being lazy
- Being tired and unproductive:
  - rarely talked about as linked to their illness, but instead as an attribute of someone being lazy
- Worried about others seeing them as lazy
- Pushing body limits to be productive

*'I'm **always feeling tired**. So like when I'm feeling tired I, I don't like, **I don't like doing nothing**, so sort of I'm like lying in bed or go sleep. But, being, **being in bed all day like it's not, it's like, it's just not, not, not good really**, it's just like, being tired all the time, lying in bed like, **you're not doing nothing, are ya?** It's like, **I wanna like try my best and not, like not get into bed**'*  
(O2, 16-18 years old)

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# Implications

- The complexities of formulating a coherent and consistent identity that young people experience, are rendered more complex for young people with sickle cell with the addition of healthcare transitions
- Our research provides a picture of young people:
  - exhausting themselves to try to be productive and achieve key goals,
  - while also trying to be responsible patients, committed to self-management and self-monitoring of own body



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# Thank you

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