



# Patients' views on improving sickle cell disease management in primary care: focus group discussion

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## DECLARATIONS

### Competing interests

None

### Guarantor

GA

### Ethical Approval

Not required for this work as it is part of a service evaluation and improvement project.

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## Summary

**Objectives** To assess sickle cell disease (SCD) patient and carer perspectives on the primary care services related to SCD that they receive from their general practitioner (GP).

**Design** A focus group discussion was used to elicit the views of patients about the quality of care they receive from their primary health-care providers and what they thought was the role of primary care in SCD management. The focus group discussion was video recorded. The recording was then examined by the project team and recurring themes were identified. A comparison was made with notes made by two scribes also present at the discussion.

**Setting** Sickle Cell Society in Brent, UK.

**Participants** Ten participants with SCD or caring for someone with SCD from Northwest London, UK.

**Main outcome measures** Patients' perceptions about the primary care services they received, and a list of key themes and suggestions.

**Results** Patients and carers often bypassed GPs for acute problems but felt that GPs had an important role to play around repeat prescriptions and general health care. These service users believed SCD is often ignored and deemed unimportant by GPs.

**Conclusion** Participants wanted the health service to support primary health-care providers to improve their knowledge and understanding of SCD. Key themes and suggestions from this focus group have been used to help develop an educational intervention for general practice services that will be used to improve SCD management in primary care.

**Contributorship**

KJP, OO and AM originally conceived the study; GA and KJP undertook the analysis; GA wrote the first draft; and all authors contributed in the revision of the manuscript.

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**Introduction**

For people with sickle cell disease (SCD), a single point mutation on the haemoglobin molecule creates a lifetime of episodic and illness, until recently, dramatically reduced life-expectancy. A better understanding of the disease and improvements in science, technology, drug therapy and health policy have all contributed to patients with SCD surviving well into adulthood.

SCD is the most common and fastest growing genetic disorder in England. About 350 babies are born each year with SCD and a further 9500 babies are found to be carriers of the disease.<sup>1</sup> England could be dealing with a sickle cell crisis as immigration from Africa and the Caribbean increases disease prevalence, while primary health-care providers still struggle with the disease's multidisciplinary management.<sup>2</sup> SCD is an illness in which recurrent pain, also referred to as vaso-occlusive crisis, is a chronic concern. Primary care professionals therefore play a key role during the initial presentation of symptoms, as well as the management of long-term complications including such recurrent pain.

In England, London residents account for approximately three quarters of all SCD admissions to hospitals,<sup>2,3</sup> with the London Borough of Brent being one of the highest risk areas for SCD.<sup>4,5</sup> Many aspects of SCD can be effectively and efficiently managed in primary care.<sup>6</sup> Previous studies have shown successful interventions that move management of SCD, particularly uncomplicated sickle cell pain episodes, from tertiary towards primary care.<sup>7,8</sup>

Focus groups may be useful for obtaining developmental input in managing SCD in primary care. Focus groups may be defined as 'thoughtful planned discussions among participants with similar experiences that allow the moderator to obtain the individuals' cognitive and emotional perceptions in a non-threatening and relaxed environment'.<sup>9,10</sup> In this paper, we report the findings of a focus group study held at the Sickle Cell Society in the London Borough of Brent. We aimed to identify patient and carer perspectives of general practitioner (GP) knowledge and treatment of SCD, and to identify areas in which improvements could be made. This information helped to design an educational intervention which could help further engage primary health-care professionals in the

care and management of their sickle cell patients. The study was part of a wider service improvement programme to improve the management of SCD in the London Borough of Brent.

**Methods**

As this study was hypothesis generating, we used qualitative methods – specifically, a focus group design – to learn about the experiences and perception of SCD patients and their carers. The discussion lasted for approximately two hours. The participants were recruited through the Sickle Cell Society in Northwest London and comprised a mixture of ages and genders. Specifically, the group was made up of 10 patients: two men and eight women, aged 9–56 years, all of African/Afro-Caribbean heritage. The focus group was held at the Sickle Cell Society which is conveniently located to where many people with SCD live. The location is also a familiar meeting point where all of the participants felt secure and at ease to voice their opinions. The focus group participants were recruited through a purposive sampling process which aimed to canvas the views of sickle patients and carers living within the specific locality in which the service improvement and evaluation work was being undertaken. Participants were recruited via the Sickle Cell Society, a national UK sickle cell charity, through a general mail out to members of the charity living within this area with information about the study. This was subsequently followed up by a telephone call (CN) to assess interest in participating in the focus group. The discussion was facilitated by a clinical psychologist (KA) from a local NHS Trust experienced in handling patients with SCD who explained the aims of the project to the participants; and who then asked the participants questions regarding their personal experience with primary health care in London. The questions were open-ended and focused on general practice utilization, what patients do first when they are in a SCD crisis, and overall satisfaction with primary care. Eleven observers from the project group were present; two were scribes. As well as making written notes, the discussions were also video recorded.

The key themes used to explore the participants' perceptions and aspirations regarding primary care

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services for SCD are listed in Table 1. The participants were also encouraged to raise their own concerns about SCD management. Following the focus group, the project team (GA and KP) read the transcripts independently and grouped the responses into key themes that would help inform planning of future SCD services. Each item in the data collected during the discussions was compared with the rest of the data to establish analytical groups. Consensus of categories and a final list of key themes identified during the discussions were achieved iteratively through discussion and re-reading of transcripts. As we aimed to present viewpoints, the data are not presented numerically.

## Results

The transcripts and recordings were reviewed to identify common perceptions and experiences among the participants.

### Accessibility

GP access was an important issue. The participants highlighted that difficulty in obtaining an appointment with the GP, and that long waiting times lead to patients' sidestepping their GP in the event of a painful crisis or other issues relating to SCD. Although GPs are seen as useful for prescribing antibiotics and other repeat prescriptions, they were seen to be unreliable during crises. Hospitals were seen to be more accessible. Participants proposed that GPs should offer more 'out of hours' and house calls for pain management, since many crises occur at night:

I cannot walk in [to a General Practitioner's office] and even if I could, I probably won't be able to see a GP immediately, so I go straight to the hospital if I am sick.

**Table 1**  
Key themes used to generate group discussion

- Frequency in accessing GP care for managing crisis
- Satisfaction level with primary health-care services
- Current use of primary health-care services
- What do you do first when in a SCD crisis?

GP, general practitioner; SCD, sickle cell disease

### Doctor-patient relationships

Participants raised the issue of the lack of time to build up rapport and relationships with their GPs. This left patients with SCD with a feeling of dissatisfaction with the quality of the doctor-patient relationship. They felt that GPs were not actively interested or engaged in the progress and treatment of their condition. They encouraged GPs to take a proactive approach and interest in getting to know their SCD patients and to focus on preventive care including preventive management of crisis:

If I take my son to hospital now, the doctors like to have a relationship and know how he is doing. If I take him to the GP there is no relationship; he is a stranger.

[You have a] five minute conversation with the GP. You are in and out. I prefer to go to the hospital, I know them there. I am safe. My nurse knows me.

I know my GP, but does he really know me? I go to the hospital. They know me.

### GP knowledge

There was a general feeling among the participants that GPs lack comprehensive knowledge of SCD, and the hospitals were viewed as more specialized in dealing with the condition. They expressed an interest in seeing GPs better informed about SCD, and its implications for management. One participant suggested a GP SCD 'champion(s)' or specialists who could further inform their health professional colleagues about SCD. Another participant added that GPs who are not specialized in SCD need to be briefed by an expert before seeing a SCD patient in the surgery.

They take time to know about other diseases; I feel my disease is not important, I feel I am not important.

### Concerns about pain management and treatment process

Because of the organizational barriers previously mentioned, many of the participants had difficulty in seeing the benefit of utilizing a GP during an uncomplicated sickle crisis. They subscribed to a

process that seemed to utilize the emergency department during a crisis and to utilize the GP for repeat prescriptions and immunizations. Patients are still waiting for facilitating factors which would encourage them to use the GP as a means of support, prevention and maintenance during crisis-free periods or during uncomplicated crisis pain episodes.

It takes too long to see a GP. Sometimes something goes wrong while you are waiting for your appointment. Other than a prescription or a non-sickle illness, there is no need for the GP. It is a waste of time. When you have access to a seven-day hospital, why go to a GP?

They [General Practitioners] don't take the time to find out about the patients they have on their books anyways.

### Continuity of care and follow-up

One discussion point that surfaced several times was the seeming lack of cohesion and communication between GPs, hospitals and specialty centres. Participants emphasized that there was never follow-up from their GP after they were discharged from the emergency department, hospital or a specialty centre. Participants felt strongly that GPs should liaise with other health-care professionals involved in the management of their sickle condition, and should follow-up with the patient soon after hospital discharge.

[There should be] review letters from the hospital. They [General Practitioners] should see how you are doing. That will be good.

[Following discharge from hospital] why don't they [GPs] ever call the patient and follow-up?

### Chronic illness management – wellbeing management

There was a general consensus that many of the frustrations felt by patients with SCD are also shared by sufferers of other chronic illnesses. GPs were seen as treatment and medication prescribers rather than actively engaged in the management of their patients' wellbeing

through prevention of disease and maintenance of health.

The GP consultation is a five minute conversation with the GP... [to get your] medication or antibiotics, or certain jabs, they don't take the time.

The key issues identified through the focus groups are summarized in Table 2.

## Discussion

### Key findings

The focus group study identified a number of barriers to patients with SCD and their carers engaging fully with primary care services. These ranged from practical difficulties accessing services when required, poor communication between primary and secondary care professionals and a perceived lack of confidence in the ability of primary care professionals to provide chronic disease management specific to SCD.

### Education, communication and quality improvement

The issues identified during the focus group discussion have helped define key areas in need of improvement for SCD management. Some of the key themes and useful suggestions have been used to develop a GP education intervention to improve GP management of SCD in primary care. Part of the education intervention has been facilitated by developing a SCD template for data entry compatible with a main electronic patient record system used by GPs. These electronic medical

**Table 2**  
Issues identified by focus group discussion

- Access and difficulty in obtaining urgent appointments
- Poor communication between health professionals
- Poor follow-up and discharge planning processes
- No proactive role in maintaining health and in preventive care
- Limited knowledge about sickle cell disease
- Limited knowledge about the standards and guidelines for disease management
- Concerns about pain management

record systems are now widespread in UK primary care and have helped improve recording on patients with other chronic diseases.<sup>11</sup> In the longer term, these electronic patient records could be linked to clinical decision support systems or disease recording templates to help improve recording of information by primary care teams and the quality of primary care received by patients.<sup>12</sup>

Future studies could focus on other issues identified such as auditing and improving communication between different health-care providers. This could be facilitated by GPs receiving timely information on hospital admission and hospitals advising patients to book an appointment with their GP for review after discharge. Receiving proactive care from the GP could also be achieved by identifying areas with a relatively high prevalence of SCD and designing a local quality improvement scheme. Many patients with chronic illnesses do receive proactive care from their GPs but these are generally patients with the diseases covered in the GP Quality and Outcomes Framework.<sup>13</sup> At present, SCD is not a part of this framework but could be considered for future inclusion in areas where there is a high prevalence of SCD.

### Comparison with existing literature

Previous studies have shown that SCD patients are dissatisfied with the quality of care that they receive from their GPs and at the primary care level.<sup>14</sup> They also show that primary care is still a strong place to deal with chronic illness as it offers continuity, coordination and comprehensiveness<sup>15</sup> and that assessing satisfaction is an important part of evaluating comprehensive quality of care.<sup>16</sup> Patient satisfaction is regarded as the 'ultimate outcome of the delivery of health care' and measuring and responding to satisfaction can be important with regard to treatment compliance and over or underutilization of the health-care system.<sup>17</sup> The strengths and limitations of the current focus group discussion also support the findings of similar studies that have identified focus group discussions as a means for qualitative data collection.

### Strengths of the focus group discussion

The focus group discussion provided a forum for a broad range of participants to express their

concerns about the quality of care they received from their primary health-care providers, their opinions on what the role of primary care in managing SCD should be and to discuss their perceived barriers to utilizing primary care services. This method has been demonstrated as an appropriate approach to investigate these issues.<sup>18</sup> Furthermore, focus groups can provide a space for an open dialogue tailored to the level of the participants<sup>19</sup> and allows the facilitator to clarify and push for more detailed responses to enrich the understanding of the issues.<sup>20</sup>

The use of a focus group as a data collection technique was particularly useful with SCD to ensure sensitivity to cultural variables, which is why they are now so often used in cross-cultural research and work particularly well with ethnic minorities. SCD is a disease that disproportionately impacts people of African and Caribbean origin; the focus group setting allowed us to reveal the frustration felt as an ethnic minority receiving health-care services for a predominantly race-related disease. Consequently, it makes them useful in studies examining why different sections of the population make differential use of health services.<sup>18,19</sup>

The group dynamic also worked to facilitate the discussion of difficult or uncomfortable topics because the less reserved members of the group 'broke the ice' for the more reserved participants.<sup>19</sup> Some researchers have also noted that group discussions can generate more criticism of the health-care system than interviews.<sup>21</sup> For example, Geis *et al.*, in their study found that 'there were more angry comments about the medical community'<sup>19</sup> in the group discussions than in the individual interviews: 'perhaps the synergism of the group "kept the anger going" and allowed each participant to reinforce another's vented feelings of frustration and rage'.<sup>22</sup>

### Limitations of the focus group discussion

Our focus group discussion results could have benefited by having more participants and more sessions. Some researchers also argue that focus groups are limited in their ability to draw inferences for large groups or populations and their incapacity to test hypotheses in traditionally designed experiments.<sup>10</sup> Others have also claimed that focus groups can lead to 'tagging' which



means that participants agree for the sake of the group's momentum and that, with regard to more sensitive topics, interviews work better because the participant feels a greater level of anonymity than when part of a group discussion.<sup>10</sup> Such points show that the use of focus groups may be subject to bias and need to be individually evaluated.<sup>20</sup> Focus groups may not add value to every study but can work well when combined with other forms of qualitative and quantitative methods.<sup>10,23</sup>

### Implications for future research and clinical practice

The focus group discussion on SCD provided an opportunity to not only voice the frustrations of participants but created a venue whereby solutions could be proposed. The discussion was candid, clear and offered perspectives about the participants' individual and collective needs that could not otherwise be obtained from health-care professionals. They offered constructive advice on what they needed to feel satisfied as health-care consumers and gave a clear understanding about which areas we needed to focus the design of the primary care practice intervention. They also earmarked issues that need to be addressed in future research including auditing and improving communication between the different providers of health care and recommending quality improvement schemes in areas with a high prevalence of SCD.

Including patients in the development and implementation of a GP educational intervention may be an efficient and effective way to help pilot a new programme aimed at meeting the needs of patients with SCD. Future focus groups may explore with what areas in particular the participants are not satisfied and how to incorporate into future programme planning some of the preliminary suggestions made at the first focus group.

### Conclusions

This study has highlighted that SCD patients and carers have many criticisms about the current quality of services for managing patients with SCD in primary care. The study has helped provide key themes and useful suggestions that

have been used to develop an educational intervention for general practices that will be used to improve SCD management in primary care.

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