Views of patients about sickle cell disease management in primary care: a questionnaire-based pilot study

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DECLARATIONS

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None declared

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Summary

Objectives To determine how patients with sickle cell disease (SCD) perceive the quality of care that they receive from their primary healthcare providers.

Design A questionnaire-based pilot study was used to elicit the views of patients about the quality of care they have been receiving from their primary healthcare providers and what they thought was the role of primary care in SCD management.

Setting Sickle Cell Society and Sickle Cell and Thalassaemia Centre, in the London Borough of Brent.

Participants One hundred questionnaires were distributed to potential participants with SCD between November 2010 and July 2011 of which 40 participants responded.

Main outcome measures Analysis of 40 patient questionnaires collected over a nine-month period.

Results Most patients are generally not satisfied with the quality of care that they are receiving from their primary healthcare providers for SCD. Most do not make use of general practitioner (GP) services for management of their SCD. Collecting prescriptions was the reason most cited for visiting the GP.

Conclusion GPs could help improve the day-to-day management of patients with SCD. This could be facilitated by local quality improvement schemes in areas with high disease prevalence. The results of the survey have been used to help develop a GP education intervention and a local enhanced service to support primary healthcare clinicians with SCD's ongoing management.

Ethical approval
Ethical approval was not required for this work as it is part of a service evaluation and improvement project

Guarantor
GA

Contributorship
KJP, YK and AM originally conceived the study; OO and KJP conducted the data analysis; GA wrote the first draft; all authors contributed in the revision of the manuscript

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Reviewer
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Introduction

Sickle cell disease (SCD) is the most common inherited blood disorder in England. Without prompt diagnosis and proper treatment, it can be a serious source of morbidity and mortality. SCD is caused by a single amino acid substitution of valine for glutamic acid in the sixth position of the beta (β)-chain of the haemoglobin tetramer.[1,2] The disease damages and changes the shape of red blood cells. The change in shape is a response to cell deoxygenation. When the oxygen uptake of the cell is low, the cells change their shape from a healthy round disk to a crescent (sickle shape), holly leaf or other similarly distorted shape. The sickled cells are rigid, less malleable and stickier than a normal cell; consequently, they may stick to each other and obstruct blood vessels. This obstruction causes harsh and painful complications. The complications can lead to frequent hospital visits and proper management of SCD is needed to minimize the risk of developing such complications.[3]

SCD clinical guidelines recommend that patients see a general practitioner (GP) for routine examination every six months and more often if new problems arise or their treatment protocol changes.[4] In addition, immunizations, prescriptions and other preventive care measures need to be delivered effectively by GPs to prevent recurring infections and pain crisis.[5]

An analysis of emergency department admissions between January 2008 and July 2010 in the Northwest London Borough of Brent showed that patients with SCD tend to use the emergency department rather than seek advice and support from their GP.[6] A focus group aimed at obtaining patient perspectives held in Brent showed that one of the reasons patients utilize the emergency department over their GP is because they perceive GPs as having limited knowledge of SCD.[7] A primary care educational intervention has been designed, informed by these studies. To further triangulate the experience of patients, this pilot study was designed to elicit the views of patients about the quality of care they have been receiving from their primary healthcare providers and what they thought was the role of primary care in SCD management.

Methods

Study design and questionnaire

The study consisted of the development and administration of a 14-item study-specific questionnaire devised by a sickle cell steering committee which examined patients' perceptions towards SCD and key management issues in primary care including severity of disease, how many times patients visited the Emergency Department in the last year, how many times patients saw or called their GP for sickle and non-sickle-related illnesses and general questions about GP satisfaction (Box 1). The validation process for the questionnaire followed several drafts reviewed by seven GPs practising across inner London, a professor of paediatric haematology specializing in SCD, a haematologist specializing in SCD in adults, a SCD specialist nurse, a SCD social worker, a SCD clinical psychologist, a number of quality improvement project managers, public health specialists, patient representatives with SCD and directors of the Sickle Cell Society (a national UK sickle cell charity). The pilot study is in itself part of the mechanism of validation for a larger questionnaire study.

Participants

One hundred questionnaires were distributed by post and in person (CN and PO) over a nine-month period from November 2010 to July 2011 to members of the Sickle Cell Society and to patients who attended the Sickle Cell and Thalassaemia Centre, using a purposive sampling method. Forty questionnaires were completed and suitable for analysis (OO and KJP).

Results

A response rate of 40% was achieved. Fifty percent (20) were completed by men and 50% (20) by women. The highest percentage of respondents (27%) was in the age range of 25–39 years. Five percent of respondents were aged 65+ years. The majority (62%) of the respondents were in good health and mobile. Nineteen (47%) respondents did not use their GP to manage a painful crisis and preferred to attend the emergency department. Twenty-four (59%) respondents went to

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Box 1
A selection of questions from the patient questionnaire

Question
In the past year, how many times have you seen or called your GP for help with a sickle cell crisis?
……

Question
Rank the three main things you do most often when in crisis:
( ) Do nothing ( ) Go to GP
( ) Call Sickle Cell Specialist Nurse ( ) Go to A&E
( ) Stay at home ( ) Other (please state):……

Question
How often do you utilise your GP to:

a) Manage a painful crisis

Never	Rarely (1-2/year)	Sometimes (3-4/year)	Fairly often (monthly)	A lot (weekly)

b) Collect repeat prescription for antibiotics, folic acid, analgesia

Never	Rarely (1-2/year)	Sometimes (3-4/year)	Fairly often (monthly)	A lot (weekly)

c) Get general advice about sickle cell disease

Never	Rarely (1-2/year)	Sometimes (3-4/year)	Fairly often (monthly)	A lot (weekly)

d) Get help with non-sickle related illness (e.g. coughs, colds, etc)

Never	Rarely	Sometimes	Fairly often	A lot

their GP to collect repeat prescriptions. Twenty-two (55%) respondents did not visit their GP to get general advice about SCD (Table 2). Nine (23%) rarely visited their GP with four (10%) visiting sometimes or fairly often (Table 1). When asked how satisfied patients are with assistance given by their GP to help manage their SCD based on a scale of 0–10 (0 being not satisfied at all and 10 being very satisfied), the majority (54%) scored satisfaction with their GP as 5 or less while 43% scored a 6 or above and 3% did not answer the question at all. Collecting prescriptions was the reason most cited for visiting the GP's office (Table 2). Some examples of comments around the services provided by GPs include:

> 'The GP should know about this disease'. (Patient Questionnaire 1)

> 'The GP does not know anything about SCD pain and crisis. I would rather manage … at home or [go] to A + E where immediate action will be taken rather than call the GP who will ask us to book an appointment and more or less does not understand how to manage the pain or how severe or serious the pain is'. (Patient Questionnaire 2)

Discussion

Key findings

The results from the survey show that many patients are generally not satisfied with the quality of care that they are receiving from their primary healthcare providers for SCD. Thus, most do not make use of GP services for management of their SCD. More importantly, the majority of the group did wish for greater involvement from their GP services, even if it was just to refer them to a tertiary care facility or social support.

Table 1
How often do you use your general practitioner to get general advice about sickle cell disease?

	Number of respondents	*% of respondents*
Never	22	55
Rarely	9	23
Sometimes	4	10
Fairly often	4	10
Not answered	1	3

Table 2
Support currently received from general practitioner

	Number of respondents	*% of respondents*
Pain control	14	35
Collecting prescription	37	93
General SCD advice	3	8
Contraception	2	5
Other (please state)	1	3

SCD, sickle cell disease

Comparison with existing literature

Primary care satisfaction and SCD

There are few data collected about SCD patients and their level of satisfaction with primary care services. However, one study showed a 46% non-adherence rate for routine primary care appointments for SCD patients during an eight-month period.[8] One of the reasons cited for the non-adherence was patient–provider relationships. Those with a positive patient and GP relationship were more likely to attend their clinic appointments.[9,10] Other studies of chronic disease management showed that poor communication, multiple treating physicians, long waiting periods and past negative experiences with healthcare providers all contributed to patient dissatisfaction with primary care and poor attendance at clinics.[11]

Patient satisfaction as an indicator of health outcomes

Patient satisfaction is an important indicator of health outcomes. Researchers and healthcare providers have become increasingly interested in measuring patient satisfaction as an indicator of quality of care. Assessing patient satisfaction is a core requirement of contract for GPs in the UK.[12] One study showed that assessing patient satisfaction allows GPs to investigate 'the extent to which their service meets the needs of their client group'.[13] Another study showed that satisfied patients are more likely to follow treatment protocol because the patient is more likely to believe that the treatment will be effective.[14] In order for satisfaction to be measured in a meaningful way, a valid and reliable measure should be applied. The use of patient questionnaires has been one reliable way to assess patient satisfaction.[12]

The use of questionnaires to measure patient satisfaction

Properly constructed patient questionnaires have been found to be useful in measuring patient satisfaction,[12] but they may also be valuable more specifically for measuring patient satisfaction in primary care and for primary care management of SCD. One study showed that a questionnaire was a valid and valuable tool to use in assessing the health-related quality of life in children with SCD and could serve as 'an important adjunct to determine the effect of SCD on the lives of children'.[15] Other studies showed questionnaires as a valuable tool in measuring quality of care or patient satisfaction in primary care[16] particularly where the questionnaire assesses a specific area that enables the GP or other healthcare provider to identify with which aspects of service patients are less satisfied. This allows for the opportunity to improve a specified area.[17]

Strengths and limitations of this study

Our pilot study successfully identified issues with SCD management at the primary care level through the use of a questionnaire which could help inform the planning of a larger survey. Moreover, this study also identified a need to improve patient satisfaction and engagement

with primary care. Raising awareness among GPs about SCD management was identified as a key method to improve GP–patient relationships and improve primary care clinic attendance.

Although this pilot study increases our understanding of the barriers associated with SCD management in primary care, it has certain limitations which could limit its transferability to areas outside of Northwest London. The questionnaire was based in an area with high prevalence of SCD and the sample size was small and consisted of purposive or volunteer sample. In addition, it is unclear how the identification of barriers in SCD management in primary care relates to the actual uptake of primary versus secondary care in SCD. Future studies would need to examine this link.

Conclusions

Despite its limitations, the study, along with the results of the focus group discussion which reinforced these findings,[6] provides some valuable information that will give an opportunity to develop a disease-specific intervention which aims to improve patient care and help to ensure that management in primary care is optimized through the establishment of a local enhanced service. In the next stage of this project, we will implement this intervention and evaluate its impact on the management of patients with SCD by general practices in Northwest London.

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