PATIENT SELF-ASSESSMENT OF HOSPITAL PAIN AND HEALTH RELATED QUALITY OF LIFE IN ADULTS WITH SICKLE CELL DISEASE

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PATIENT SELF-ASSESSMENT OF HOSPITAL PAIN AND HEALTH RELATED QUALITY OF LIFE IN ADULTS WITH SICKLE CELL DISEASE

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SUMMARY

Article Focus:

Acute pain is a hallmark of sickle cell disease for which hospital admissions may be required. This study explores the relationship between patient self-assessments of pain, mood, and health related quality of life with health utility (measured on the EQ-5D) during and after hospital admissions.

Key Messages:

Mood, general health, and quality of life steadily improve with reduction of pain during and after an acute sickle cell pain episode.

A multidimensional approach to assessing sickle cell pain in hospital is useful. This helps to identify co-morbidities such as mood changes that may affect length of stay with health care coat implications.

Strengths and Limitations:

Health utility indices for an in-patient sickle cell pain population are reported for the first time. Quality of life and emotional changes are also highlighted. Nonetheless, this is based on information from one setting, and may be different from others.

ABSTRACT

Objectives:

To characterize the relationship between adult patient self-reported sickle cell pain, mood and quality of life during and after hospital admissions.

Design:

Longitudinal study across three time points.

Setting:

Secondary care, single specialist sickle cell centre

Participants:

510 adult patients with sickle cell disease admitted to hospital daycare or inpatient units.

Outcome measures:

Self-assessments of pain, mood, and health related quality of life with health utility (measured on the EQ-5D) on admission, before discharge, and at one-week post discharge.

Results:

Mood, general health, and quality of life showed significant steady improvements with reduction of pain in patients with sickle cell disease on admission to hospital, before discharge, and at one-week follow-up ($p<0.01$). Health utility scores derived from the EQ-5D showed a negative association with pain in regression analysis over the three time points.

Conclusion:

Examining health related quality of life and health utility in relation to pain during hospital admissions is valuable in terms of targeting appropriate psychological interventions within the context of a multidisciplinary approach to managing sickle cell pain. This has implications for health care costs.

KEY WORDS

Sickle cell disease, Pain, Quality of life, Health utility

INTRODUCTION

Pain associated with vaso-occlusion in sickle cell disease (SCD) is a life-long persistent and significant problem, which has profound medical, psychological, and social implications for affected patients and their families. Recurrent acute pain episodes in SCD are variable for which frequent hospitalisations may be required [1,2]. More than 90% of hospital admissions of patients with SCD in the UK have been shown to be for acute pain treatment[3], and the management of acute painful episodes continues to pose a challenge for clinicians.

Sickle cell pain assessment is a crucial and difficult task. Accurate estimation of this pain is important in its control and management. Inadequate treatment for sickle cell pain continues to be an important problem, and a major issue is the restricted assessment methods utilised. Firstly, similar to other types of pain, there is no medical assessment or physiological measure of sickle cell pain that is objective. Pain assessment in patients with SCD is usually based on the opinion of clinical staff, and this may lead to discrepancies between their ratings of pain severity or the amount of pain relief required and that of patients[4]. Secondly, pain experiences are multidimensional, and quite importantly in sickle cell pain other dimensions including mood, general health, activity levels and sleep have to be considered[5]. In order to address these issues different strategies for the clinical management of sickle cell pain should be adopted to incorporate psychological assessments.

Patients with sickle cell pain who are admitted to Central Middlesex Hospital in London are treated with morphine (or alternative opioid) via a patient controlled analgesia (PCA) pump as standard. The multidisciplinary approach to the clinical management of sickle cell pain includes routine psychological assessments, which have been incorporated into the inpatient

protocols, and allow for appropriate interventions. These patients self-complete assessments referred to as the 'Sickle Cell Patient Self Assessment of Own Health State' (Diagram 1), which are administered on admission, before discharge, and at one week after discharge (by telephone call from a psychologist). This assessment form is mainly a combination of Health Related Quality of Life / Health Utility[6] and pain status measures. The EQ-5D is a standardised instrument for use as a measure of health outcome and health utility, which provides a simple descriptive profile and a single index value for health status. Pain status includes assessments of pain intensity and pain relief; there is also a mood score. The present study is based on a retrospective audit review of standard psychological assessments in adults with sickle cell pain admitted to Central Middlesex Hospital over a five-year period until the end of 2010.

OBJECTIVE

The main aim of the study was to define the relationship between adult patient self-reported sickle cell pain, mood and health related quality of life (HRQoL) across three time-points during and after hospital admissions.

METHODS

The 'Sickle Cell Patient Self Assessment of Own Health State' form comprises three sections (Diagram 1). The first section taken from the EQ-5D measures HRQoL in five dimensions: mobility; self-care; usual activities; pain/discomfort; anxiety/depression at three levels (1) no problems, (2) some problems, (3) extreme problems. There is also a general rating of health state on a scale of 0 (worst imaginable) to 100 (best imaginable). In the second section, there are ratings of pain intensity 0 (no pain) to 10 (worst possible pain), pain relief 0 (no relief) to

10 (complete relief), mood 0 (worst mood) to 10 (best mood) and drowsiness 0 (not drowsy) to 10 (asleep) on visual analogue scales (VAS). The final section requires patients to indicate the location of their pain on a diagram of the body.

Data were extracted from consecutive cases of patients who were admitted over the five-year period. These included patients admitted to the hospital Day-care centre, and Inpatient units via the Accident and Emergency (A&E) department. There were three assessment time-points: T1 – on admission to hospital; T2 – before discharge from hospital; T3 – 7 days post discharge from hospital (telephone). Initial statistical analyses of demographic characteristics and clinical characteristics included all patients.

The relationship between pain and HRQoL was examined over the three time-points since this was of initial interest, and unique to this study. Health utility values were calculated from the EQ-5D with a special calculator tool with data from various countries presented by Szende *et al*[7]. UK health utility data is based on the time trade-off (TTO) valuation method with weights derived from 3395 UK adults first reported by Kind *et al*[8]. The relationship between pain score and EQ-5D-derived health utility was explored. Preliminary analysis showed that there was no significant interaction between time-point and pain score in predicting utility (i.e. although pain score decreased and utility increased over time, the relationship between the two variables remained constant). Therefore, data from all time-points were used in a single analysis. This approach meant that it was necessary to account for within-person correlation, so a random-effects time-series regression model with *patient ID* as a panel variable was used (xtreg command in Stata 8.0). Polynomial functions of pain score were explored to improve model fit. Patient age and sex were not significant predictors of utility (either as individual variables or in interaction with pain score), so these covariates

were not included in the model.

RESULTS

There were 510 admissions in total. Most of the patients had more than one hospital admission for acute sickle cell pain during the study period. Demographic characteristics of the patients are presented in Table 1.

Table 1: Demographic and Clinical Characteristics of Adult Patients with Sickle Cell Disease

Variable	Frequency
Gender	
Male	199 (39%)
Female	305 (60%)
Unreported	6 (1%)
Location	
Inpatient	463 (91%)
Day-care	47 (9%)
	Mean (SD)
Age	28.9 (10.2)

Day-care cases were excluded from t-test analyses owing to the difference in the length of stay from inpatient hospital admissions. Pain, mood, and general health status scores obtained from Inpatient cases are presented in Figure 1; in addition their health utility values obtained from the EQ-5D are presented in Figure 2.

Pain

There was a significant reduction of pain VAS scores from admission T1 (Mean 5.1, SD 2.5) to discharge T2 (Mean 3.0, SD 2.4), t=9.29, df=482, p<0.001 and from discharge T2 to one-week telephone follow up T3 (Mean 2.0, SD 2.2), t=4.69, df=427, p<0.001.

Mood

There was a significant improvement in mood VAS scores from admission T1 (Mean 5.0, SD 2.2) to discharge T2 (Mean 5.7, SD 2.3), t=-3.23, df=479, p=0.001, and from discharge T2 to one week follow up T3 (Mean 6.8, SD 2.2), t=-4.90, df=425, p<0.001.

General Health Status

Patients' reports of their general health on the VAS in addition showed significant improvements from admission T1 (Mean 47.7, SD 22.3) through discharge T2 (Mean 59.4, SD 21.7), t=-5.70, df= 459, p<0.001, to one-week follow up T3 (Mean 71.0, SD 20.0), t=-5.63, df=413, p<0.001.

Health Related Quality of Life and Health Utility

Furthermore, health utility values derived from the EQ-5D showed that patients significantly got better between T1 (Mean 0.39, SD 0.40) and T2 (Mean 0.65, SD 0.29), t= -7.95, df=475, p<0.001, and from T2 to T3 (Mean 0.75, SD 0.26), t=-3.94, df=421, p<0.001.

Pain and Health Related Quality of Life / Health Utility

Figure 3 shows the relationship between pain and health utility for all patients across all three time-points. A simple linear model estimates the relationship as: $utility = 0.890 - 0.089pain$

($R^2 = 0.437$). A slightly better fit to the data was obtained by introducing square and cube functions to the model: $utility = 0.887 - 0.124pain + 0.014pain^2 - 0.001pain^3$ ($R^2 = 0.445$).

DISCUSSION

Acute pain episodes are the hallmark of SCD. Furthermore, adults with SCD have been shown to have an impaired HRQoL as compared with the general population with pain and psychological distress being contributors[1,9]. Unsurprisingly in this study, there was a significant reduction in pain scores from admission to discharge and at one-week follow-up. Nonetheless, it was interesting to observe that patients were not completely pain free on discharge and importantly at one-week follow-up. A large 6-month pain diary study of adult patients with SCD showed that 29% had sickle cell pain everyday[2]. This supports the notion that acute pain episodes could develop into a type of chronic sickle cell pain.

Health utilities are cardinal values that reflect the preferences of an individual – or a society – for different health outcomes. They are measured on an interval scale with zero (0) reflecting states of health equivalent to death and one (1) reflecting perfect health. Some health states are considered to be worse than death, and have a negative value. Combined with survival estimates, health utilities can be used to generate quality-adjusted life years (QALYs) for use in cost–utility analyses of medical treatment. The EQ-5D is one of the commonly used HRQoL instruments for measuring health utilities. In this study, HRQoL and health utility values improved over the three time-points. This demonstrates that, although HRQoL in patients with SCD is considerably impaired during acute painful episodes in hospital with improvements after discharge, daily function may not be restored for quite some time and steady-state HRQoL is likely to remain impaired. The mean health utility index of 0.75 at

one-week follow-up is comparable to the mean health utility index of 0.72 obtained from SF-36 scores in a similar UK community based adult SCD population[1]. Studies from USA have also reported similar HRQoL (SF-36) for people with SCD [9,10].

Although a correlation between pain and health utility is clearly identifiable in our dataset, it is subject to a substantial degree of variability at the individual level. For example, it can be seen in Figure 3 that one participant rated their pain level as 9 out of 10, suggesting very intense discomfort, yet identified no health-state limitation on the EQ-5D questions (in the process, answering 'I have no pain or discomfort' for the pain dimension of the instrument). Nevertheless, on average, the expected negative correlation between pain score and health utility is observed.

When estimating health utility from pain score, it may be appropriate to prefer the polynomial model to the simple linear fit, on the mathematical basis that it provides a very slightly superior reflection the data, and also on the theoretical basis that it is more sensitive to high pain scores (producing lower estimated utility values). It is known that EQ-5D measurements are subject to 'floor' effects, and it is credible that most people would prefer death to the prospect of spending the rest of their lives with a pain score of 10 (i.e. in the most excruciating pain imaginable); this is consistent with a utility value of less than zero for such health states.

Pain is an important dimension in the HRQoL of patients with SCD. Patients with sickle cell pain who are admitted to day-care, and through A&E seemed to have impaired HRQoL as a result of pain, however this improved during the course of the admission, and at home over 7 days after discharge. In general, HRQoL is a crucial aspect of illness perception from the

patient's viewpoint, incorporating psychological, social, and disease related factors. In the absence of a universal cure in SCD, the primary aim of treatment is to reduce the impact of the disease (pain in this case), thus enhancing quality of life.

Mood changes in terms of anxiety and depression can be associated with sickle cell pain[11,12]. General health status is also of importance because it affects the psychological well-being of the patient. Mood and general health improved through admission to one-week follow-up. Apart from pain, these could contribute to length of stay in hospital. That is, co-morbidity could lead to poorer health outcomes and reduced HRQoL in patients with SCD. People with long-term medical conditions including pain, frequently use health services, and are likely to have mental health problems such as depression and anxiety[13]. Providing psychological interventions can lead to better outcomes and a reduction in health care costs[14].

CONCLUSION

The study yielded results suggesting that a multidimensional approach to assessing patients with SCD admitted to hospital is beneficial. This approach helps to identify problems for which psychological support is required during and after the hospital admission, and is in accordance with National Institute of Health and Clinical Excellence (NICE) guideline for the management of patients with chronic illnesses[15]. Psychological interventions can be targeted at inpatients to enhance the use of appropriate pain coping techniques, and strategies to improve quality of life. Together with their treatment for sickle cell pain, this will help reduce length of stay and related hospital costs.

AUTHORS CONTRIBUTION

Kofi Anie conceived, designed the study, and performed some statistical analyses. Hannah Grocott and Lauren White were responsible for data collection and entry into the study database. Gabriel Rogers and Mendwas Dzingina performed statistical analyses. Gavin Cho was involved in the study oversight. Kofi Anie took the lead in the write up with review and editing by Gabriel Rogers, Mendwas Dzingina, and Gavin Cho. All authors read and approved the final manuscript.

COMPETING INTERESTS

Kofi Anie was a co-opted expert to the NICE Guideline Development Group for the Sickle Cell Acute Painful Episode.

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Diagram 1: Pain and Health Related Quality of Life Assessment Form

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Sickle Cell Patient Self Assessment of Own Health State

Write in black ink, using clear capitals. Items in bold MUST be completed. Circles must be completely filled in.

Patient to complete form on admission, before discharge and one week after discharge.

1. Demographic Data

NHS No. (UK Patients only)	
Med. Rec. No. or ID No.	
Date of Assessment	/ / **Time of Assessment** :
Assessment Completed	○ On Admission ○ Before Discharge ○ One Week After Discharge
Last Name	
First Name	
Telephone No.	–

2. Which Statement Best Describes Your Own Health State Today?

Mobility	I have no problems in walking about I have some problems in walking about I am confined to bed	○ ○ ○
Self-Care	I have no problems with self-care I have some problems with washing and dressing I am unable to wash and dress myself	○ ○ ○
Usual Activities	I have no problems performing my usual activities I have some problems performing my usual activities I am unable to perform my usual activities	○ ○ ○
Pain/Discomfort	I have no pain or discomfort I have some pain or discomfort I have extreme pain or discomfort	○ ○ ○
Anxiety/Depression	I am not anxious or depressed I am moderately anxious or depressed I am extremely anxious or depressed	○ ○ ○

3. What Level Best Describes Your Own Health State Today?

How Good or Bad is Your Health Today?
Worst Imaginable ○ 0 ○ 5 ○ 10 ○ 15 ○ 20 ○ 25 ○ 30 ○ 35 ○ 40 ○ 45 ○ 50 ○ 55 ○ 60 ○ 65 ○ 70 ○ 75 ○ 80 ○ 85 ○ 90 ○ 95 ○ 100 Best Imaginable

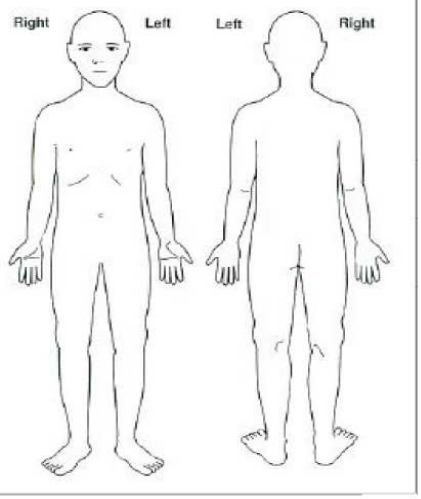
Describe Your Pain Right Now
No Pain ○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10 Worst Possible Pain

Describe Your Pain Relief
No Relief ○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10 Complete Relief

Describe Your Mood
Worst Mood ○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10 Best Mood

How Drowsy do you Feel?
Not Drowsy ○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10 Asleep

Shade the Figure Where You Feel Pain
Mark an X Where You Hurt Most



Doctor/Nurse Initials

Signature

Figure 1: Pain, Mood, and General Health Status Scores of Adult Patients with Sickle Cell Disease

(General Health Scores are scaled down from 100 to 10)

Figure 2: Health Utility Indices of Adult Patients with Sickle Cell Disease

Figure 3: Relationship between Sickle Cell Pain and Health Utility

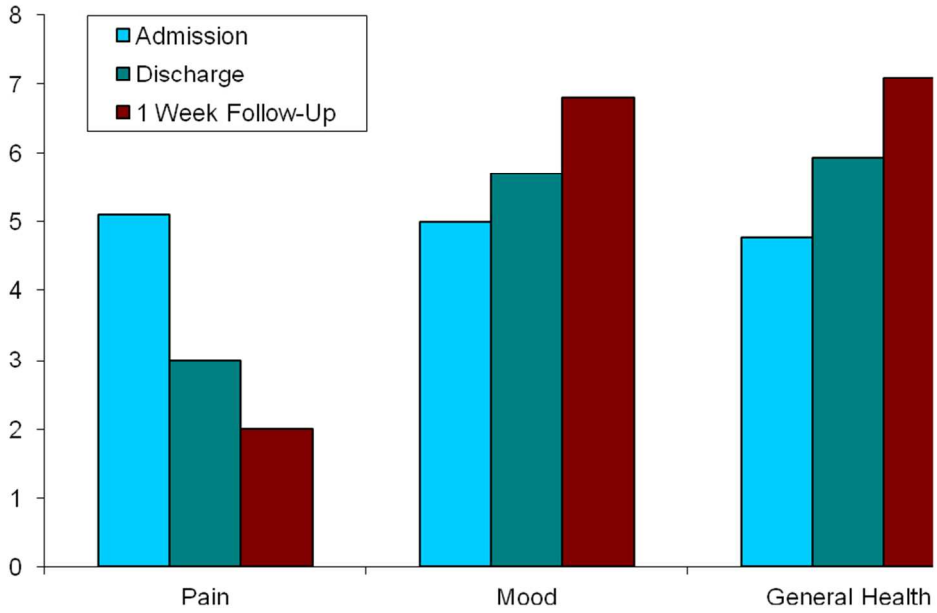


Figure 1
342x226mm (72 x 72 DPI)

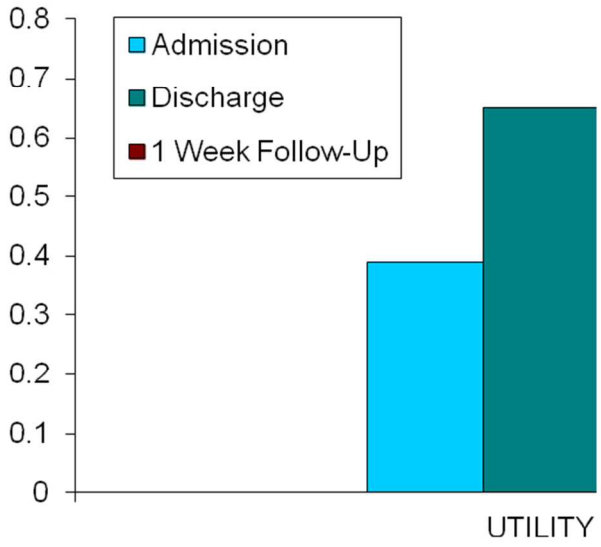


Figure 2
301x170mm (72 x 72 DPI)

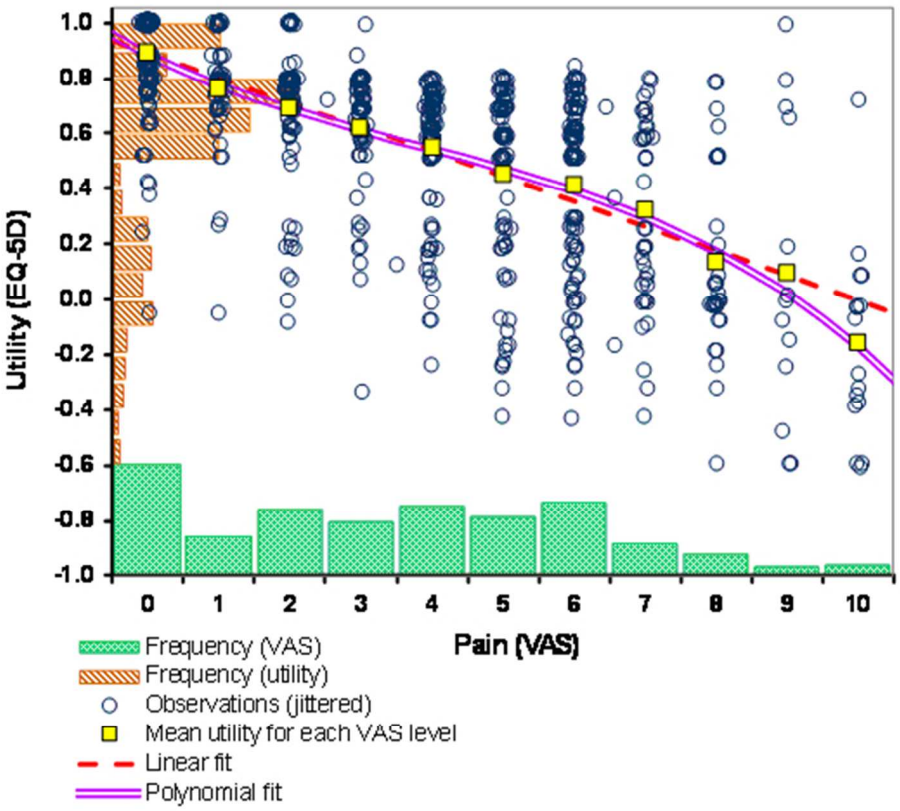


Figure 3
203x175mm (72 x 72 DPI)

PATIENT SELF-ASSESSMENT OF HOSPITAL PAIN, MOOD AND HEALTH RELATED QUALITY OF LIFE IN ADULTS WITH SICKLE CELL DISEASE

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ABSTRACT

Acute pain is a hallmark of sickle cell disease for which frequent hospital admissions may be required, affecting the quality of life of patients. This study examined 510 adult inpatient self-assessments of pain, mood, and health related quality of life with health utility (measured on the EQ-5D) across three time points on admission, before discharge, and at one-week follow-up. Results showed that mood and health related quality of life steadily improve with reduction of pain during and after an acute sickle cell pain episode. Moreover, examining health utility in relation to pain during hospital admissions is valuable in terms of targeting appropriate psychological interventions within the context of a multidisciplinary approach to managing sickle cell pain. This has implications for health care costs.

INTRODUCTION

Pain associated with vaso-occlusion in sickle cell disease (SCD) is a life-long persistent and significant problem, which has profound medical, psychological, and social implications for affected patients and their families. Recurrent acute pain episodes in SCD are variable for which frequent hospitalisations may be required [1,2]. More than 90% of hospital admissions of patients with SCD in the UK have been shown to be for acute pain treatment[3], and the management of acute painful episodes continues to pose a challenge for haematologists.

Sickle cell pain assessment is a crucial and difficult task. Accurate estimation of this pain is important in its control and management. Inadequate treatment for sickle cell pain continues to be an important problem, and a major issue is the restricted assessment methods utilised. Firstly, similar to other types of pain, there is no medical assessment or physiological measure of sickle cell pain that is objective. Pain assessment and treatment in patients with SCD have historically been based on the opinion of clinical staff within a particular medical setting. This may have led to discrepancies between their ratings of pain severity or the amount of pain relief required and that of patients, as highlighted in an earlier study[4]. Secondly, pain experiences are multidimensional, and quite importantly in sickle cell pain other dimensions including mood, general health, activity levels and sleep have to be considered[5]. In order to address these issues different strategies for the clinical management of sickle cell pain should be adopted to incorporate psychological assessments.

Patients with sickle cell pain who are admitted to Central Middlesex Hospital in London are treated with morphine (or alternative opioid) via a patient controlled analgesia (PCA) pump as standard. The multidisciplinary approach to the clinical management of sickle cell pain

includes routine psychological assessments, which have been incorporated into the inpatient protocols, and allow for appropriate interventions. These patients self-complete assessments referred to as the 'Sickle Cell Patient Self Assessment of Own Health State' (Diagram 1), which are administered on admission, before discharge, and at one week after discharge (by telephone call from a psychologist). This assessment form is mainly a combination of Health Related Quality of Life / Health Utility[6] and pain status measures. The EQ-5D is a standardised instrument for use as a measure of health outcome and health utility, which provides a simple descriptive profile and a single index value for health status. Pain status includes assessments of pain intensity and pain relief; there is also a mood score. The present study is based on a retrospective audit review of standard psychological assessments in adults with sickle cell pain admitted to Central Middlesex Hospital over a five-year period until the end of 2010.

OBJECTIVE

The main aim of the study was to define the relationship between adult patient self-reported sickle cell pain, mood and health related quality of life (HRQoL) across three time-points during and after hospital admissions.

METHODS

This is a longitudinal hospital based study examining data from a retrospective audit review. Therefore, no research question or hypotheses was proposed, and formal ethics approval was not required. The 'Sickle Cell Patient Self Assessment of Own Health State' form comprises three sections (Diagram 1). The first section taken from the standardised EQ-5D measures HRQoL in five dimensions: mobility; self-care; usual activities; pain/discomfort;

anxiety/depression at three levels (1) no problems, (2) some problems, (3) extreme problems. There is also a visual analogue scale to record self-rated health state on a scale of 0 (worst imaginable) to 100 (best imaginable). The second section is adapted from the Memorial Pain Assessment Card (Fisherman et al. 1987), a standardised measure of pain which provides ratings of pain intensity 0 (no pain) to 10 (worst possible pain), pain relief 0 (no relief) to 10 (complete relief), mood 0 (worst mood) to 10 (best mood) and drowsiness 0 (not drowsy) to 10 (asleep) on visual analogue scales (VAS). The final section requires patients to indicate the location of their pain on a diagram of the body.

Data were extracted from consecutive cases of patients who were admitted over the five-year period. These included patients admitted to the hospital Day-care centre, and Inpatient units via the Accident and Emergency (A&E) department. There were three assessment time-points: T1 – on admission to hospital; T2 – before discharge from hospital; T3 – 7 days post discharge from hospital (telephone). Initial statistical analyses of demographic characteristics and clinical characteristics included all patients.

The relationship between pain and HRQoL was examined by combining all the data points across three time-points since this was of initial interest, and unique to this study. Health utility values were calculated from the EQ-5D with a special calculator tool with data from various countries presented by Szende *et al*[7]. UK health utility data is based on the time trade-off (TTO) valuation method with weights derived from 3395 UK adults first reported by Kind *et al*[8]. The relationship between pain score and EQ-5D-derived health utility was explored. Preliminary analysis showed that there was no significant interaction between time-point and pain score in predicting utility (i.e. although pain score decreased and utility increased over time, the relationship between the two variables remained constant).

Therefore, data from all three time-points were combined in a single analysis. This approach meant that it was necessary to account for within-person correlation, so a random-effects time-series regression model with *patient ID* as a panel variable was used (xtreg command in Stata 8.0). Polynomial functions of pain score were explored to improve model fit. Patient age and sex were not significant predictors of utility (either as individual variables or in interaction with pain score), so these covariates were not included in the model.

RESULTS

There were 510 admissions in total. Most of the patients had more than one hospital admission for acute sickle cell pain during the study period. Demographic characteristics of the patients are presented in **Error! Reference source not found.**. Day-care cases were excluded from t-test analyses, and Figures 1 and 2 (not from the utility analysis, Figure 3, as described above). The average length of stay for inpatient hospital admissions with uncomplicated pain episodes at Central Middlesex Hospital is about 3 days, whereas patients treated in day-care are discharged within the same day, meaning the data are not comparable hence day-care cases were removed from the analyses. Pain, mood, and general health status scores obtained from Inpatient cases are presented in Figure 1; in addition their health utility values obtained from the EQ-5D are presented in Figure 2.

Pain

There was a significant reduction of pain VAS scores from admission T1 (Mean 5.1, SD 2.5) to discharge T2 (Mean 3.0, SD 2.4), t=9.29, df=482, p<0.001 and from discharge T2 to one-week telephone follow up T3 (Mean 2.0, SD 2.2), t=4.69, df=427, p<0.001.

Mood

There was a significant improvement in mood VAS scores from admission T1 (Mean 5.0, SD 2.2) to discharge T2 (Mean 5.7, SD 2.3), t=-3.23, df=479, p=0.001, and from discharge T2 to one week follow up T3 (Mean 6.8, SD 2.2), t=-4.90, df=425, p<0.001.

General Health Status

Patients' reports of their general health on the VAS in addition showed significant improvements from admission T1 (Mean 47.7, SD 22.3) through discharge T2 (Mean 59.4, SD 21.7), t=-5.70, df= 459, p<0.001, to one-week follow up T3 (Mean 71.0, SD 20.0), t=-5.63, df=413, p<0.001.

Health Related Quality of Life and Health Utility

Furthermore, health utility values derived from the EQ-5D showed that patients significantly got better between T1 (Mean 0.39, SD 0.40) and T2 (Mean 0.65, SD 0.29), t= -7.95, df=475, p<0.001, and from T2 to T3 (Mean 0.75, SD 0.26), t=-3.94, df=421, p<0.001.

Pain and Health Related Quality of Life / Health Utility

Figure 3 shows the relationship between pain and health utility for all patients across all three time-points combined. A simple linear model estimates the relationship as: $utility = 0.890 - 0.089pain$ ($R^2 = 0.437$). A slightly better fit to the data was obtained by introducing square and cube functions to the model: $utility = 0.887 - 0.124pain + 0.014pain^2 - 0.001pain^3$ ($R^2 = 0.445$).

DISCUSSION

Acute pain episodes are the hallmark of SCD. Furthermore, adults with SCD have been shown to have an impaired HRQoL as compared with the general population with pain and psychological distress being contributors[1,9]. Unsurprisingly in this study, there was a significant reduction in pain scores from admission to discharge and at one-week follow-up. Nonetheless, it was interesting to observe that patients were not completely pain free on discharge and importantly at one-week follow-up. A large 6-month pain diary study of adult patients with SCD showed that 29% had sickle cell pain everyday[2]. This supports the notion that acute pain episodes could develop into a type of chronic sickle cell pain. The ongoing prevalence of pain further highlights the need for a multidimensional approach to pain management which extends beyond hospitalisation, and incorporates psychological interventions with coping strategies which can relieve pain and psychological distress whilst enhancing quality of life post-discharge.

Health utilities are cardinal values that reflect the preferences of an individual – or a society – for different health outcomes. They are measured on an interval scale with zero (0) reflecting states of health equivalent to death and one (1) reflecting perfect health. Some health states are considered to be worse than death, and have a negative value. Combined with survival estimates, health utilities can be used to generate quality-adjusted life years (QALYs) for use in cost–utility analyses of medical treatment. The EQ-5D is one of the commonly used HRQoL instruments for measuring health utilities. In this study, HRQoL and health utility values, improved over the three time-points. This demonstrates that, although HRQoL in patients with SCD is considerably impaired during acute painful episodes in hospital with improvements after discharge, daily function may not be restored for quite some time and

steady-state HRQoL is likely to remain impaired. The mean health utility index of 0.75 at one-week follow-up is comparable to the mean health utility index of 0.72 obtained from SF-36 scores in a comparable UK community based adult SCD population[1]. Studies from USA have also reported similar HRQoL (SF-36) for people with SCD [9,10].

Although a correlation between pain and health utility is clearly identifiable in our dataset, it is subject to a substantial degree of variability at the individual level. For example, it can be seen in Figure 3 that one participant rated their pain level as 9 out of 10, suggesting very intense discomfort, yet identified no health-state limitation on the EQ-5D questions (in the process, answering 'I have no pain or discomfort' for the pain dimension of the instrument). Nevertheless, on average, the expected negative correlation between pain score and health utility is observed.

When estimating health utility from pain score, it may be appropriate to prefer the polynomial model to the simple linear fit, on the mathematical basis that it provides a very marginally superior reflection the data, and also on the theoretical basis that it is more sensitive to high pain scores (producing lower estimated utility values). It is known that EQ-5D measurements are subject to 'floor' effects, and it is credible that most people would prefer death to the prospect of spending the rest of their lives with a pain score of 10 (i.e. in the most excruciating pain imaginable); this is consistent with a utility value of less than zero for such health states.

Pain is an important dimension in the HRQoL of patients with SCD. Patients with sickle cell pain who are admitted to day-care, and through A&E seemed to have impaired HRQoL as a result of pain, however this improved during the course of the admission, and at home over 7

days after discharge. In general, HRQoL is a crucial aspect of illness perception from the patient's viewpoint, incorporating psychological, social, and disease related factors. In the absence of a universal cure in SCD, the primary aim of treatment is to reduce the impact of the disease (pain in this case), thus enhancing quality of life.

It should also be noted that HRQoL has a relationship with the psychological well-being and experience in patients with pain, and this is influenced by their coping strategies. These finding could have been influenced by these phenomena.

Mood changes in terms of anxiety and depression can be associated with sickle cell pain[11,12]. General health status is also of importance because it affects the psychological well-being of the patient. Mood and general health improved through admission to one-week follow-up. In addition to pain, these factors could contribute to length of stay in hospital and would be an interesting area for future research. People with long-term medical conditions including pain, frequently use health services, and are likely to have co-morbid mental health problems such as depression and anxiety[13]. The provision of psychological assessments and interventions, in an acute hospital setting, could improve health outcomes by facilitating the use of effective coping strategies[1] and managing co-morbid mood disorders. This could result in a reduced length of stay in hospital, and a reduction in health care costs.

CONCLUSION

The study yielded results suggesting that a multidimensional approach to the assessment and treatment of patients with SCD admitted to hospital is beneficial. This approach helps to identify problems for which psychological support is required during and after the hospital

admission, and is in accordance with National Institute of Health and Clinical Excellence (NICE) guideline for the management of patients with chronic illnesses[15]. Psychological interventions can be targeted at inpatients to enhance the use of appropriate pain coping techniques, alleviate any co-morbid mental health difficulties, and ultimately improve quality of life. Together with their usual treatment for sickle cell pain, this will help reduce length of stay and related hospital costs.

AUTHORS CONTRIBUTION

Kofi Anie conceived, designed the study, and performed some statistical analyses. Hannah Grocott and Lauren White were responsible for data collection and entry into the study database. Gabriel Rogers and Mendwas Dzingina performed statistical analyses. Gavin Cho was involved in the study oversight. Kofi Anie took the lead in the write up with review and editing by Gabriel Rogers, Mendwas Dzingina, and Gavin Cho. All authors read and approved the final manuscript.

COMPETING INTERESTS

Kofi Anie was a co-opted expert to the NICE Guideline Development Group for the Sickle Cell Acute Painful Episode.

The authors declare that there is: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

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Diagram 1: Pain and Health Related Quality of Life Assessment Form

4461

Sickle Cell Patient Self Assessment of Own Health State

Write in black ink, using clear capitals. Items in bold MUST be completed. Circles must be completely filled in.

Patient to complete form on admission, before discharge and one week after discharge.

1. Demographic Data

NHS No. (UK Patients only)	
Med. Rec. No. or ID No.	
Date of Assessment	/ / **Time of Assessment** :
Assessment Completed	○ On Admission ○ Before Discharge ○ One Week After Discharge
Last Name	
First Name	
Telephone No.	–

2. Which Statement Best Describes Your Own Health State Today?

Mobility	I have no problems in walking about I have some problems in walking about I am confined to bed	○ ○ ○
Self-Care	I have no problems with self-care I have some problems with washing and dressing I am unable to wash and dress myself	○ ○ ○
Usual Activities	I have no problems performing my usual activities I have some problems performing my usual activities I am unable to perform my usual activities	○ ○ ○
Pain/Discomfort	I have no pain or discomfort I have some pain or discomfort I have extreme pain or discomfort	○ ○ ○
Anxiety/Depression	I am not anxious or depressed I am moderately anxious or depressed I am extremely anxious or depressed	○ ○ ○

3. What Level Best Describes Your Own Health State Today?

How Good or Bad is Your Health Today?

Worst Imaginable ○ 0 ○ 5 ○ 10 ○ 15 ○ 20 ○ 25 ○ 30 ○ 35 ○ 40 ○ 45 ○ 50 ○ 55 ○ 60 ○ 65 ○ 70 ○ 75 ○ 80 ○ 85 ○ 90 ○ 95 ○ 100 Best Imaginable

Describe Your Pain Right Now

No Pain ○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10 Worst Possible Pain

Describe Your Pain Relief

No Relief ○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10 Complete Relief

Describe Your Mood

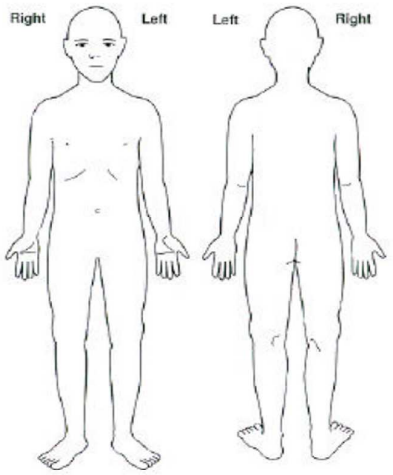
Worst Mood ○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10 Best Mood

How Drowsy do you Feel?

Not Drowsy ○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10 Asleep

Shade the Figure Where You Feel Pain

Mark an X Where You Hurt Most



Doctor/Nurse Initials	
Signature	

Table 1: Demographic and Clinical Characteristics of Adult Patients with Sickle Cell Disease

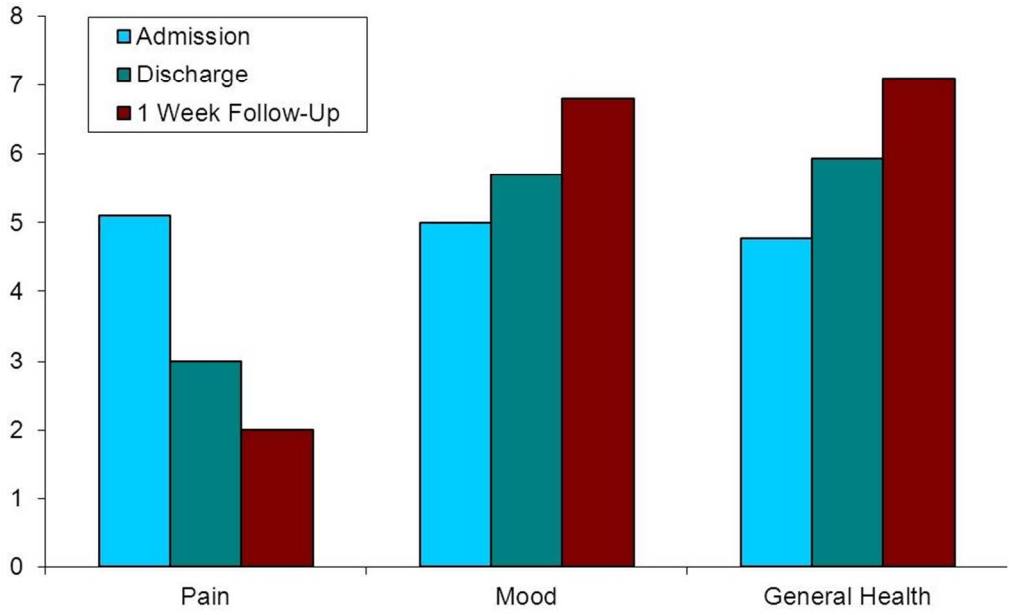
Variable	Frequency
Gender	
Male	199 (39%)
Female	305 (60%)
Unreported	6 (1%)
Location	
Inpatient	463 (91%)
Day-care	47 (9%)
	Mean (SD)
Age	28.9 (10.2)

Figure 1: Pain, Mood, and General Health Status Scores of Adult Patients with Sickle Cell Disease

(General Health Scores are scaled down from 100 to 10)

Figure 2: Health Utility Indices of Adult Patients with Sickle Cell Disease

Figure 3: Relationship between Sickle Cell Pain and Health Utility



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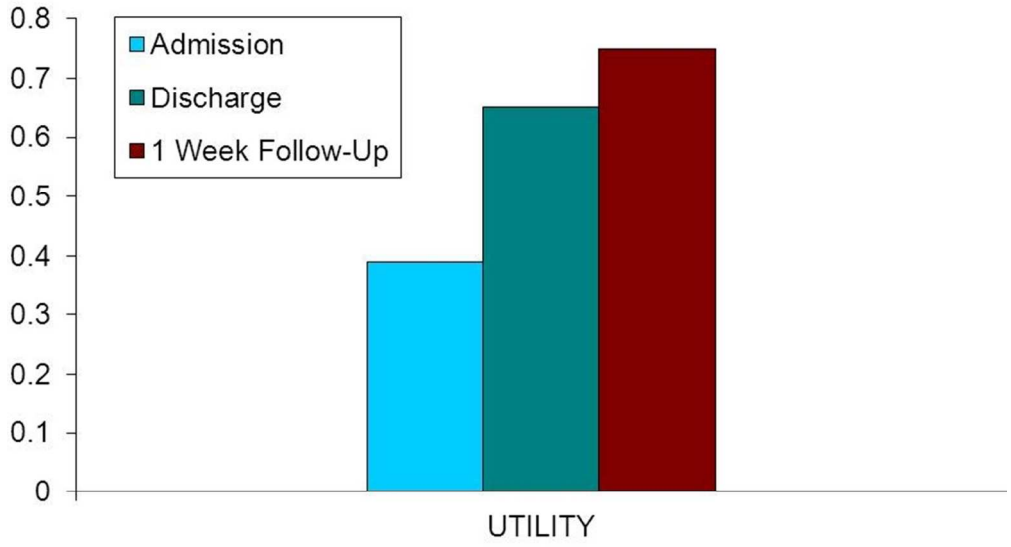

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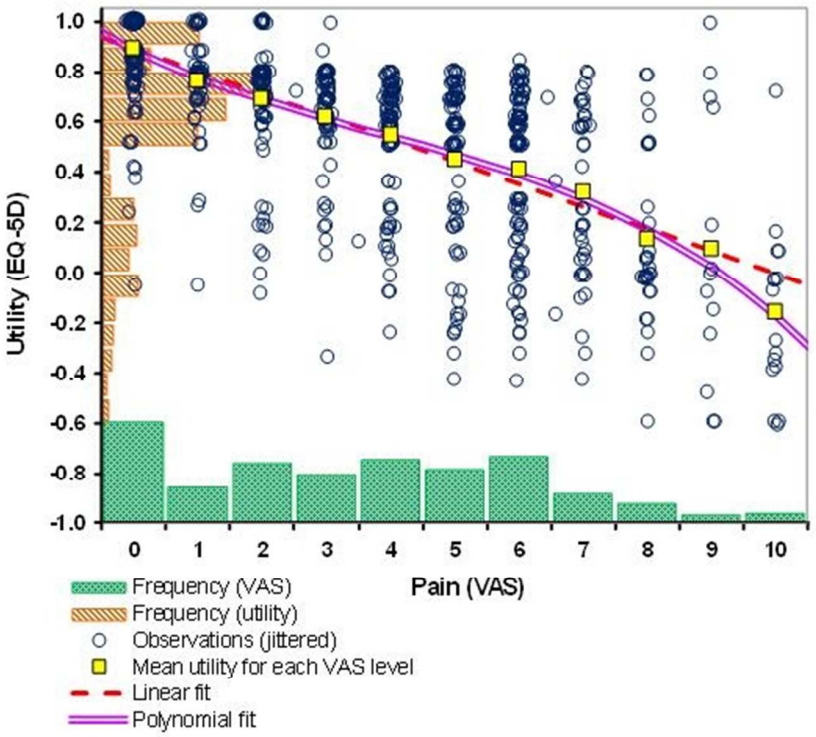

169x135mm (96 x 96 DPI)