Development and validation of the Satisfaction with Treatment for Pain Questionnaire (STPQ) among patients with sickle cell disease

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Abstract
A brief measure of patient satisfaction with treatment for pain is needed to help improve the treatment of painful episodes caused by sickle cell disease (SCD), especially during and after the transition from paediatric to adult care. Focus groups of 28 adolescent and adult patients were consulted about the content, clarity and relevance of 30 potential items, resulting in an 18-item version. This was validated by analysing questionnaire responses from 120 patients aged 12-53 years. Confirmatory factor analysis and item analysis indicated five subscales with high internal reliability: 'Communication and Involvement' (6 items, α=0.87); 'Respect and Dignity' (3 items, α=0.82); 'Pain Control' (3 items, α=0.91); 'Staff Attitudes and Behaviour' (4 items, α=0.88); and 'Overall Satisfaction' (2 items, α=0.85); plus a Total Satisfaction score (18 items, α=0.96). High negative correlations with the Picker Patient Experience Questionnaire, a measure of problem experiences, indicated good convergent validity. Lower satisfaction scores among patients aged over 18 years, those admitted via the emergency department, those treated by non-specialist hospital staff, and those reporting more breakthrough pain indicated good concurrent validity. The questionnaire provides a convenient brief measure that can be used to inform and evaluate improvements in healthcare for adolescent and adult patients with SCD, and could potentially be adapted for other painful conditions.

Keywords: Sickle, pain, treatment, patient, satisfaction

Introduction

Admission to hospital with acute pain is a frequent experience for patients with sickle cell disease (SCD), yet patients' experiences of how acute painful episodes are managed in hospital are often negative. Questionnaire, interview and focus group studies are consistent in highlighting deficiencies in knowledge, expertise and training amongst medical and nursing staff, who are also sometimes perceived by patients as unsympathetic and unwilling to believe that patients are in pain (Haywood et al., 2014a; Lattimer et al., 2010; Elander et al., 2011).

Problematic hospital pain management for patients with SCD is an international problem that reflects a range of factors, including how hospital staff perceive and make judgements about SCD patients' pain (Elander et al., 2006; 2011). Recognition of these problems has led to interventions to improve the quality of hospital care for sickling episodes, including initiatives focusing on community services (Lottenberg et al., 2014), hospital emergency departments (Morris et al., 2012; Tanabe et al., 2012), analgesic medication management (Mager et al., 2017), and staff attitudes (Haywood et al., 2015; Singh et al., 2016).

One study showed that satisfaction was higher among SCD patients receiving care at specialist rather than non-specialist treatment centres (Aisiku et al., 2007), so it seems likely that satisfaction directly reflects quality of care. Another showed that satisfaction was associated with better treatment adherence among patients with SCD (Haywood et al., 2014b), so there are multiple reasons for focusing on improving patient satisfaction in order to improve health outcomes for patients with SCD.

An important group of SCD patients who often experience poorer quality care are young people transitioning from paediatric to adult services (Wojciechowski et al., 2002). One analysis showed that young adults had more SCD complications than paediatric patients (Blinder et al., 2013), and another showed that acute care encounters, re-hospitalisations and emergency department attendance all increased around the time of transition (Brousseau et al., 2010). Large cohort studies show increases in deaths among young adult SCD patients soon after the transition to adult care (Quinn et al., 2010). One review of 90 young adult SCD patients showed that 20% died and 32% developed chronic pain problems within 10 years of transition (Ballas & Dampier, 2004).

Understanding the causes of poor quality care and improving standards of care require valid and reliable measures of patients' experiences, and a Cochrane Review of pain management for sickle cell disease in children and adults recommended developing measures of pain management outcomes that are most relevant to patients and families (Dunlop & Bennett, 2006). There is also a broader trend towards greater use of patient-reported outcomes (PROs), which are any reports of patients' health status that come directly from the patient, like the Patient-Reported Outcomes Measurement Information System (PROMIS; Cella et al., 2010) or the Pediatric Quality of Life Inventory (PedsQL; Varni et al., 2003). PRO measures generally assess patients' symptoms, functioning or quality of life, and are often intended to inform clinical practice and individual case management as well as to evaluate services and treatment protocols (Dobrozsi & Panepinto, 2015; Elander & Spitz, 2017). Measures of patient-reported satisfaction with hospital care can therefore contribute to a developing bank of PRO measures for use to improve clinical practice and quality of care.

Some studies of SCD patients' satisfaction with care (Aisiku et al., 2007; Lattimer et al., 2010) have used satisfaction measures developed for general use with patients (Jenkinson et al., 2002; Marshall & Hays, 1994). A satisfaction survey conducted by the UK Sickle Cell Society was designed specifically for SCD patients (Chalkley et al., 2012) but not for psychometric analysis, which assesses an instrument from a measurement point of view and estimates 'reliability' (the extent to which it produces similar results under consistent conditions) and 'validity' (the extent to which it measures what it purports to measure) (Furr, 2018).

A SCD-specific measure of patient-reported quality of care that was developed from psychometric analysis of 13 items from a larger quality of life survey identified three composites called Access, Provider Interaction, and Emergency Department Care (Evensen et al., 2016). However, this measure asked about pain management only in the emergency department, and was developed and validated only with adult patients, whereas we wished to develop a measure of satisfaction with treatment for pain in any hospital department, which could also be used by both adolescent and adult patients to help improve SCD patients' transitions from paediatric to adult services. The aim of the present study was therefore to produce a valid and reliable measure of satisfaction with treatment for pain that was designed specifically to evaluate hospital treatment of painful sickling episodes among adolescent and adult SCD patients.

Methods
Development of the questionnaire
We adopted a deductive approach to generating content, rather than beginning with patient interviews or focus groups about experiences of care, because there is already considerable qualitative research on SCD patients' experiences of care (eg., Maxwell et al., 1999; Strickland et al., 2001). A set of pre-identified potential items was therefore used to prompt and facilitate more focused consultation and discussion with patients in focus groups, which were also invited to address issues of content, for example by identifying aspects of treatment that needed to be included in addition to those already identified. The initial 'top down' approach was therefore intended to make use of existing knowledge and enable patients to contribute more effectively to the development process.

Following established good practice for scale development (DeVellis, 2012), we first identified potential questionnaire items from previous measures. These included the Picker Patient Experience Questionnaire (Jenkinson et al., 2002), the Patient Satisfaction Questionnaire (Marshall & Hays, 1994) and the UK Sickle Cell Society's survey of service users (Chalkley et al., 2012). This produced an initial pool of 64 potential items covering communication and involvement in care, respect and dignity, pain control, staff attitudes and behaviour, and overall satisfaction. Items that were not relevant to SCD pain were eliminated in a panel assessment process. First, each of six members of a panel rated each item as relevant or not relevant. Items the panel agreed were not relevant were eliminated, and then items the panel disagreed about were discussed to reach consensus. The criteria were that retained items should be about issues that could affect hospital treatment of painful episodes, so items specifically referring to screening, treatment of other symptoms, financial costs of care etc. were eliminated. This resulted in a shorter list of 30 potential items, with 13 about communication and involvement, 4 about respect and dignity, 3 about pain control, 3 about staff attitudes and behaviour, and 7 about overall satisfaction.

Health professionals with specific expertise in the management of SCD pain were then consulted to assess the 30 items for coverage and content validity, and to adapt wording where necessary. This

was achieved by providing the 30 items with instructions about what issues to consider, and asking the subject matter experts to rate each item for relevance and make comments, in the format of the example given in Appendix 1.

Focus groups
Focus groups of adolescent and adult SCD patients were then consulted about the 30 items to: a) assess item relevance, importance, comprehensibility, acceptability and usability; b) identify other potential aspects of treatment that should also be covered; and c) select a smaller number of items for a briefer measure.

This was achieved by giving participants the 30 items to look at before the meetings; they were asked to bring their copies, together with any notes, to the focus groups for discussion. The group discussions began by considering points that participants brought from their advance reading and went on to further discussion of the items and the issues to be considered when measuring people's satisfaction with their care in hospital during treatment for painful sickling episodes. This included exploring participants' views about their own care experiences and factors that influenced their own satisfaction with hospital care, as well as issues like wording, language and response formats.

The criteria were defined with prompts, for example: 'Is this question about something that affects how you feel about how you are looked after in hospital during a painful sickling episode?' (Relevance); 'Does this question refer to something that really makes a difference to how you feel about the hospital care?' (Importance); 'Is this question easy for you or other people to understand?' (Comprehensibility); 'Is this question saying what it means in the right way, and not being rude or strange at all? (Acceptability); and 'Is it possible to give a proper answer to this question?' (Usability).

Focus group participants were identified from lists of patients attending sickle cell clinics at Bart's Health NHS Trust who had at least one acute painful sickling episode treated in hospital in the past two years. All potential participants or their parents/carers were given patient information sheets explaining the study and signed an informed consent form. Adolescent patients under age 16 signed an assent form. Separate focus groups were conducted for adolescents (aged 14–19 years) and adults (aged 20+ years). The focus group participants comprised 10 adolescents and 18 adults with SCD. Most were of African family origin and all spoke English. One adult and one adolescent focus group were held at the Royal London Hospital and the other two were held at Newham University Hospital. The focus groups lasted between 45 and 90 minutes, and were facilitated by two of the authors (JE and DB). A postgraduate student also helped to facilitate two of the groups. Participants were paid £25 each for participating in recognition of the time and effort involved.

The discussions were audio-recorded and transcribed verbatim. Transcripts were analysed using an adaptation of the Delphi method to elicit and summarise expert opinion (Brady, 2015). This involved first identifying content in the transcripts that met the criteria for addressing relevance, importance, comprehensibility, acceptability or usability, then establishing whether or not there was reasonable consensus among participants. A descriptive thematic analysis was then applied to organise participants' contributions into themes (Braun & Clarke, 2006), which were then used as a framework for translating focus group suggestions into proposed modifications to the questionnaire.

Validation of the questionnaire
The aim of the validation phase was to test the questionnaire as modified following the patient focus groups for factor structure, internal reliability, convergent validity and concurrent validity. For factor structure, we tested 1-factor, 2-factor and 5-factor models. The 1-factor model included all the items together, assuming that satisfaction is a general, unidimensional phenomenon. The 2-factor model comprised pain control and medication issues as one factor and interpersonal issues as another, based on a broad distinction between pharmacological pain management and more interpersonal aspects of care. The 5-factor model comprised communication and involvement, respect and dignity, pain control, staff attitudes and behaviour, and overall satisfaction, based on specific areas of content identified during the development phase.

The participants were SCD patients recruited at East London and Essex Clinical Haemoglobinopathy Network hospitals, who completed paper-based questionnaires in hospital clinics, and patients at other hospitals who were recruited via the Sickle Cell Society and completed the questionnaire online. Eligibility criteria were age 12-55 years, diagnosis of SCD (any genotype), and at least one acute painful sickling episode treated in hospital in the past two years. For those recruited via the Sickle Cell Society, an invitation message was e-mailed to eligible members and affiliates by the Society and posted on the Society web pages.

Participants were asked to report their age, gender, SCD type, family origins and place of residence. They were then asked to give information about painful episodes they had experienced in the past year and their last hospital treatment for a painful episode. Then they completed the STPQ and the Picker Patient Experience Questionnaire (PPE-15; Jenkinson et al., 2002). The PPE-15 is a 15-item measure of patients' experiences covering seven aspects of healthcare: information and education, coordination of care, physical comfort, emotional support, respect for patient preferences, involvement of family and friends, continuity and transition, and overall impression. . Two of the response options for each question indicate a problem, one more severe than the other. Two scores can be computed to show the numbers of items for which problems were reported, each with a potential range of 0-15; one counting only more severe problems, the other counting both more and less severe problems.

Data were analysed for normality using the Kaiser-Meyer-Olkin (KMO) measure (Kaiser, 1970) and Bartlett's (1950) Test of Sphericity. Because we wished to compare specific pre-identified factor structures, confirmatory factor analysis was used to compare the fit between data and factor structures of the 1-factor, 2-factor and 5-factor models (Harlow, 2014).

Seven indicators of model fit were computed for each model: Chi Square (recommended value ≤ 3.00; Gefen et al., 2000) was used to assess whether data differed from the models. The Goodness-of-Fit Index (GFI) (recommended value ≥ 0.90; Hoyle, 1995), Root Mean-Square Error of Approximation (RMSEA) (recommended value ≤ 0.06; Hu & Bentler, 1999) and Standardised Root Mean Square Residual (SRMR) (recommended value ≤ 0.08; Hu & Bentler, 1999) were used to assess how much of the variance in the data was explained by the models. The Comparative Fit Index (CFI) (recommended value ≥ 0.95; Hu & Bentler, 1999), Tucker Lewis Index (TLI) (recommended value ≥ 0.95; Hu & Bentler, 1999) and Normed Fit Index (NFI) (recommended value ≥ 0.95; Hu & Bentler, 1999) were used to test the models against the worst possible model outcome. The Maximum Likelihood estimator method was used in each case (Brown, 2015). For data scaling, the first variable for each scale was set at one.

The internal reliability or internal consistency of each factor (the extent to which a given group of items measure the same thing) was assessed by computing Cronbach's Alpha (α). For the model with the best fit to the data, subscale scores were computed by summing across the items in each factor, with higher scores indicating greater satisfaction. Convergent validity was assessed by examining relationships between STPQ scores and PPE-15 scores using Pearson correlations. We predicted negative correlations because STPQ scores measure satisfaction and PPE-15 scores measure problematic experiences. Concurrent validity was assessed by comparing STPQ scores between patients with different specific experiences and histories of treatment, using t tests and Pearson correlations. This bi-variate approach, testing associations between satisfaction and individual variables, was chosen to give the most comprehensive picture of concurrent validity, in which all the patient and treatment factors associated with STPQ scores would be identified, and also to test a number of specific predictions. Based on previous evidence about factors affecting quality of pain management for sickle cell disease, we predicted that STPQ scores would be:

1. Higher among younger participants treated in paediatric hospital wards (Wojciechowski et al., 2002; Blinder et al., 2013);
2. Lower among participants admitted to hospital via Accident and Emergency departments (Aisiku et al., 2009; Glassberg et al., 2013);
3. Lower among participants treated with shorter-acting analgesics and delivery methods (Rees et al., 2003; Sickle Cell Society, 2008);
4. Lower among participants reporting adverse effects of hospital pain management (Krishnamurti et al., 2014; Whelan et al., 2004).

Ethics and governance
The study protocol was approved by the NHS National Research Ethics Committee (Ref 14/YH/1288) and by the NHS Health Research Authority, and was sponsored by Bart's Health NHS Trust. The main source of funding was a strategic research grant from Bart's Charity. Funders had no part in drafting or reviewing the protocol, conducting the study or analysing and reporting results.

Results
Focus groups
The themes that resulted from the analysis of focus group data were: a) *content* – questions that should be retained or discarded, and topic areas that needed to be covered; b) *modification of existing questions*; and c) *technical aspects*, including clarity (making the meaning of questions quickly and easily grasped), repetition (ensuring that each question addressed a distinct issue), overall length (making each question as brief and concise as possible), and interpretation (avoiding ambiguous wording and statements that could have different meanings). These provided a framework for organising specific proposed modifications, which were checked to ensure they captured the intentions of a consensus of participants before being implemented. A commentary on focus group feedback is given in Appendix 2.

The resulting 18 items are given below, for use with 5-point response scales: 'strongly agree' (coded 5), 'agree' (4), 'not sure' (3), 'disagree' (2), 'strongly disagree' (1). The instructions were 'Please think about the last time you were in hospital for a painful episode, and tick one box for each statement to show how much you agree or disagree'.
1. I was satisfied with the communication between me and the people looking after me.
2. I felt comfortable enough to ask questions.
3. When I asked questions, I got answers I could understand.

4. The people looking after me spent enough time with me.
5. The people looking after me treated me with respect and dignity.
6. The people looking after me had a good attitude.
7. I was involved enough in decisions about my treatment and care.
8. I was told enough about my medications.
9. The people looking after me responded to my pain in good time.
10. The people looking after me believed how serious my pain was.
11. The people looking after me did everything they could to control my pain.
12. Overall I was satisfied with how my pain was treated.
13. The people looking after me knew enough about my condition.
14. I felt good about the knowledge and ability of the people looking after me.
15. The people looking after me were careful to check everything when treating me.
16. I or my family had all the information we needed when I left hospital.
17. Overall, I was happy with the support and care I received.
18. I would recommend the hospital to other people with sickle cell disease.

Validation survey

The 18-item STPQ was completed by 120 SCD patients, including 94 (78%) who completed paper-based versions in hospital clinics and 26 (22%) who completed the questionnaire online. Characteristics of the participants completing paper-based and online versions of the questionnaire, and tests of differences between them, are shown in Table 1.

Table 1. Demographic and other features of participants in the validation phase.

	Paper-based	Online	X^2 or t	Total
N (%)	94 (78.3%)	26 (21.7%)	-	120
N (%) Female	51 (54.3%)	21 (80.8%)	X^2=5.97*	72 (60.0%)
Mean (SD) years age	22.72 (8.76)	30.50 (11.83)	t=3.12**	24.4 (9.98)
N (%) Age <18 years	38 (40.4%)	4 (15.4%)	X^2=5.61*	42 (35.0%)
N (%) Age <16 years	16 (17.0%)	3 (11.5%)	X^2=0.14	19 (15.8%)
N (%) Married/co-habiting	8 (8.5%)	6 (23.1%)	X^2=2.90	14 (11.7%)
Ln (%) living in London	88 (93.6%)	12 (46.2%)	X^2=29.71***	100 (83.3%)
N (%) African family origin	81 (86.2%)	16 (61.5%)	X^2=6.47**	97 (80.8%)
N (%) HbSS genotype[a]	81 (89.0%)	19 (73.1%)	X^2=2.95	100 (85.5%)
N (%) Attend London hospital	93 (98.9%)	12 (46.2%)	X^2=47.16***	105 (87.5%)
N (%) Arrived in hospital via A & E[a]	80 (87.9%)	17 (65.4%)	X^2=5.74*	97 (82.9%)
Mean (SD) painful episodes last year when did not see doctor	6.70 (8.57)	6.96 (10.38)	t=0.13	6.76 (8.95)
Mean (SD) painful episodes last year when did see doctor	4.21 (6.56)	3.39 (3.61)	t=0.61	4.02 (6.01)
Mean (SD) nights in hospital last admission	5.55 (5.38)	4.92 (7.12)	t=0.48	5.40 (5.60)

Notes: a n=117 because three participants did not give information about their SCD genotype or how they arrived in hospital; * p<0.05; ** p<0.01; *** p<0.001.

Compared with participants who completed paper-based versions, respondents to the online survey were more likely to be female and were older, with fewer individuals aged under 18 years, and less likely to have African family origins. They were also less likely to live in London, to attend hospital in London, and to have arrived at hospital via the accident and emergency department at their last admission. However the groups did not differ significantly in the proportions who were married or

cohabiting or who had HbSS genotype, nor how many painful episodes they had in the last year or how many nights they spent in hospital during their last admission.

Factor structure

The Kaiser-Meyer-Olkin (KMO) value was 0.944, showing adequate sampling (Field, 2013; Hutcheson & Sofroniou, 1999). Bartlett's test of Sphericity was highly significant (X^2=1810.28, df=153, p< .001) indicating that the correlations were significantly different from zero, making factor analysis appropriate. Table 2 shows values of seven fit indices along with the values they should be at least 'close to' for a good fit between model and data (Hu & Bentler, 1999). The 1-factor model comprised all 18 items. The 2-factor model comprised Pain Control and Medication (Qs 8, 9, 10, 11 & 12) and Interpersonal Issues (Qs 1, 2, 3, 4, 5, 6, 7, 13, 14, 15, 16, 17 & 18). The 5-factor model comprised Communication and Involvement (Qs 1, 2, 3, 7, 8 & 16), Respect and Dignity (Qs 4, 5 & 6), Pain Control (Qs 9, 11 & 12), Staff Attitudes and Behaviour (Qs 10, 13, 14 & 15), and Overall Satisfaction (Qs 17 & 18).

Table 2. Fit indices and recommended values

Fit indices	1-factor	2-factor	5-factor	Recommended values	Source
X^2	319.64	307.757	251.974	<=3.00	Gefen et al. (2000)
Df	135	134	125	N/A	N/A
P	<0.001	<0.001	<0.001	>.05	N/A
GFI	0.774	0.783	0.820	>=0.90	Hoyle (1995)
RMSEA	0.107	0.104	0.092	<= 0.06	Hu & Bentler (1999)
SRMR	0.052	0.053	0.049	<= 0.08	Hu & Bentler (1999)
CFI	0.896	0.903	0.929	>=0.95	Hu & Bentler (1999)
TLI	0.883	0.889	0.913	>=0.95	Hu & Bentler (1999)
NFI	0.835	0.841	0.870	>=0.95	Hu & Bentler (1999)

Notes: X^2=Chi Squared; *df*=degrees of freedom; *p*=probability; GFI=Goodness of fit index; RMSEA=root mean squared error of approximation; SRMR=standardized root mean squared residual; CFI=Comparative Fit Index; TLI=Tucker-Lewis Index; NFI=Normed Fit Index.

While X^2 was significant in each case, indicating differences between the data and the model, X^2 was much lower for the 5-factor model than both the 1-factor and 2-factor models, showing that the 5-factor model was a better fit to the data. Indeed, for all the other fit indices, the values for the 5-factor model were more favourable than those for the 1-factor or 2-factor models, suggesting that the 5-factor model fitted the data better than the other models. For one of the indices (SRMR), the value for the 5-factor model exceeded the recommended value, and for the remainder they were close to recommended values, indicating the 5-factor model was an acceptable though not ideal fit to the data.

Cronbach's alpha coefficients (α), measuring internal consistency or internal 'reliability', for the five factors were: Communication and Involvement 0.87; Respect and Dignity 0.82, Pain Control 0.91, Staff Attitudes and Behaviour 0.88, Overall Satisfaction 0.85. Cronbach's alpha for the two factors were 0.92 for Pain Control and Medication and 0.94 for Interpersonal Factors. Cronbach's alpha for the 18-item total was 0.96. These show that five subscales and the total score had very high internal consistency. Descriptive statistics for the five subscales and total score (computed by summing across items) are given in Table 3. Higher scores indicate greater satisfaction in each case.

Table 3. Subscale and total satisfaction scores

	Min-max	Mean (SD)
Communication & Involvement	7-30	23.39 (4.54)
Respect & Dignity	3-15	10.99 (2.87)
Pain Control	3-15	10.69 (3.22)
Staff Attitudes & Behaviour	4-20	14.77 (3.83)
Overall Satisfaction	2-10	7.73 (2.09)
Total Satisfaction	21-90	67.57 (15.13)

Convergent validity

The first score derived from the PPE-15 questionnaire, which counted only responses indicating more severe problems, ranged from 0 to 13 with a mean of 2.76 (SD 2.66). The second, which counted responses indicating both more and less severe problems, ranged from 0 to 15 with a mean of 8.08 (SD 4.25). The correlations between STPQ scores and the first PPE-15 score ranged from -0.610 for Staff Attitudes and Behaviour to -0.691 for Total Satisfaction, and those between STPQ scores and the second PPE-15 score ranged from -0.544 for Overall Satisfaction to -0.677 for Total Satisfaction, with $p < 0.001$ in each case. For both PPE-5 scores, the highest correlation was with Total Satisfaction. The correlations between STPQ scores and PPE-15 scores were similar in size to the correlation between the two PPE-15 scores, which was 0.626.

Concurrent validity

Because there were six questionnaire scores for each person (five subscales and a Total Satisfaction score), we adjusted the critical value of *p* to 0.0083 (0.05 divided by 6) for all the tests in which STPQ scores were compared between groups of participants or correlated with other measures (Bonferroni, 1936).

We first examined possible differences in satisfaction scores between demographic sub-groups. Mean STPQ scores for male and female participants, and those aged under and over 18 years are shown in tables 4 and 5. Male participants had higher scores than females for Communication and Involvement. Participants aged under 18 years had higher scores for Respect and Dignity, Pain Control, Staff Attitudes and Behaviour, and Total Satisfaction, but not Communication and Involvement or Overall Satisfaction. Age in years was also negatively correlated with Respect and Dignity (r=-0.28, p=0.002), Staff Attitudes and Behaviour (r=-0.24, p=0.007), and Total Satisfaction (-0.24, p=0.007).

Table 4. Mean (SD) scores for male (n=48; 40%) and female (n=72; 60%) participants

	Male	Female	t
Communication & Involvement	24.75 (3.61)	22.49 (4.88)	2.75*
Respect & Dignity	11.81 (2.50)	10.44 (2.99)	2.62
Pain Control	11.06 (2.97)	10.44 (3.37)	1.03
Staff Attitudes and Behaviour	15.81 (3.25)	14.07 (4.05)	2.49
Overall Satisfaction	8.17 (1.80)	7.44 (2.23)	1.88
Total Satisfaction	71.60 (12.39)	64.89 (16.24)	2.43

Note: * p < 0.0083 (0.05 divided by 6)

Table 5. Mean (SD) scores for participants aged under (n=42; 35%) and over (n=78; 65%) 18 years

	<18 years	=>18 years	t
Communication & Involvement	24.60 (4.14)	22.74 (4.64)	2.17
Respect & Dignity	12.24 (2.50)	10.32 (2.85)	3.66*
Pain Control	11.91 (2.77)	10.04 (3.27)	3.30*
Staff Attitudes and Behaviour	16.48 (3.59)	13.85 (3.66)	3.78*
Overall Satisfaction	8.36 (1.83)	7.40 (2.15)	2.45
Total Satisfaction	73.57 (13.83)	64.35 (14.89)	3.32*

Note: * $p < 0.0083$ (0.05 divided by 6)

Participants who were single had higher scores than those who were married or cohabiting for Respect and Dignity, Overall Satisfaction, and Total Satisfaction (group means and significance tests are given in Appendix 3, table A4). However, there were only 14 participants who were married or cohabiting, and those who were single were also significantly younger than those who were married or cohabiting (mean 22.71 years [SD 8.70] compared with 37.29 [SD 9.96]; t=5.80, p<0.001), so the differences between groups may have reflected age differences as much as relationship status differences.

There were no significant differences in STPQ subscale or total scores between those who completed the questionnaire online versus in hospital clinics, nor between those with African versus other family origins, or those living in London versus outside London, or those attending hospitals in London versus outside London (group means and significance tests are given in Appendix 3).

We next examined relationships between STPQ scores and participants' histories of painful episodes and treatment during their last hospital admission. Participants who arrived in hospital via the Accident and Emergency department had lower scores for Respect and Dignity, Pain Control, Staff Attitudes and Behaviour, Overall Satisfaction and Total Satisfaction (Table 6). Participants treated by general doctors and nurses had lower satisfaction scores for Communication and Involvement, Respect and Dignity, Staff Attitudes and Behaviour, and Total Satisfaction (Table 7).

Table 6. Mean (SD) scores for participants who did (n=97; 82.9%) and did not (n=20; 17.1%) arrive in hospital via the Accident and Emergency department[a]

	Arrived via A & E	Did not arrive via A & E	t
Communication & Involvement	22.92 (4.66)	25.15 (3.48)	2.03
Respect & Dignity	10.57 (2.95)	12.65 (1.63)	4.41*
Pain Control	10.20 (3.28)	12.60 (1.90)	4.45*
Staff Attitudes & Behaviour	14.20 (3.88)	17.05 (2.61)	4.06*
Overall Satisfaction	7.45 (2.18)	8.85 (1.04)	4.35*
Total Satisfaction	65.33 (15.49)	76.30 (8.85)	4.34*

Notes: a n=117 because three participants did not give information about how they arrived in the hospital; * $p < 0.0083$ (0.05 divided by 6).

Table 7. Mean (SD) scores for participants treated (n=83; 70.3%) and not treated (n=35; 29.7%) by general (not specialist) doctors and nurses[a]

	Treated by general doctors and nurses	Not treated by general doctors and nurses	t
Communication & Involvement	22.41 (4.73)	25.57 (3.21)	3.62*
Respect & Dignity	10.46 (2.88)	12.14 (2.57)	2.99*
Pain Control	10.19 (3.12)	11.71 (3.26)	2.39
Staff Attitudes & Behaviour	13.95 (3.89)	16.57 (3.12)	3.53*
Overall Satisfaction	7.45 (2.07)	8.34 (2.06)	2.15
Total Satisfaction	64.46 (15.14)	74.34 (13.15)	3.37*

Notes: a n=118 because two participants did not give information about being treated by general doctors and nurses; * $p < 0.0083$ (0.05 divided by 6).

Frequency of breakthrough pain was correlated with Communication and Involvement (r=-0.259, p=0.005), Respect and Dignity (r=-0.317. p<0.001), Pain (r=-0.414, p<0.001), Staff (r=-0.292, p=0.001), Overall Satisfaction (r=-0.244, p=0.008), and Total Satisfaction (r=-0.333, p<0.001), but STPQ scores were not correlated with how often participants experienced side effects of analgesics. There were also no significant correlations between STPQ scores and numbers of painful episodes in the last year where participants saw a doctor or went to hospital, nor those where participants did not see a doctor or go to hospital. Scores were also not correlated with the number of nights participants spent in hospital in their last admission, and they did not differ significantly between participants who were and were not treated in each of Accident and Emergency, a general ward, or a specialist haematology ward (correlations, group means and significance tests are given in Appendix 4).

STPQ scores also did not differ between participants who were and were not treated with Morphine, Diamorphine, Oxycodone, Pethidine or Fentanyl. Participants treated with subcutaneous analgesics had lower satisfaction scores for Respect and Dignity, but scores did not differ between participants who were and were not treated with oral, intramuscular, intranasal or sublingual analgesics, or with continuously infused or patient-controlled analgesics (group means and significance tests are given in Appendix 5).

The pattern of associations between STPQ scores and other measures is summarised in Table 8. This shows that Respect and Dignity was the STPQ subscale most sensitive to influence, followed by Total Satisfaction, then Staff Attitudes and Behaviour. More frequent breakthrough pain influenced all six satisfaction measures, and arriving in hospital via Accident and Emergency influenced five out of six. Being older than 18 years was associated with lower satisfaction for Respect and Dignity, Pain Control, and Staff Attitudes and Behaviour. Being female was associated only with lower satisfaction for Communication and Involvement, and being treated with subcutaneous analgesics was associated only with lower satisfaction for Respect and Dignity.

	STPQ subscales					Total satisfaction score
	Communication & Involvement	Respect & Dignity	Pain Control	Staff Attitudes & Behaviour	Overall Satisfaction	
Female	Less satisfied					
Aged over 18 years		Less satisfied	Less satisfied	Less satisfied		Less satisfied
Married or cohabiting		Less satisfied			Less satisfied	Less satisfied
Admitted via A and E		Less satisfied	Less satisfied	Less satisfied	Less satisfied	Less satisfied
Treated by general staff	Less satisfied	Less satisfied		Less satisfied		Less satisfied
Subcutaneous analgesics		Less satisfied				
Breakthrough pain	Less satisfied	Less satisfied	Less satisfied	Less satisfied	Less satisfied	Less satisfied

Discussion

The factor analysis and item analysis supported a 5-factor structure, making the scale a simple, brief measure of several key aspects of patient satisfaction, each with very good internal reliability. Convergent validity was supported by highly significant negative correlations with scores from the PPE-15, which is a widely used and positively evaluated measure of patient experiences in healthcare (Beattie et al., 2015).

Concurrent validity was supported by predicted relationships with participants' recent hospital experiences: four of the six satisfaction scores were higher among participants under 18 years old, supporting prediction one; five scores were lower among patients admitted via the accident and emergency department, supporting prediction two; four scores were lower among patients treated by general rather than specialist staff and all six scores were lower among patients who experienced more breakthrough pain, supporting prediction four. However, the only analgesic type or delivery method associated with satisfaction was subcutaneous administration of analgesics, which was associated only with lower Respect and dignity, so there was little support for prediction three.

These findings are consistent with research showing that quality of care is reduced when patients transition from paediatric to adult services (Wojciechowski et al., 2002; Blinder et al., 2013), and that patients have poorer experiences in hospital emergency departments (Aisiku et al., 2009; Glassberg et al., 2013) and when their pain is less well controlled (Krishnamurti et al., 2014; Whelan et al., 2004). The scale's validity as a specific measure of satisfaction with treatment for pain was also supported by the fact that scores were not related to more general measures of illness severity, such as numbers of painful episodes or nights spent in hospital.

The satisfaction with treatment for pain questionnaire (STPQ) has a strong emphasis on behavioural and interpersonal aspects of care, as do the Patient Satisfaction Questionnaire (PSQ; Marshall & Hays, 1994), the PPE-15 (Jenkinson et al., 2002), and the ASCQ-Me Quality of Care survey (Evensen et al., 2016). However, the PSQ does not ask about pain at all, the PPE-15 has just one question about pain, and the ASCQ-Me Quality of care survey has three items about pain but all three are about pain in the emergency room. Two of these loaded on the Emergency Department Care composite and the third loaded on the Access composite ('what is the longest you had to wait in the emergency room before your pain was treated') (Evensen et al., 2016). By comparison with those measures, the STPQ was specifically designed to measure satisfaction with treatment for pain and includes 4 items about pain and a specific 3-item subscale dealing specifically with pain control. (One item about pain is in the Staff Attitudes and Behaviour subscale; Q11: 'The people looking after me

believed how serious my pain was.') The STPQ asks about treatment of pain in hospital generally, not just the emergency department, so it could be used to compare experiences between patients treated in different hospital wards or departments, or those admitted to hospital in different ways.

The STPQ was developed in close consultation with SCD patients in order to identify aspects of care that impact on patients' hospital experiences, consistent with the recommendations of a Cochrane Review (Dunlop & Bennett, 2006). This is the reason for the inclusion of so many items that do not deal specifically with pain management, for the focus group consultation revealed the extent to which interpersonal and non-pharmacological aspects of hospital care influence patients' experiences of treatment for pain. Given that, as a measure of hospital treatment of pain, the STPQ includes so many items dealing with interpersonal and other aspects of treatment not directly and specifically related to the clinical/pharmacological management of pain, one might ask why we did not begin with an existing patient-reported outcome measure. For example, global and disease specific PRO measures, including pain and fatigue, were used to inform the improved clinical management of a teenage boy with sickle cell disease in one example (Dobrozsi & Panepinto, 2015, pp. 504-5). However, the PROs used in that example provided information about the patients' own symptoms, functioning, quality of life etc., which could be used to direct, tailor or coordinate care, whereas a measure of satisfaction with care like the STPQ provides information about patients' direct experience of care, rather than their own health and wellbeing.

The ASCQ-Me Quality of Care survey and the STPQ have a number of similarities but also deal with subtly different aspects of hospital care; the ASCQ-Me Quality of Care survey was developed from existing patient-reported outcome measures and has a special focus on pain management in emergency departments, whereas the STPQ focuses on the hospital treatment of painful episodes, including during hospital admissions as well as in outpatient clinics and emergency departments. Also, the STPQ was designed to measure satisfaction with treatment for pain among adolescents and adults with SCD, so that it could be used in research and practice to improve transitions from paediatric to adult hospital services for SCD.

The approach we adopted was neither wholly bottom-up nor wholly top-down, but rather a hybrid as we began in a top-down way with items selected as relevant from existing measures, then developed from that starting point in a more bottom-up way with direct input from patients. The STPQ can contribute to a growing number of patient-reported outcome measures suitable for sickle cell disease, including the PROMIS, the PedQL and the ASCQ-Me Quality of Care survey. All these measures can contribute to improving clinical practice and quality of care, but the STPQ is best suited for evaluations of care for painful episodes across different hospital departments, including paediatric and adult services.

The study does have some limitations. First, it was a questionnaire study, so all the data were self-reported. This is arguably the only approach to measuring patient satisfaction, but certain information, eg. SCD genotype, could be recorded more reliably from medical records or laboratory tests, for there is evidence of misreporting of SCD status among people recruited from the general population (Bean et al., 2014). However, 78% (94/120) of the participants in the validation study were recruited and completed questionnaires in hospitals where they were known as patients, so the scope for misreporting SCD status is very small, although it is possible that some participants could have confused HbSS and HbSC genotypes.

Second, in the confirmatory factor analysis, the models were all approximate fits, and no model was an ideal fit. In these circumstances, exploratory factor analysis is sometimes performed after the confirmatory factor analysis to identify a best fitting model (eg., Evensen et al., 2016). We decided against this because we began with hypothesised models for which confirmatory analyses were the appropriate tests (Kline, 2014), and combining confirmatory and exploratory factor analyses of the same data is not regarded as good practice (Worthington & Whittaker, 2006).

Hu and Bentler (1999) point out that testing model fit by applying absolute cut-off values for fit indices is 'arbitrary' (p. 10), and it has been suggested that fit indices should be treated as guides rather than cut-offs, as model complexity and sample size can affect their values (Brown, 2015). Hu and Bentler (1999) instead recommend considering combinations of fit indices to minimise the probability of type I and type II error. They do not actually define 'close to', but the differences between our values and the recommended values are genuinely small in several cases (CFI 0.929 compared with 0.95; TLI 0.913 compared with 0.95; NFI 0.870 compared with 0.95), and our values are at the upper end of the range of values considered by Hu and Bentler (1999). The analyses also allowed us to discriminate between models because fit indices can be used to test competing models (Worthington & Whittaker, 2006).

Whereas the fit indices were less than ideal in most cases, the Cronbach's Alpha coefficients of internal reliability were extremely high. These indicate the internal consistency of items within each individual subscale, whereas the model fit indices assess the model as a whole. This indicates that each of the five subscales and the total score had very high internal consistency, even though the overall fit of the five-factor model could be better.

Third, the tests of convergent validity were correlations between the STPQ and PPE-15 scores. The PPE-15 was one of the measures employed in the development phase, so it could be argued that this is not a strong test of convergent validity. However, the two measures do not in fact have any items in common, and although they both deal with patients' experiences of hospital care, they are in some ways quite different. For example, the PPE-15 asks direct questions about specific negative experiences with responses options like, 'yes always', 'yes sometimes', or 'no', whereas the STPQ presents positive statements with response options on a five-point 'strongly agree' to 'strongly disagree' scale.

Fourth, the tests of concurrent validity were bivariate rather than multivariate. This identified all the individual factors associated with STPQ scores and enabled us to test specific predictions, but it does not give a broader picture of how patient and treatment factors influence satisfaction together. Future research could use multivariate models to identify such relationships or test models of how different factors act together to influence patient satisfaction with treatment.

The STPQ and scoring instructions are given in Appendix 6. Future research could also examine the detail of patients' experiences that are associated with high and low satisfaction scores, for example by conducting content analyses of responses to the open-format parts of the questionnaire to explore the reasons for high and low scores. Further research could also assess the scale with other groups of patients treated in hospital for pain, for example those with cancer, joint pain or other chronic pain syndromes, for the only change needed to adapt the scale for other conditions is to replace the words 'sickle cell disease' in the final question with 'my condition' or the name of another illness. However, considering that the entire development and validation process was

conducted with SCD patients, a version adapted for other pain conditions would need to be validated for those conditions.

In conclusion, the STPQ provides a convenient brief measure of patients' satisfaction with hospital treatment for painful sickling episodes, which can be used in research and practice to understand better what influences patient satisfaction and to improve healthcare for patients with sickle cell disease.

Conflict of interest disclosure

The authors stated that they had no interests which might have been perceived as posing a conflict or bias.

Authorship contribution

JE and PT were responsible for the study protocol. PT and BK identified potential patients and recruited patients into the study. DB, RK, AO and NK were responsible for the data collection. MBS was responsible for the confirmatory factor analysis. JE was responsible for analysing the data and writing the manuscript. PT edited the manuscript. All the authors reviewed the manuscript and approved the final version.

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Appendix 1. Illustration of the instructions and format in which potential items were presented to subject matter experts

Please look at each item in the draft questionnaire, make a rating of how relevant you think each item is for a scale measuring patient satisfaction with hospital care during painful sickling episodes, and record any comments about each item. These are some things to consider:

- Which of the questions do you think are the most important? Why is that?
- Are there questions that relate to positive aspects of care, as well as negative aspects?
- Which are least important, do you think? Why is that?
- Are there any questions that are badly worded, or don't make sense? How could those items be improved?
- Are there any questions that are offensive, or inappropriate, or irrelevant?
- Which aspects of quality of hospital care for sickle cell disease pain are not covered by any of these questions?
- What do you think of the response formats? Do these make sense?

1. I was satisfied with the communication between myself, my doctor and the hospital staff who cared for me

Strongly Agree / Agree/ Uncertain / Disagree / Strongly Disagree

Not at all relevant [ ]   [ ]   [ ]   [ ]   [ ]   [ ]   [ ]   Very relevant

Comments:

Appendix 2. Commentary on patients' feedback during focus groups

Some participants made direct suggestions about specific items which ought to be retained or discarded. In some cases, participants related questionnaire items to their own or others' experiences to show how items were relevant. For example:

> "*I find that patients say it a lot, that they are overridden* [by doctors] *so that would be a good question to ask*". (Lines 317-318, Adult, Royal London).
>
> "*I think it is important, I think it is a good question cause not everyone, like, they don't have the confidence to tell people that they want this or they want that and like, they're too scared to say, and like whatever decisions they make they just go along with it.* (Lines 633-635, Adolescent, Newham).

Other advice concerned items that could be discarded completely, and topics that ought to be included. There was a general view taken by nearly all participants about the need for a question about attitude. For example:

> "*I haven't seen one yet, but a question of what do you feel they could have done to have better take care of me in my time of need, in terms of attitude, the way staff approach their work etc etc.*" (Lines 607-609, Adult, Royal London)

The focus groups made many suggestions for amending wording in order to avoid repetition, clarify meanings, or make questions read more easily and be easier to answer. Some participants identified issues with overlap and the impact of this on the length and clarity of the questionnaire. As a result, suggestions to combine certain questions were put forward: Some of the discussion produced advice about meaning and clarity of items that required further context for more relevant answers about satisfaction of care. The discussion also highlighted the importance of using simple, accessible language to ensure that all patients could answer the questions with ease. This was because patients come from a range of different backgrounds, but also because patients could be completing the questionnaire when they were fatigued and recovering from a sickling episode. For example:

> "*You see respect and dignity? That topic? Question 4 says, my doctor treated me in a very friendly and cautious manner. I understand what cautious is but not everyone will understand what cautious is …. like, make it so easy that you don't even have to use your brain to say, oh what does this mean*" (Lines 1012-1014 and 1027-1028, Adolescent, Royal London).

Some participants identified issues with positively-framed versus negatively-framed questions, and other types of leading questions that could influence perceptions of care previously received from hospital staff. The issue of possible leading questions was usefully highlighted by participants who had first-hand experience of the situations depicted within questions, and the discussion about negatively-framed and positively-framed questions was extremely useful.

Numerous practical points were noted by participants, including the length and format of the questionnaire, the response format, and the inclusion of a comments box with each question. Some participants felt that the comments box after each question lengthened the questionnaire so that completing it could take longer. However, others felt that allowing respondents to express their views in their own words was important and the comment boxes provided space for expanding on rating responses or giving further feedback about experiences of care. As emphasised by a focus group participant, tick box exercises cannot fully reflect the true nature of personal experiences of SCD care:

> *"I don't want it to be a tick box exercise, for the quality of the service to improve I think sometimes the comments will be needed so they can actually look at, okay this is something consistent, not just oh I'm not satisfied I wasn't so happy with it or I was happy with it, erm, investigate it, there are people in the health service to do so".* (Lines 1021-1024, Adult, Royal London).

Appendix 3. Satisfaction with Treatment for Pain Questionnaire (STPQ) scores in relation to demographic and other patient factors

Tables A1-A6 below show mean (SD) STPQ scores among patient groups and the results of independent groups t-tests.

Table A1. Participants who completed questionnaires on paper (n=94; 78.3%) versus online (n=26; 21.7%)

	On paper	Online	t
Communication & Involvement	23.95 (3.93)	21.39 (5.95)	2.07
Respect & Dignity	11.21 (2.82)	10.19 (2.97)	1.61
Pain Control	10.80 (3.07)	10.31 (3.75)	0.69
Staff Attitudes & Behaviour	15.06 (3.61)	13.69 (4.48)	1.63
Overall Satisfaction	7.90 (1.96)	7.12 (2.44)	1.72
Total Satisfaction	68.93 (13.91)	62.69 (18.40)	1.88

Table A2. Participants with SCD type HbSS (n=100; 85.5%) versus HbSC or hBSThal (n=17; 14.5%) (3 participants did not know or did not answer)

	HbSS	HbSC or HbSThal	T
Communication & Involvement	23.61 (4.66)	21.65 (3.69)	1.65
Respect & Dignity	11.04 (2.95)	10.29 (2.42)	0.99
Pain Control	10.56 (3.29)	10.94 (2.84)	0.45
Staff Attitudes & Behaviour	14.81 (3.83)	13.82 (3.78)	0.98
Overall Satisfaction	7.78 (2.10)	7.24 (2.17)	0.99
Total Satisfaction	67.80 (15.39)	63.94 (13.78)	0.67

Table A3. Participants with African (n=97; 80.8%) versus other[a] (n=23; 19.2%) family origins

	African family origins	Other family origins	t
Communication & Involvement	23.39 (4.63)	23.39 (4.23)	0.00
Respect & Dignity	11.01 (3.01)	10.91 (2.28)	1.45
Pain Control	10.77 (3.19)	10.35 (3.39)	0.57
Staff Attitudes & Behaviour	14.91 (3.88)	14.17 (3.65)	0.82
Overall Satisfaction	7.78 (2.05)	7.52 (2.27)	0.54
Total Satisfaction	67.87 (15.41)	66.35 (14.14)	0.43

a There were 15 (12.5%) with Caribbean, 4 (3.3%) with Asian, and 4 (3.3%) with other family origins.

Table A4. Single (n=106; 88.3%) versus married or cohabiting (n=14; 11.7%) participants

	Single	Married or cohabiting	t
Communication & Involvement	23.82 (4.15)	20.14 (6.05)	2.21
Respect & Dignity	11.29 (2.69)	8.71 (3.29)	3.28*
Pain Control	10.96 (2.98)	8.64 (4.24)	1.99
Staff Attitudes & Behaviour	15.09 (3.68)	12.29 (4.23)	2.64
Overall Satisfaction	7.93 (1.95)	6.29 (2.59)	2.84*
Total Satisfaction	69.09 (14.02)	56.07 (18.60)	3.14*

* p < 0.0083 (0.05 divided by 6)

Table A5. Participants living in London (n=100; 83.3%) versus outside London (n=20; 16.7%)

	Living in London	Living outside London	t
Communication & Involvement	23.53 (4.30)	22.70 (5.68)	0.75
Respect & Dignity	10.88 (2.89)	11.55 (2.82)	0.95
Pain Control	10.61 (3.15)	11.10 (3.60)	0.62
Staff Attitudes & Behaviour	14.73 (3.78)	14.95 (4.20)	0.23
Overall Satisfaction	7.69 (2.08)	7.95 (2.19)	0.51
Total Satisfaction	67.44 (14.75)	68.25 (17.29)	0.22

Table A6. Participants attending hospitals in London (n=105; 87.5%) versus outside London (n=15; 12.5%)

	Attending hospital in London	Attending hospital outside London	t
Communication & Involvement	23.65 (4.26)	21.60 (6.03)	1.65
Respect & Dignity	11.10 (2.86)	10.27 (2.96)	1.05
Pain Control	10.76 (3.15)	10.20 (3.77)	0.63
Staff Attitudes & Behaviour	14.89 (3.75)	13.93 (4.41)	0.90
Overall Satisfaction	7.78 (2.08)	7.40 (2.20)	0.66
Total Satisfaction	68.17 (14.65)	63.40 (18.15)	1.14

Appendix 4. STPQ scores in relation to participants' treatment histories

Table A7. Pearson correlations between STPQ scores, painful episodes, and last hospital admission

	No. painful episodes last year without seeing doctor	No. painful episodes last year when saw doctor	No. nights in hospital last admission
Communication & Involvement	-0.11	0.01	-0.10
Respect & Dignity	-0.21	-0.16	-0.11
Pain Control	-0.19	-0.15	-0.18
Staff Attitudes & Behaviour	-0.15	-0.17	-0.12
Overall Satisfaction	-0.20	-0.00	-0.11
Total Satisfaction	-0.18	-0.10	-0.13

Tables A8-A10 below show mean (SD) STPQ scores among patients treated in different hospital departments during their last admission, and the results of independent groups t-tests. For these tests n=117 because three participants did not give information about hospital departments/wards.

Table A8. Participants not treated (n=36; 30.8%) versus treated (n=81; 69.2%) in the Accident and Emergency (A & E) Department

	Not treated in E & A	Treated in A & E	T
Communication & Involvement	23.08 (4.38)	23.43 (4.67)	0.38
Respect & Dignity	11.17 (2.85)	10.84 (2.92)	0.56
Pain Control	11.17 (2.84)	10.38 (3.38)	1.30
Staff Attitudes & Behaviour	15.22 (3.85)	14.44 (3.84)	1.01
Overall Satisfaction	7.86 (2.02)	7.63 (2.15)	0.55
Total Satisfaction	68.50 (14.48)	66.73 (15.57)	0.58

Table A9. Participants not treated (n=64; 54.7%) versus treated (n=53; 45.3%) in general hospital wards

	Not treated in general ward	Treated in general ward	T
Communication & Involvement	23.72 (4.56)	22.85 (4.58)	1.03
Respect & Dignity	11.17 (2.75)	10.66 (3.06)	0.95
Pain Control	10.84 (3.25)	10.36 (3.22)	0.81
Staff Attitudes & Behaviour	14.95 (3.70)	14.36 (4.02)	0.83
Overall Satisfaction	7.84 (1.99)	7.53 (2.24)	0.81
Total Satisfaction	68.53 (14.77)	65.75 (15.71)	0.98

Table A10. Participants not treated (n=86; 73.5%) versus treated (n=31; 26.5%) in a specialist haematology ward

	Not treated in a haematology ward	Treated in a haematology ward	T
Communication & Involvement	23.14 (4.94)	23.84 (3.36)	0.73
Respect & Dignity	10.92 (2.96)	11.00 (2.75)	0.13
Pain Control	10.58 (3.31)	10.74 (3.06)	0.24
Staff Attitudes & Behaviour	14.56 (4.09)	15.03 (3.07)	0.59
Overall Satisfaction	7.67 (2.18)	7.77 (1.91)	0.23
Total Satisfaction	66.87 (16.10)	68.39 (12.55)	0.47

Appendix 5. STPQ scores in relation to treatment with different analgesics and delivery methods

Tables A11-A15 below show mean (SD) STPQ scores among patients treated with different analgesics during their last admission, and the results of independent groups t-tests. For these tests n=115 because five participants did not give information about analgesics.

Table A11. Participants not treated (n=30; 26.1%) versus treated (n=85; 73.9%) with morphine

	Not treated with morphine	Treated with morphine	t
Communication & Involvement	23.90 (4.74)	23.18 (4.58)	0.74
Respect & Dignity	11.37 (3.03)	10.78 (2.88)	0.95
Pain Control	11.07 (3.11)	10.48 (3.32)	0.84
Staff Attitudes & Behaviour	15.10 (4.20)	14.59 (3.81)	0.62
Overall Satisfaction	8.00 (2.02)	7.60 (2.17)	0.89
Total Satisfaction	69.43 (15.89)	66.62 (15.23)	0.86

Table A12. Participants not treated (n=106; 92.2%) versus treated (n=9; 7.8%) with diamorphine

	Not treated with diamorphine	Treated with diamorphine	t
Communication & Involvement	23.13 (4.65)	26.11 (3.18)	1.88
Respect & Dignity	10.86 (2.95)	11.78 (2.59)	0.91
Pain Control	10.56 (3.31)	11.56 (2.65)	0.88
Staff Attitudes & Behaviour	14.59 (3.96)	16.33 (2.92)	1.29
Overall Satisfaction	7.67 (2.13)	8.11 (2.15)	0.60
Total Satisfaction	66.80 (15.52)	73.89 (12.60)	1.33

Table A13. Participants not treated (n=86; 74.8%) versus treated (n=29; 25.2%) with Oxycodone

	Not treated with Oxycodone	Treated with Oxycodone	t
Communication & Involvement	23.12 (4.67)	24.10 (4.45)	1.00
Respect & Dignity	11.07 (2.90)	10.52 (2.98)	0.88
Pain Control	10.77 (3.18)	10.24 (3.51)	0.75
Staff Attitudes & Behaviour	14.86 (4.01)	14.31 (3.60)	0.66
Overall Satisfaction	7.73 (2.04)	7.76 (2.40)	0.24
Total Satisfaction	67.55 (15.45)	66.79 (15.44)	0.23

Table A14. Participants not treated (n=113; 98.3%) versus treated (n=2; 1.7%) with pethidine

	Not treated with pethidine	Treated with pethidine	t
Communication & Involvement	23.30 (4.61)	27.00 (4.24)	1.13
Respect & Dignity	10.90 (2.92)	12.50 (3.4)	0.77
Pain Control	10.58 (3.26)	13.50 (2.12)	1.26
Staff Attitudes & Behaviour	14.66 (3.90)	18.00 (2.83)	1.20
Overall Satisfaction	7.69 (2.14)	8.50 (0.71)	0.53
Total Satisfaction	67.14 (15.38)	79.50 (13.44)	1.13

Table A15. Participants not treated (n=89; 77.4%) versus treated (n=26; 22.6%) with fentanyl

	Not treated with fentanyl	Treated with fentanyl	t
Communication & Involvement	23.07 (4.70)	24.39 (4.23)	1.28
Respect & Dignity	10.96 (2.88)	10.85 (3.12)	0.17
Pain Control	10.73 (3.23)	10.31 (3.43)	0.58
Staff Attitudes & Behaviour	14.70 (3.93)	14.81 (3.90)	0.13
Overall Satisfaction	7.61 (2.18)	8.04 (1.95)	0.91
Total Satisfaction	67.06 (15.53)	68.38 (15.13)	0.39

Tables A16-A23 below show mean (SD) STPQ scores among patients treated with different analgesic delivery methods during their last admission, and the results of independent groups t-tests. For these tests n=117 because three participants did not give information about delivery methods.

Table A16. Participants not treated (n=34; 29.1%) versus treated (n=83; 70.9%) with oral analgesics

	Not treated with oral analgesics	Treated with oral analgesics	t
Communication & Involvement	22.59 (4.15)	23.64 (4.73)	1.13
Respect & Dignity	10.09 (2.78)	11.29 (2.88)	2.07
Pain Control	10.00 (2.84)	10.90 (3.37)	1.38
Staff Attitudes & Behaviour	13.65 (3.39)	15.16 (3.99)	1.94
Overall Satisfaction	7.09 (2.04)	7.96 (2.10)	2.07
Total Satisfaction	63.41 (13.54)	68.95 (15.69)	1.80

Table A17. Participants not treated (n=75; 64.1%) versus treated (n=42; 35.9%) with subcutaneous analgesics

	Not treated with subcutaneous analgesics	Treated with subcutaneous analgesics	t
Communication & Involvement	23.67 (4.81)	22.74 (4.10)	1.05
Respect & Dignity	11.61 (2.85)	9.74 (2.59)	3.53*
Pain Control	11.16 (3.27)	9.71 (2.30)	2.36
Staff Attitudes & Behaviour	15.27 (4.13)	13.74 (3.16)	2.08
Overall Satisfaction	7.87 (2.22)	7.43 (1.89)	1.08
Total Satisfaction	69.57 (16.11)	63.36 (12.81	2.15

* p < 0.0083 (0.05 divided by 6)

Table A18. Participants not treated (n=100; 85.5%) versus treated (n=17; 14.5%) with intramuscular analgesics

	Not treated with intramuscular analgesics	Treated with intramuscular analgesics	t
Communication & Involvement	23.77 (4.34)	20.77 (5.19)	2.56
Respect & Dignity	11.12 (2.91)	9.88 (2.62)	1.64
Pain Control	10.84 (3.23)	9.47 (3.09)	1.62
Staff Attitudes & Behaviour	15.08 (3.85)	12.59 (3.34)	2.51
Overall Satisfaction	7.86 (2.04)	6.82 (2.38)	1.89
Total Satisfaction	68.67 (15.02)	59.53 (14.61)	2.33

Table A19. Participants not treated (n=110; 94.0%) versus treated (n=7; 6.0%) with intranasal analgesics

	Not treated with intranasal analgesics	Treated with intranasal analgesics	t
Communication & Involvement	23.22 (4.57)	25.14 (4.53)	1.08
Respect & Dignity	10.86 (2.88)	12.14 (3.13)	1.14
Pain Control	10.55 (3.23)	12.14 (3.19)	1.27
Staff Attitudes & Behaviour	14.62 (3.77)	16.29 (5.31)	1.11
Overall Satisfaction	7.66 (2.11)	8.43 (2.15)	0.93
Total Satisfaction	66.91 (15.05)	74.14 (17.89)	1.22

Table A20. Participants not treated (n=103; 88.0%) versus treated (n=14; 12.0%) with sublingual analgesics

	Not treated with sublingual analgesics	Treated with sublingual analgesics	t
Communication & Involvement	23.07 (4.62)	25.29 (3.81)	1.72
Respect & Dignity	10.89 (2.88)	11.29 (3.10)	0.48
Pain Control	10.59 (3.29)	11.00 (2.88)	0.44
Staff Attitudes & Behaviour	14.63 (3.90)	15.36 (3.71)	0.66
Overall Satisfaction	7.60 (2.17)	8.50 (1.45)	1.50
Total Satisfaction	66.79 (15.46)	71.43 (13.35)	1.07

Table A21. Participants not treated (n=113; 96.6%) versus treated (n=4; 3.4%) with analgesic patches

	Not treated with analgesic patch	Treated with analgesic patch	t
Communication & Involvement	23.30 (4.63)	24.25 (2.50)	0.42
Respect & Dignity	10.99 (2.91)	9.50 (2.38)	1.01
Pain Control	10.65 (3.27)	10.50 (2.38)	0.09
Staff Attitudes & Behaviour	14.79 (3.90)	12.75 (2.63)	1.04
Overall Satisfaction	7.70 (2.14)	8.00 (0.82)	0.28
Total Satisfaction	67.42 (15.59)	65.00 (4.32)	0.31

Table A22. Participants not treated (n=101; 86.3%) versus treated (n=16; 13.7%) with continuously infused analgesics

	Not treated with continuously infused analgesics	Treated with continuously infused analgesics	t
Communication & Involvement	23.43 (4.56)	22.75 (4.78)	0.55
Respect & Dignity	10.92 (2.96)	11.06 (2.49)	0.18
Pain Control	10.69 (3.24)	10.31 (3.28)	0.44
Staff Attitudes & Behaviour	14.94 (3.77)	13.31 (4.35)	1.57
Overall Satisfaction	7.73 (2.10)	7.56 (2.22)	0.30
Total Satisfaction	67.71 (15.21)	65.00 (15.76)	0.66

Table A23. Participants not treated (n=107; 91.5%) versus treated (n=10; 8.5%) with patient-controlled analgesia

	Treated with patient-controlled analgesia	Not treated with patient-controlled analgesic	t
Communication & Involvement	23.48 (4.57)	21.80 (4.54)	1.11
Respect & Dignity	11.12 (2.85)	9.00 (2.71)	2.26
Pain Control	10.78 (3.13)	9.20 (4.08)	1.48
Staff Attitudes & Behaviour	14.92 (3.86)	12.60 (3.50)	1.83
Overall Satisfaction	7.76 (2.05)	7.20 (2.74)	0.80
Total Satisfaction	68.05 (15.08)	59.80 (15.73)	1.65

Appendix 6. The Satisfaction with Treatment for Pain Questionnaire (STPQ)

Please think about the last time you were in hospital for a painful episode, and tick one box for each statement to show how much you agree or disagree.

1. I was satisfied with the communication between me and the people looking after me.
2. I felt comfortable enough to ask questions.
3. When I asked questions, I got answers I could understand.
4. The people looking after me spent enough time with me.
5. The people looking after me treated me with respect and dignity.
6. The people looking after me had a good attitude.
7. I was involved enough in decisions about my treatment and care.
8. I was told enough about my medications.
9. The people looking after me responded to my pain in good time.
10. The people looking after me believed how serious my pain was.
11. The people looking after me did everything they could to control my pain.
12. Overall I was satisfied with how my pain was treated.
13. The people looking after me knew enough about my condition.
14. I felt good about the knowledge and ability of the people looking after me.
15. The people looking after me were careful to check everything when treating me.
16. I or my family had all the information we needed when I left hospital.
17. Overall, I was happy with the support and care I received.
18. I would recommend the hospital to other people with sickle cell disease.

Response format for each statement:

Strongly agree [ ]
Agree [ ]
Not sure [ ]
Disagree [ ]
Strongly disagree [ ]

If you want to, you can add a comment here:

_____

Please think about the last time you were in hospital for a painful episode, and write answers in your own words to these questions:

19. What do you think the people looking after you did well?

20. What was not done so well, or could be improved?

STPQ scoring instructions

Score each item so that strongly agree=5, agree=4, not sure=3, disagree=2, strongly disagree=1.

Communication and involvement: Q1+Q2+Q3+Q7+Q8+Q16.

Respect and dignity: Q4+Q5+Q6.

Pain: Q9 + Q11+Q12.

Staff: Q10 + Q13+Q14+Q15.

Overall satisfaction: Q17+Q18.

Total satisfaction score:

Q1+Q2+Q3+Q4+Q5+Q6+Q7+Q8+Q9+Q10+Q11+Q12+Q13+Q14+Q15+Q16+Q17+Q18.