Evaluation of a measure of sickle cell disease patients' satisfaction with hospital care: A student researcher's perspective

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Abstract

This article provides a reflective account of our work on a project at the University of Derby and Bart's Health NHS Trust, London, to evaluate a questionnaire measure of sickle cell disease (SCD) patients' satisfaction with hospital care. Romaana Kapadi's involvement was supported by a University internship and scholarship, and this article covers the skills she gained as an undergraduate student researcher, and how the opportunity helped with her plans to become a health psychologist. We hope this article will inspire other undergraduate students to grasp opportunities like this, and encourage lecturers to get students more involved with their research, as well as illustrating the role that health psychologists can play in improving healthcare for people with SCD.

Background to the research

Sickle cell disease (SCD) is an inherited serious lifelong condition that in Western countries primarily affects minority groups such as people with African or Caribbean family backgrounds. The red blood cells of people with SCD become distorted and elongated, so they restrict blood flow by becoming stuck in small blood vessels, causing painful episodes which can be severe and long lasting (NHS, 2017). SCD patients experience pain in the chest, abdomen, joints and bones, in addition to painful swelling of the abdomen, hands, and feet (Mayo Clinic, 2017). The incidence of pain is highly variable as some individuals are mildly affected and experience less than one painful episode a year, whereas others have frequent severe pain requiring hospitalisation (NHS, 2017).

Some people with SCD experience significant delays receiving analgesia and report problems with the ways they are treated by hospital staff, such as not being consulted about their treatment and not having things explained to them (Lattimer et al., 2010). Problems with these interpersonal aspects of hospital treatment are an international problem that may reflect social, cultural, and behavioural factors (Elander et al., 2011), including the ways that hospital staff perceive and make judgements about SCD patients' pain (Elander et al., 2006). Greater recognition of these problems has led to various 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).

The purpose of our research was to develop and psychometrically evaluate a questionnaire measure of SCD patients' satisfaction with hospital care during acute painful episodes, for use as an outcome measure in a clinical trial of enhanced analgesic protocols for acute sickling pain. This was part of an NHS project called 'Sickle Cell Analgesic Protocol Evaluation' (SCAPE) taking place in East London and led by consultant haematologist Dr Paul Telfer, which aims to improve the quality of hospital care for painful sickling episodes.

Study methods and preliminary findings

The questionnaire was developed during the first, qualitative, part of the study, which we are presently writing up for publication (Bij & Elander, 2017), when potential questionnaire items were assessed for relevance, acceptability, comprehensibility, importance and usability, using focus groups with adolescent and adult sickle cell disease patients registered with haemoglobinopathy outpatient clinics at three London hospitals. The participants had to have had at least one painful sickling episode treated in hospital in the previous two years, and not have any co-existing medical conditions. The adolescent and adult patients took part in separate focus groups, each consisting of six to eight participants. Those in the adolescent groups were aged between fourteen and eighteen years.

Each participant was sent a list of potential questionnaire items in advance and invited to write notes about them before the focus group, so they could act as prompts for discussion at the focus group. The focus groups were audio-recorded and transcribed verbatim, then anonymised and analysed using an adaptation of the Delphi method to elicit and summarise expert opinion (Brady, 2015). Some of the focus group feedback helped to select the most useful items (e.g., "... I think that question 7 is a very good one, that should be kept"), and other feedback helped to refine the wording of items (e.g., "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…"). This allowed the researchers to reject certain items and adapt the wording of others, resulting in a questionnaire comprising a smaller number of carefully chosen, carefully worded items. Examples of refined items following the focus groups were; 'the people looking after me responded to my pain in good time', and 'the people looking after me treated me with respect and dignity', each with five-point Likert-type response scales (Strongly Agree/Agree/Not Sure/Disagree/Strongly Disagree).

Once this version of the questionnaire was ready, SCD patients aged between fourteen and fifty years old who had at least one painful episode treated in hospital in the last two years were invited to take part in a larger survey to pilot the questionnaire. The data was collected from patients attending haematology outpatient clinics at London hospitals as well as via an online survey supported by the Sickle Cell Society.

To date, 115 participants (46 males and 69 females) have completed the questionnaire, including 26 online survey responses and 89 paper questionnaires from the outpatient clinics (age range 12-53 years, mean = 30 years). The majority lived in London and had either an African or Caribbean family background. Most had homozygous (SS) SCD, and had arrived in hospital via the Accident and Emergency department at their last admission. Preliminary findings suggest the questionnaire has high internal consistency, with a Cronbach's Alpha of 0.96.

Participants were also able to write qualitative comments explaining their ratings for each item, and a preliminary analysis of these revealed tentative themes including 'lack of communication', which dealt with how information was shared and how patients' questions were answered; 'negative attitudes', which dealt with how patients felt the doctors and nurses showed respect for patients and treated them considerately; and 'lack of knowledge', which dealt with how well patients felt the hospital staff understood sickling pain and knew how it should be treated. Comments related to these tentative themes included: "… once I moved over to a ward there was little contact with nurses"; "I had to literally beg for my hourly pain relief"; "Doctors and nurses still do not have enough knowledge of sickle cell crisis and how pain affects us, mentally and physically"; and "There needs to be a sickle cell protocol worldwide, we need pain medication ASAP, our pain is just as important as someone with kidney stones". There was also an emerging theme called 'effective practices' which dealt with positive aspects of patients experiences, for example: "I was assessed quickly" and "They administered pain medication without treating me like a liar or a druggie".

The preliminary findings therefore showed that the questionnaire may be a useful outcome measure for evaluations of new initiatives to improve hospital pain management, but also that from patients' points of view there is a strong need for such initiatives.

Conclusions

This has been quite a challenging study to undertake because it is part of a larger trial in which many other researchers and clinicians are involved. The topic is also a sensitive one for patients, who sometimes have strong views about how hospital treatment for painful episodes should be improved. There are many ethical aspects to be considered, especially as the participants are adolescents as well as adults. The data collection and analysis are ongoing, but the preliminary findings seem to show that patients' experiences of hospital care are important aspects of treatment that need to be considered in any evaluation of new treatments. They also show that there is a role for health psychologists in working with people with SCD, and the professionals responsible for their care, in order to improve patient experiences of hospital pain management. This might include helping to train hospital staff in the assessment and management of sickling pain, or working with patients to understand their experiences in hospital, or contributing to improved treatment protocols and care standards.

A student researcher's experience – Romaana's personal reflection

"My involvement in this research project commenced during Summer 2017 when I was accepted onto an Undergraduate Research Scholarship Scheme (URSS) project at the University of Derby, following an application and interview. During my time on the URSS scheme I had the opportunity to visit The Royal London Hospital and meet with the consultant haematologist and the research nurses who were carrying out the data collection. In addition to this, on another occasion I was also able to attend a haematology transitions clinic and meet some of the adolescent SCD patients who were transitioning from the children's clinic to the adult clinic. This enabled me to better understand the patients' experiences of their condition, and gain first-hand experience of data collection as part of a multidisciplinary team comprising of clinicians and psychologists. From meeting both the health care professionals and adolescent patients, I learnt about the importance of a clinician-patient relationship, finding that for some of the younger patients, just seeing a friendly and familiar face helps put them at ease during consultations and especially when undergoing treatments to relieve pain. As part of the URSS scheme I also presented a poster and gave a presentation about the research to delegates at the University of Derby Learning and Teaching Conference 2017 in Buxton, which afforded me with valuable experience in presenting research within an academic setting, and obtaining feedback from my peers as well as more experienced researchers. The research project has continued beyond the URSS timeframe, and I am now fortunate enough to be employed by the University of Derby's Student Employment Agency on an On-campus Research Internship, as a Research Assistant, to continue working on the project. This has enhanced my experience of conducting research within an area of Health Psychology, which will be beneficial to me during my postgraduate degree next year.

During my time as a student researcher working on this project, I have had a once in a lifetime opportunity to visit the haematology department at The Royal London Hospital, gained experience of conducting research with patients and vulnerable groups, and enhanced my knowledge of working with questionnaires and analysing psychometrics. This project has benefited me greatly, by providing me with hands-on experience and the confidence to go out into the field and carry out independent research. As an undergraduate student, there is often limited opportunity to conduct research with specific clinical populations, therefore I would encourage other students to recognise the value of applying to schemes such as this and seek work experience in a field that they wish to pursue a career in, as this project has prepared me for work in the real

world by allowing me to apply my knowledge of Health Psychology to helping patients with a lifelong condition. This study has strengthened my desire to pursue a career as a health psychologist by demonstrating the impact that research such as this can have on improving the wellbeing of patients with serious health conditions."

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