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Is our healthcare system working for spinal surgery patients? Towards individualised care pathways and person-centered supports

Alison H. McGregor PhD\textsuperscript{a}, Ania Henley\textsuperscript{b}, Tim P. Morris BSc\textsuperscript{c} and Caroline J. Doré BSc\textsuperscript{d}

\textsuperscript{a} Professor of Musculoskeletal Biodynamics, Department of Surgery and Cancer, Faculty of Medicine, Imperial College London, Charing Cross Hospital Campus, London, UK
\textsuperscript{b} Trial Co-ordinator, Department of Surgery and Cancer, Faculty of Medicine, Imperial College London, Charing Cross Hospital Campus, London, UK
\textsuperscript{c} Statistician, MRC Clinical Trials Unit, Aviation House, London, UK
\textsuperscript{d} Senior Statistician, MRC Clinical Trials Unit, Aviation House, London, UK

Abstract

As part of a randomised controlled study into the post-operative management of spinal surgery, this qualitative sub-study sought to explore the patients’ experience of the healthcare system and their perceptions of how the system had worked for them, with a view to establishing more appropriate care pathways and improved support materials for patients undergoing surgery.

Patients taking part in the FASTER study (Function after spinal treatment, exercise and rehabilitation) were invited during their one year post-operative review to provide feedback on their healthcare experience following surgery. This study comprised 245 patients recruited from 7 hospitals, with 20 different spinal surgeons contributing patients.

The majority (82%) of patients were referred through their general practitioner (GP). Forty percent identified a specific event that led to their pain; of these 48% reported a longstanding pain and 33% noted a sudden injury. Thirty percent waited less than a month for surgery and 32% 1-3 months. Eighteen percent experienced surgical cancellations. Many respondents felt that they had not been managed well by their GP pre-operatively, although it appeared that most GPs had followed current guidelines. In terms of their hospital stay the majority felt prepared and content with the care received and expressed faith in their surgical team. Although it appeared that patients were happy with their post-operative care, closer inspection revealed concerns with inadequate information, feelings of abandonment and poor communication from some healthcare professionals. Many reported that taking part in the research itself was a positive experience.

Both negative and positive patient experiences have been identified. Patients express concern at the paucity of information they are given concerning their clinical journey, particularly in relation to discharge from hospital. In this era of social media and the internet there is a clear need to explore new methods of addressing patients’ information needs.

Keywords

Care pathways, clinical information, communication, FASTER study, patient experience, person-centered care, quality of care, skills, spinal surgery

Correspondence address

Professor Alison H. McGregor, Department of Surgery and Cancer, Faculty of Medicine, Imperial College London, Charing Cross Hospital Campus, London, W6 8RP, UK. E-mail: a.mcgregor@imperial.ac.uk

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Background

As the size of the ageing population increases, the rate of surgical procedures on the spine has risen [1,2]. Patients’ criteria for surgical outcome are diverse and range from measures of global outcome [3-5], patient-rated measures of outcome and satisfaction [2,6-8] and more novel approaches such as symptom bothersomeness [9].

Measures of patient satisfaction have gained popularity [6,10-12], but such measures are known to be influenced by a range of factors including the patient’s perception and expectation of what the treatment will achieve and the actual outcome achieved as well as aspects of the care process including the environment, staff and patient journey [13,14]. Many approaches are being employed to explore satisfaction with treatment, but less is being done to examine the individual patient experience in terms of the journey from diagnosis to surgery and subsequent recovery. This is surprising, since it is known to influence patient satisfaction [11] and there is currently a drive to improve patient experience and quality of healthcare delivery. It has been suggested that monitoring the patient’s experience can be used to improve care quality.
[15], although its impact on outcome is less clear. Recent work has, however, suggested that satisfaction itself is a poor outcome, since it represents healthcare experience and should not be used as a quality metric for determining the quality of a surgical intervention [16]. However, it could be argued that dissatisfied patients are more likely to complain and incur additional time and costs to the health service and as such the patient experience should where possible be optimised in terms of quality of care delivery.

This study sought to elicit information concerning aspects of patients’ healthcare experiences following a spinal surgical procedure and was performed as a sub-study of a larger randomised controlled trial evaluating the post-operative management of these patients.

Methods

This brief survey was conducted as part of a multi-centre, factorial, randomised controlled trial “Function after spinal treatment, exercise and rehabilitation” (FASTER) that compared the effectiveness of a rehabilitation programme and an education booklet over usual care for the post-operative management of patients undergoing spinal surgery for either disc prolapse or spinal stenosis. The trial details and study findings are published elsewhere [17-20]. Following ethical approval, patients scheduled for primary spinal surgery were recruited into the study and randomised, stratified by surgeon and procedure, creating 4 sub-groups: rehabilitation-only, booklet-only, rehabilitation-plus-booklet and usual care only and written informed consent obtained. Patients were asked to complete questionnaires on function, pain, anxiety and distress pre-operatively (baseline) and then at 6 weeks, 3, 6, 9 and 12 months post-operatively [18]. In addition, at the 12 month review, patients were asked to complete a brief survey of their healthcare experience, this was divided into their experiences with the healthcare system and surgical team prior to surgery and after surgery. This included questions about their referral, the scheduling of surgery, the approachability of staff and the availability and quality of healthcare information. In addition, at the end of the survey there was a general section including open questions pertaining to positive and negative healthcare experiences and suggestions on how they felt their healthcare could be improved. The survey was included with their final 12 month post-operative postal review.

Study Population

Patients were recruited from the surgical waiting list of our 20 participating surgeons from the West London Region between January 2005 and March 2009. Eligible patients included those who presented to the surgeon with either (a) signs, symptoms and radiological evidence of lateral nerve root compression; that is, patients presenting with radicular pain with an associated neurological deficit or with neurogenic claudication, or (b) lumbar disc prolapse; that is, patients with root symptoms and signs and MRI confirmation of lumbar disc herniation and for whom a decision to operate was made. The following patients were excluded from participation in the study: those with any condition where either the intervention or the rehabilitation may have an adverse effect on the individual; previous spinal surgery; spinal surgery where a fusion procedure was planned due to the unknown hazards of the activity programme for this type of surgery; pregnant women; inadequate ability to complete the trial assessment forms; unable to attend or unsuitable for rehabilitation classes.

Post-operative Trial Interventions

Rehabilitation Programme

Patients were invited to a course of 12 one hour twice weekly classes run by a physiotherapist commencing 6 to 8 weeks following their surgery. The classes were standardised and included: general aerobic fitness work; stretching; stability exercises; strengthening and endurance training for the back, abdominal and leg muscles; ergonomic training; advice on lifting and setting targets and self-motivation.

Educational Booklet

Patients received a copy of “Your Back operation” [21] on discharge from hospital.

Usual care

Patients randomised to the usual care control group were managed according to the relevant surgeon’s usual practice.

Results

A total of 1288 patients were approached to take part in the study, 124 did not meet the inclusion criteria and 363 were enrolled, 25 were excluded for failing to complete baseline forms, leaving 338 in the study. Of these, 91 (27%) were randomised to receive rehabilitation and a booklet, 86 (25%) to receive rehabilitation only, 70 (21%) to receive a booklet only and 91 (27%) to usual care. At one year, 293 (87%) participants remained in the study and of these 245 (72%) completed the survey; 66 (27%) in the usual care group; 48 (19%) in the booklet only group; 58 (24%) in the rehabilitation only group and 73 (30%) in the rehabilitation and booklet group. The mean age of those completing the survey was 55.8 ± 15.6 years and of these 110 were male and 135 female.

Experience of healthcare system and surgical team prior to surgery

On first experiencing the symptoms that led to surgery, 200 respondents (82%) consulted their general practitioner while the remainder either consulted a physiotherapist,
chiropractor or attended accident and emergency. Disappointingly, when asked to rate on a scale of 0-100 whether or not they felt that their condition had been managed appropriately (100 indicating most appropriate management), the average rating was only 54 ± 35. In terms of management routes, the fact that 97 (40%) were referred to an NHS consultant immediately suggests that their symptoms had been identified as a red flag; 23% were referred to some form of manual therapy; with the remainder managed primarily through their GP.

In line with the general discontent patients expressed about their management, 68 (28%) felt that they were wrongly diagnosed and in 32 (47%) of these cases this criticism was directed at their general practitioner. When asked to rate on a scale out of 100 if they had ever felt criticism was directed at their general practitioner. When questioned regarding the type of information received, this consisted primarily of an information sheet of bed exercises and measures to prevent deep vein thrombosis. Thus, at this level both patient groups appeared equally happy with the care they received.

Healthcare experience

We employed a section of free text asking patients to list up to 3 positive experiences from their overall healthcare experience. Initially looking at the respondents as a single group, these comments could be grouped broadly into the following categories; those pertaining to relief of pain and symptoms as a result of the surgery; the attitudes and support of the surgical team and staff; taking part in the clinical trial - particularly the access to the exercise classes; the hospital environment and, lastly, the speed with which surgery was received. The balance of experience varied by group assignment within the study. Not surprisingly, the usual care groups’ comments were limited to relief of pain and symptoms, the surgical team and hospital environment. Key phrases that stood out in this group included; “whatever I have done I have done for myself” to “the whole experience was 100%” and “being blissfully pain-free for the first 6 months after surgery”. A similar response was received from those in the booklet only group. Interestingly, only a very small number commented on the positive experience of simply taking part in the research study and having the questionnaires as part of their follow-up.

In contrast, those groups receiving rehabilitation, in addition to symptomatic relief and the quality of care from the surgeon and their team, highly praised the research study and in particular the rehabilitation intervention, with less emphasis on the hospital stay. There were no negative comments noted with comments including “peace of mind”, “hope” and “happy to be alive” and more practical gains such as “I learnt to look after my back” and “FASTER is a great programme”. There were also positive comments about the opportunity to meet and talk to other patients in the same condition and the reassurance they felt that both the rehabilitation and reporting of their progress to the trial team through questionnaires given them.

Similarly, patients were asked about suggestions for improvements to their care; unlike the positive comments, there was less variability in the themes of the comments between the groups. There were, however, 4 common themes which pertained to outcome, informational needs, management by their general practitioner particularly with regards to diagnosis and surgeon attitude. Expressions of disappointment in the outcome of their surgery were frequent but not universal and were associated with comments such as “feeling that no-one cares about your
condition”. Several drew attention to the limited information they received both in regard to their surgery but particularly in relation to post-operative care and discharge from hospital. Many expressed concern at lack of information in relation to changing their wound dressing and pain relief. Interestingly, these comments also appeared in the booklet group but were usually associated with terms such as “more detailed information”. Those receiving rehabilitation classes also noted that without the class they would have needed more information to recover. Many used this free text section to express their anger and frustration at their general practitioners with comments such as “GP could have taken me seriously” to simply “GP useless” and “GP’s need to know more about spines”. Many of the surgeons also faced criticism in relation to their attitude with comments such as “appalling lack of respect” and “consultants and surgeons showing more interest and explaining in more detail” and “pay doctors and nurses more money, maybe they will care more!” One of the noticeable differences between groups was that those in the rehabilitation group, rather than requesting rehabilitation, requested more sessions earlier and also the opportunity to have follow-up re-checks and progression sessions with the therapist.

When asked directly about negative experiences, patients referred to both general practitioners’ and surgeons’ communication skills and attitudes with many patients expressing concern with their bedside manner and being made to feel unimportant. Another common theme was the expression of abandonment or isolation after surgery which again related to the lack of information or preparation they had been given for this time period. Comments included; “I didn’t know how long anything would take and was unsure about surgery. There was no one to talk to and I could have done with some advice/medical support on a more frequent basis”. “Once you have had the op you are left to sink or swim” and “due to my back (spinal) operation I was left incontinent and nobody cared or looked after me. I was not given any prognosis. Pain has gone but left me in a great mess.”

Many praised the support they had received due to participating in a clinical trial and those attending rehabilitation spoke highly of it and of their surprise that this was not part of normal care. Two comments particularly stood out in relation to the rehabilitation; “it was the kick up the ass that I needed” and “it depends on the mental and physical state of the patient regarding recovery, some simply cannot do it on their own.” Praise was not only attributed to the trial: many patients simply said that the surgery had been “a big improvement on my life” and “the team were absolutely amazing and have given me back my life”.

**Discussion**

This exploratory study has highlighted some key areas for improvement, but has also revealed that participating in healthcare research can be a positive experience. Other studies have described a positive patient experience from inclusion in a research study with this factor largely attributed to patients’ perception that they receive better healthcare [22,23]. In the present study, patients’ responses indeed appeared to indicate that they felt better supported and appreciated, having a point of contact with someone who they felt was concerned about their condition.

In the current study, patients perceived shortfalls in their referrals to specialists and their management in primary care. However, the referral process did appear to be in line with current NICE guidelines [24] for the management of low back pain, although it might be anticipated that more patients would have generated “red flags”. Following the completion of the trial, there has been a revision of the management of musculoskeletal conditions and evaluations of these changes have reported amongst other issues more appropriate referrals to secondary care [25].

While there is a growing belief that patients who receive the healthcare they expect recover more rapidly and to a higher level [26], there are others who feel that for interventions such as surgery this does not influence the outcome [16]. In our study, waiting times for surgery did appear to be within current government criteria in the UK. There were a large number of operative cancellations, although reasons for cancellation varied. However, in a number of instances this cancellation was by the patient and those by the health service were often related to lack of post-operative beds frequently due to emergency procedures. Cancellation rates appeared to be in line with published work [27,28], although the high number of patient-initiated cancellations is of concern.

A common theme was the desire for greater information and clearer communication pathways. While there was a feeling that staff were knowledgeable and that they were in “safe hands”, patients often wanted more information about what was happening to them and what they should and should not do, particularly in relation to discharge from hospital. The demand for such information is not new with many patients seeing it as an essential component of healthcare provision [29]. Similarly, dissatisfaction and difficulty obtaining information is not new [30]. However, it has been suggested that some patients are not receptive to information or are unable to understand or recall what they have been told or indeed read [31] and that this may be particularly pertinent to surgical populations where anxiety about the procedure may make it difficult for patients to absorb the information provided. Whilst clearer pictures are emerging of the types of information patients require [32,33], careful consideration is required on how we align this information to individual patients needs and how we can develop novel approaches to conveying the pertinent messages [34]. The internet may be a key vehicle for the exchange of information and it is one that patients frequently turn to. However, we need to guide patients to appropriate websites with accurate and up to date information [35].

For the patients in our trial receiving rehabilitation, the ability and opportunity to meet and talk to other patients who had undergone surgery was seen as a positive experience. Many gained understanding, support, camaraderie and inspiration from this. Observations of
these benefits by others have led to the concept of ‘expert patients’ and, as a result, research has been conducted exploring the use of expert patients in the management of chronic conditions with varying success [36,37]. Clearly, we have to explore this area further since it also develops further the role of patients as active partners in healthcare provision and clinical decision-making.

One area of concern that did emerge clearly was the expressions of isolation and abandonment. These feelings also emerged from focus groups held with trial participants [17]. This appeared to be attributed to the lack of information provided prior to discharge from hospital. It is known from other surgical fields that the initial post-operative period can be perceived as stressful as patients have to independently manage their healthcare, symptom distress and self-care at home, with many feeling anxious and depressed once they return home [38]. Other studies report patients expressing a lack of control and social support during this period [39,40], akin to the expression of abandonment in this study.

Conclusion

This paper has highlighted some positive and negative patient experiences. A clear and consistent problem was in relation to the paucity of information provided concerning their clinical journey. Increasingly in the health service, “clinical care pathways” have been emerging and these pathways need to include tools to provide patients with information that will not only help them to understand their condition, but also to describe their options and subsequent management pathways. For surgical patients, such pathways are required not only to communicate what is wrong, but also to explain the operative procedures, the hospital admission, discharge and subsequent recovery. There is clearly a need to employ a variety of methods of communication and to explore how such information can be tailored to an individual patient’s needs.

Acknowledgements and Conflicts of Interest

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References


