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Patient Information Leaflets for Lumbar Spine Surgery: A Missed Opportunity

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Abstract

Background: High-quality patient information is recommended to help reduce procedure-related anxiety and encourage patients to become active participants in their recovery. The objective of this study was to analyze the quality of patient information leaflets (PILs) given to National Health Service (NHS) patients ahead of lumbar spine surgery. **Methods:** The DISCERN tool was used to evaluate the quality of PILs, sourced from NHS websites. **Results:** Thirty-two PILs on lumbar surgery were included. Two (6%) leaflets were considered poor, 13 (41%) were marked as fair, 14 (44%) were of good quality, and 3 (9%) were scored as excellent. The total mean score was 55 (30-74), which corresponds to good quality. The lowest scoring questions were sources of information (Q4), balanced/unbiased content (Q6), and explanation of no treatment (Q12). **Conclusions:** There is considerable variation in the quality of PILs provided ahead of lumbar spine surgery. The scope for improvement is clear, and as the move toward patient-centered, evidence-based care continues, it is important that hospital resources provide recommendations based upon evidence of clinical effectiveness.

Keywords

patient education, patient information leaflets, lumbar spine surgery, enhanced recovery after surgery

Introduction

Enhanced recovery after surgery (ERAS) is a multimodal approach to patient care, introduced to prepare patients for surgery, reduce the surgical stress response, and enable them to recover faster (1). Enhanced recovery after surgery has recently been applied to spinal surgery, using evidence-based practice and improved pathways, to encourage lower rates of morbidity and improve longer term outcomes (2–5). A recent systematic review has summarized the implementation of ERAS to spine surgery, with results demonstrating a reduced length of stay with no increase in rates of readmission or complication (6); however, the evidence for its adoption is still limited. Low back pain and sciatica is a widely reported musculoskeletal disorder (7), and lumbar spine surgery has been associated with uncertain expectations of success and concerns of adverse events (8). Poor outcome appears to be associated with a number of complex elements, including psychological responses such as fear and anxiety (8). Evidence suggests that many patients undergoing lumbar spine surgery may suffer from central sensitization, depression, anxiety, and poor coping strategies (9,10).

Enhanced recovery guidelines support a patient-centered approach to health care and strongly recommend implementing preoperative education and counseling (11). Preoperative consumer health information can complement formal patient education and encourage active participation in the recovery process (12), while also reducing procedure-related stress, anxiety, and fear (13). The nature of the preoperative information a patient receives can positively influence their expectations, and those who receive a sufficient explanation of the surgical journey may have higher levels of satisfaction than those who receive insufficient information (14). The wealth of written consumer health information on treatment choices is

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ever expanding and available from a wide variety of sources (15). However, challenges may arise if this information is not informed by clinically respected research and evidence-based practice. Despite the importance of treatment based upon evidence of clinical effectiveness, not all patients have access to information that is relevant and the quality of health information can vary between providers (15).

The National Health Service (NHS) often provides written health information, in the form of patient information leaflets (PILs), to patients following diagnosis or regarding treatments, with an aim of helping to ensure they are fully prepared and aware of the next steps in their management. As increasing workload pressure continues to reduce the time clinicians have to spend with patients, leaflets are an invaluable source of information to facilitate the retention of important health information during the consent to treatment process. In addition, when anxious or worried patients receive verbal information about their condition, treatment, or procedure, it may be difficult for them to recall, and therefore, clear written information is important to complement formal patient education. Poor communication within the medical setting can negatively affect patient satisfaction and PILs are thought to improve patients' knowledge and adherence to treatment (16). The rationale for needing high-quality preoperative patient information is clear; however, as knowledge and the evidence base evolves, there may be scope to improve current publications. Therefore, the aim of this research study is to analyze the current quality of PILs given to NHS patients ahead of lumbar spine surgery, in order to continue the development of patient-centered care for spinal procedures.

Table 1. Eligibility Criteria for Inclusion.

Inclusion	Exclusion
Patient	
Lumbar spinal fusion patients (all surgical techniques) for back and leg pain or for the treatment for low back pain following previous decompression surgery for predominant leg pain.	Any other spine surgery (lumbar disc replacement, correction of spinal deformity, removal of spinal tumors)
Lumbar decompressions surgery (laminectomy, discectomy, microdiscectomy) for predominant leg pain	Patients younger than 16 years old
Patients aged older than 16 years	
Information	
Patient information on lumbar spine surgery	
Source	
English NHS Hospitals	Independent providers of health care
Hospital Trusts	Charity or research institute information
	Blogs or social media posts
Format	
PDF Document	Archived versions
Hospital provided web page	
Word document	
Latest version	

Abbreviation: NHS, National Health Service.

Methodology

Procedures

To identify PILs, a full list of English NHS hospitals that perform lumbar fusion, laminectomy, or discectomy was sourced from the NHS "find a procedure" online tool (17). Each hospital website was then examined thoroughly in an attempt to source PILs. The patient information resources that were selected were in the public domain, and thus ethical approval was not pursued for this study.

Eligibility Criteria

Patient information leaflets were only included within the study if they met the eligibility criteria listed in Table 1. Patient information on other types of spine surgery was excluded due to the specific objectives of the study. The leaflets were included if they were (1) patient information, (2) exercise prescription, or (3) both patient information and exercise prescription. The recent National Institute for Health and Care Excellence NG59 (2016) guidelines for low back pain and sciatica for patients older than 16 advise to not offer spinal fusion for people with low back pain unless as part of a randomized controlled trial and also to not offer disc replacement in people with low back pain (18). The study therefore excludes lumbar disc replacement for low back pain but includes lumbar spine fusion including decompression surgery and following previous lumbar decompression surgery.

Evaluation

Leaflet quality was evaluated independently by 2 reviewers (L.C.B. and M.L.) using a modified DISCERN tool, a standardized 16-item instrument designed to help the users of consumer health information judge the quality of the written information about treatment choices (19). Both reviewers were blinded to the other reviewer's scores, and once both evaluations were complete, results were compared and any discrepancies were resolved through discussion. DISCERN cannot be used to assess scientific quality or the accuracy of evidence in which the publication is based; however, it can be used to assess whether the sources of evidence are explicit and the common cause of inaccurate or unreliable information (19). The tool consists of 15 key questions plus an overall quality rating, with questions 1 to 8 addressing the reliability of the publication and questions 9 to 15 focusing on the specific details if the information about treatment

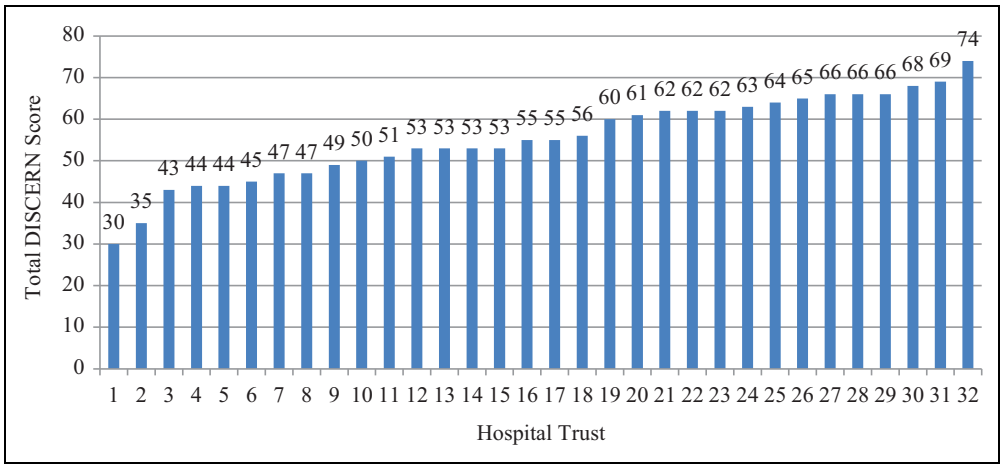

Figure 1. The quality (DISCERN) in lumbar surgery patient information leaflets provided by English National Health Service (NHS) hospitals.

choices. Reviewers assigned each question a score on a 5-point Likert scale (one for low quality with extensive shortcomings, 5 for a high quality with minimal short comings). A score of 2, 3, or 4 was given if the publication meets the criterion in question only partially. Classifications for each of the 3 sections were based on a previous evaluation of patient information using the DISCERN tool (20) whereby an overall DISCERN score of 16 to 28 was rated as very poor, 29 to 41 as poor, 42 to 54 as good, 55 to 67 as fair, and 68 to 80 as excellent.

Organizations are authorized to reproduce the DISCERN instrument without permission, provided it's used in accordance to the instructions provided (21). The DISCERN handbook (21) advises the exclusion of a question that is not relevant to the publication being analyzed, and therefore item 3, entitled "is it relevant?" was replaced with a readability score, calculated on Microsoft Word. The leaflet would only be supplied to a patient if they were on the waiting list for lumbar spine surgery, and thus it was assumed that all leaflets would be considered "relevant." Readability, or comprehensibility, has long been recognized as vital in the preparation of PILs (22), and the absence of a readability test within the DISCERN tool has previously been highlighted as a limitation (20). It is important for the authors of patient information to consider how patients can cope with medical terminology and language, and although readability tests do not account for varying levels of education, intelligence, and socioeconomic positions, we believe it to be an important determinant of publication quality.

Microsoft Word generates both Flesch Reading Ease and Flesch-Kincaid Grade Level scores. The Flesch Reading Ease test uses the length of sentences and the number of polysyllabic words to determine the overall readability score, while the Flesch-Kincaid Grade utilizes the mean sentence and word length to calculate the complexity of the reading level (23). The Flesch Reading Ease score was used to determine the overall readability of the PILs in this study. The test is based on a 100-point scale, with a higher score indicating that a document is easier to read than a lower score. Readability was scored by copying 200 words from the PIL, pasting it into Microsoft Word, and running the Flesch Reading Ease test. To remain consistent with the other items on the DISCERN tool, a score of 1 was awarded if the document had a readability score of between 0 and 19, a 2 for between 20 and 39, a 3 for between 40 and 59, a 4 for between 60 and 79, and a 5 for between 80 and 100. To prevent variability between leaflets, the 200 words were copied from the section on postoperative care/return to activities of daily living.

Results

Thirty-two PILs were sourced from English NHS hospitals or trusts (see Supplementary Material 1). Leaflets were grouped into (a) lumbar fusion surgery (n = 11), (b) lumbar decompression surgery (laminectomy, discectomy, and microdiscectomy; n = 15), or (c) all lumbar surgeries (fusion and decompression; n = 6) to account for the range of lumbar procedures available. Not all of the hospitals that offered the procedures provided PILs that were available online. In addition, some NHS trusts that encompass several hospitals share online resources. Some hospitals and trusts provided different leaflets for various lumbar spinal procedures; however, the content of the leaflet was identical, and therefore, this information was only analyzed once. Exemplar text extracted from high scoring leaflets is presented in Supplementary Material 2. The reviewers had 100% agreement on the DISCERN scores of 31 of the 32 PILs included. In the PIL provided by Cambridge University Hospitals NHS Foundation Trust, the first reviewer gave a score of 5 for items 13 and 15 on the DISCERN checklist, whereas the second reviewer scored both of these items with a 3. A second review was made by each reviewer and following discussion it was decided to score both items with a 3.

Table 2. Patient Information Leaflets Scores by Question: Discern Score, Mean (Range).

Criterion	Lumbar Fusion Surgery (n = 11)	Lumbar Decompression Surgery (n = 15)	All Lumbar Surgeries (n = 6)
1: Aims clearly described	2.8 (1–5)	3.8 (1–5)	2.7 (1–5)
2: Aims achieved	3.4 (1–5)	4.1 (1–5)	2.7 (1–5)
3: Readability	3.6 (3–4)	3.9 (3–4)	4.2 (4–5)
4: Sources of information	1.9 (1–5)	1.8 (1–5)	1.3 (1–3)
5: Date of publication	5 (5)	4.5 (1–5)	5 (5)
6: Balanced/ unbiased	1.9 (1–5)	1.8 (1–5)	1.3 (1–3)
7: Support/other sources	3.2 (1–5)	3.7 (1–5)	3.7 (3–5)
8: Uncertainty	4.3 (1–5)	4.2 (3–5)	4 (1–5)
9: Description of treatment	4.6 (1–5)	4.5 (1–5)	4.3 (1–5)
10: Benefits of treatment	3.7 (1–5)	3.5 (1–5)	3 (1–5)
11. Risks of treatment	4.1 (1–5)	4.2 (1–5)	3.7 (1–5)
12: Results of no treatment	1.2 (1–3)	1 (1)	1.7 (1–5)
13: Quality of life	5 (5)	5 (5)	4.7 (3–5)
14: Alternatives described	3.4 (1–5)	2.3 (1–5)	4.3 (1–5)
15: Support shared decision-making	4.1 (3–5)	3.8 (3–5)	4.7 (3–5)
16: Overall score	3.4 (2–4)	3.4 (3–4)	3.5 (2–4)
Total DISCERN score[a]	55.5 (35–69)	55.5 (44–74)	54.7 (30–65)
Score per questions[b]	3.5 (1.2-5)	3.5 (1–5)	3.4 (1.3-5)

[a]Minimum = 16; maximum = 80.
[b]Minimum = 1; maximum = 5.

Figure 1 summarizes the assessment of information in the 32 PILs using the DISCERN tool. Two (6%) leaflets were considered poor (DISCERN score 29-41), 13 (41%) were marked as fair (DISCERN score 42-54), 14 (44%) were of good quality (DISCERN score 55-67), and 3 (9%) were scored as excellent (DISCERN score 68-80). The total mean score was 55 (30–74) which corresponds to good quality.

Table 2 shows how the PILs performed per question on the 5-point Likert scale. Leaflets have been grouped per procedure with an average mean calculated for each question in the DISCERN tool. The lowest scoring questions were sources of information (Q4), balanced/unbiased (Q6), and results of no treatment (Q12). Consistently high scoring questions were date of publication (Q5), description of treatment (Q9), and quality of life (Q13).

Table 3 presents the quality of the PILs within the 3 DISCERN sections (reliability, treatment options, and overall quality). The majority of leaflets were considered fair for reliability (n = 18 ≈ 56%) and overall quality (n = 16 ≈ 50%) and good for treatment options (n = 23 ≈ 72%).

Table 3. Quality of Patient Information Leaflets Within 3 Discern Sections.[a]

Section	Very Poor: Score 16-26	Poor: Score 27-38	Fair: Score 39-50	Good: Score 51-62	Excellent: Score 63-80
Reliability	–	3 (9)	18 (56)	8 (25)	3 (9)
Treatment options	–	5 (16)	3 (9)	23 (72)	1 (3)
Overall quality	–	2 (6)	16 (50)	13 (41)	1 (3)

[a]Values are n (%).

Discussion

The application of ERAS to spinal procedures aims to reduce the surgical stress response and accelerate return to function (3). Despite improved rates of recovery, symptoms of preoperative anxiety and depression occur in approximately one-third of patients with chronic back pain undergoing surgery (24,25). Pain, information, disability, employment, and mental health are factors associated with health-related anxiety, as well as depression both before and after spine surgery. The importance of mediating the association between these factors through information assists in the cognitive construction of patient anticipations; therefore, increasing patient knowledge is a vital aspect of disease management (9). Providing patients with accurate preoperative information may encourage them to participate in their own postoperative care and rehabilitation, as those who gain further insight are able to improve their coping ability and subsequently engage in appropriate attitudes and behaviors (26).

The rationale for needing high-quality preoperative patient information is well-documented; however, there is a significant degree of variation in the content provided in patient leaflets and sources of information are poorly cited. There is a clear scope for improvement, and as exemplar leaflets can act as a template, change should be relatively easy to implement. Despite clinical and research evidence changing over time, one of the few variables that can be controlled with respect to preoperative and postoperative care is the quality of information that is provided to patients. The PILs included within our study suggest the majority of lumbar surgery patients are receiving fair or good quality preoperative information, which they are able to read and understand (Q3). Nevertheless, there are some patients receiving low-quality information, and the evidence for excellent, high-quality information within patient resources is sparse, which may represent a lack of agreement of health-care professionals with regard to postoperative care. Although treatment choices are generally well described (Q9), with detailed benefits (Q10) and risks (Q11) listed clearly for patients, there is an absence of

information on what would happen if no treatment occurred (Q12) and many leaflets do not list alternative treatment options (Q14). However, as the patients who received the leaflets are likely to have already consented to have surgery, it is reasonable to assume that the authors framed their content with this in mind.

Evidence-Based Recommendations

As the move toward evidence-based care continues, it is important that patient resources provide advice based upon evidence of clinical effectiveness. Despite this, the majority of PILs do not refer to the underpinning evidence for the recommendations presented (Q4) and only 4 (13%) leaflets provide a reference list. An example can be found in the exercise prescription section, where several hospitals recommend specific "core" strengthening exercises, Pilates and Yoga over general exercise, which is not supported by the research evidence for low back pain (27–29) or following spinal surgery. Likewise, many of the leaflets provide specific advice with regard to activity and lifting restrictions following lumbar decompression surgery that are not supported by the evidence base (30–32); however, these recommendations may not accurately reflect the practice implemented by clinicians.

Bias and Uncertainty

Perhaps due to an absence of underlying evidence, or up-to-date evidence, question 6, "is the publication balanced and unbiased?" was consistently scored as "very poor" as the majority of leaflets did not provide evidence that a range of sources of information were used. This assimilates with other studies that have used the DISCERN tool in health-care literature (33,34). The degree of bias and unbalanced opinion used in the information leaflets highlights areas for concern when providing patients with appropriate information to enable shared decision-making. Likewise, uncertainty is a pervasive and important problem that has attracted increasing attention since the growth of evidence-based medicine, shared decision-making, and patient-centered care (35). There are many varieties of uncertainty in health care, but largely the concept relates to ambiguity in knowledge or differences in expert opinions concerning treatment choices. Although the PILs generally scored highly when referring to areas of uncertainty (Q8), 2 (6%) leaflets were marked as "very poor" which again highlights the lack of consensus on clinical evidence for a common surgical procedure.

Shared Decision-Making

Shared decision-making is a collaborative process through which a clinician supports a patient to reach a decision about their treatment (36). The NHS encourages shared decision-making to ensure that patients make choices that are most appropriate for their preferences, personal circumstances, goals, and beliefs (37), and ERAS programs reinforce the importance of this approach (11). The PILs included within this study consistently scored either good or excellent for details of shared decision-making (Q15). One of the challenges of providing individualized care in a shared decision-making context is that universal information may not convey the nuance required for an individual case (38,39). Future efforts in providing patient-centered information should be made within a biopsychosocial framework that recognizes dimensions other than the anatomy, pathology, and tissue-based recovery paradigms exemplified by biomedicine (40). The majority of PILs did not mention the psychological aspects of lumbar surgery such as anxiety and depression, which are important outcome predictors of physical impairment, greater pain, and lower health-related quality of life (10). In addition, information was omitted regarding the social contexts and roles of supportive figures, such as family and carers. Exploration of these topics could be individually assessed with a health-care professional if introduced in PILs and thus impact on shared decision-making before surgery (40) and during rehabilitation.

Limitations

This study provides a comprehensive review of PILs provided ahead of lumbar spine surgery; however, as a previously highlighted limitation (41), the information provided within these resources may not accurately reflect clinical practice, and it may be that patients are offered additional support to the information provided. The leaflets included within this study are not inclusive of all English NHS hospitals, and it is possible that online versions differ from the printed copies given in hospital to patients. In addition, although there is a rationale on how to use the DISCERN tool as it's meant to be an objective instrument, there is an element of subjectivity required while scoring which may affect the reproducibility of scores. Although published guidelines for reviews in health-care recommend that 2 independent researchers should be involved in the quality assessment process to minimize bias and error (42), including a third reviewer in the assessment of the PILs may have increased the reliability of our results. However, the very high level of agreement between reviewers within this work signifies that the quality assessment process was not controversial in this instance and so it may be considered unlikely that a third review would have altered the findings. The assessment of leaflets was performed by 2 researchers to improve reliability; however, it remains unknown if a layperson would assess the leaflets in the same manner. Another limitation of the DISCERN tool is that it does not evaluate the scientific quality of the information within the leaflets.

Conclusions

The rationale for needing high-quality preoperative patient information is well-documented; however, there is

considerable variation in the quality of the leaflets provided ahead of lumbar spine surgery. Particular areas that were identified as requiring improvement were the provision of the sources of information, the delivery of balanced or unbiased material, and the recommendations for activity advice following lumbar discectomy. The scope for improvement is clear, and exemplar leaflets can act as a template for the NHS trusts that are currently providing limited or outdated advice. As the move toward patient-centered evidence-based care continues, it is important that hospital resources provide recommendations based upon shared decision-making and evidence of clinical effectiveness. Further research into the provision of consensus surrounding return to activity and postoperative rehabilitation is recommended.

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Supplemental Material

Supplemental material for this article is available online.

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