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Comparison of Terminology in Patient Education Booklets for Lumbar Surgery

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Abstract

Purpose: To compare the usage of 'provocative' terms in two patient education booklets for lumbar surgery. Background: The recently completed FASTER trial failed to support the use of an evidence-based educational booklet to significantly improve postsurgical outcomes over rehabilitation and usual care. The use of a different booklet in another recently completed trial resulted in a significant saving in healthcare utilization; earlier return to work; and greater patient satisfaction with surgery. We propose that the terminology used in these booklets may account for the differing results. Methods: An expert review panel was identified and tasked with identifying and highlight 'provocative' words within two patient educational booklets - Booklet A 'Your Back Operation' and Booklet B' Your Nerves are Having Back Surgery'. Reviewers were blinded to title and authorship of the booklets. Data **Analysis:** Descriptive statistics including means, total scores. Results: Seventeenreviewers from 7 different countries participated and found that Booklet A had almost 3 times as many provocative terms as Booklet B. Booklet A had an average of 67.2 provocative terms per reviewer compared to only 22.6 terms for Booklet B. Conclusions: The findings of this study suggest that use of an educational booklet that minimizes the use of provocative terminology may have the potential to decrease fear, anxiety and patient pain experiences following lumbar surgery. Further research is warranted.

Keywords: Preoperative; Education; Orthopedics; Lumbar Surgery; Pain

Introduction

Lumbar radiculopathy is often cited as an indication for lumbar surgery [1]. Lumbar discectomy for radiculopathy has shown a success rate of between 60% and 90% [2,3], indicating 10 – 40% of patients will have a poor outcome, with resulting pain, loss of movement and function [4].

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Perioperative pain has been shown to be a determining factor to the success of surgery [5,6]. Louw et al [7] interviewed patients 4 weeks after lumbar surgery regarding their preoperative education and reported that those patients wanted more information/ education about pain. This concurs with the study by Ronnberg et al [8] which showed that patients undergoing disc surgery are, in general, satisfied with the care given to them preoperatively, but not with the content of the information regarding their impending surgery. One strategy to help perioperative pain is patient education, which is common in orthopedic and lumbar surgery [5,9]. To date, however, perioperative educational strategies in lumbar surgery and orthopedics in general have shown little efficacy in decreasing post-surgical pain and disability [9,10]. Most education programs used in orthopedic patient populations utilize anatomical and biomechanical models for addressing pain [11], which has not only been shown to have limited efficacy [11], but may also lead to an increase in patients' fear, anxiety and stress, thus potentially negatively impact their outcomes [12,13]. Considering the complexity of pain, newer educational models for lumbar surgery have called for a wider use of a biopsychosocial model of pain [14,15].

The pain neuromatrix concept redefines pain as a multiple system output, activated by the neuromatrix in response to what a patient perceives as a threatening situation [16,17]. It is proposed that, with pain, the larger the threat perceived by an individual, the more pain is produced by the brain to defend and protect. It has also been demonstrated that if a perceived threat is decreased, less pain will be produced by the brain to defend [16,17]. It is well established that various medical terminology and descriptions, although aimed at educating, assisting and empowering patients may in fact provide an opposite effect by increasing fear and anxiety [18,19]. In orthopedic spine literature, terms such as "disc degeneration", "wear and tear", "disc space loss", "crumbling", "instability" and "collapsing" are often used. These words may be used to help patients better understand their pain, but they have also been shown to increase fear and anxiety [18,19]. Additionally, there is evidence that patients with persistent pain may in fact pay increased attention to words and descriptors of pain [20]. The pain neuromatrix concept, originally described by Melzack [21] and subsequently supported by imaging studies [22,23] suggests that the biomedical terminology describing a patient's pain via pathoanatomical models, may in fact produce a heightened sensitivity of the CNS by inducing fear and anxiety.

In a recent comprehensive, randomized controlled trial, McGregor et al [24] attempted to determine whether the functional outcome of spinal surgery could be improved by a program of postoperative rehabilitation and/or an educational booklet. The trial was called FASTER (Function After Spinal Treatment, Exercise, and Rehabilitation) [24] and the educational booklet was 'Your Back Operation*[25]. Using a 2 X 2 factorial design, 308 patients were randomized to four groups; rehabilitation only, booklet-only, rehabilitation-plus-booklet, and usual care only. Outcome measures were collected preoperatively, then at 6 weeks, 3, 6, 9 and 12 months postoperatively. The study found that although all four groups demonstrated a significant improvement from baseline, the addition of the education booklet failed to show any benefit in regards to function, pain and healthcare utilization [24,26]. In their discussion, the authors suggested the possibility that heterogeneity in the nature of the surgeries (combining disc surgery and nerve root surgery) and variations in the rehabilitation program, may have accounted for the lack of significant differences between the groups at the end of the trial.

In contrast, we recently completed a similar study using a newly designed pain neuroscience education (NE) booklet – 'Your Nerves are having Back Surgery'[27]. The booklet is based on an updated view of pain science [15,28], and designed to educate pre-surgical patients more about the neurophysiology and neurobiology of pain than the pathoanatomical aspects of their condition. At one year outcome from the multicenter randomized controlled trail, the NE program provided similar results to the FASTER program in terms of pain and function, but the NE resulted in a significant saving in healthcare utilization/cost following lumbar surgery for radiculopathy; earlier return to work; and greater patient satisfaction with their surgical experience. (Louw, et al [28] – submitted for publication). A key feature of the newly designed NE booklet was a deliberate attempt to avoid the use of anatomical and pathoanatomical language which is associated with increased fear and anxiety [18,19].

The aim of this study was to compare the educational booklets of the two programs, to determine if the choice of words (terminology) in the FASTER program booklet may have been an additional possible factor for the failure to observe significant differences in postoperative pain, function, or healthcare cost/utilization.

Methodology

Educational Material

Two booklets, designed for pre/postoperative education for discectomy or decompressive surgery for radiculopathy were compared for this study. The first booklet, 'Your Back Operation' [25], associated with the recent comprehensive spinal surgery rehabilitation trial (FASTER) has undergone extensive development and subsequent implementation [6,24,26]. The second booklet, 'Your Nerves are Having Back Surgery' [27], is based on a recent systematic review of neuroscience education for musculoskeletal conditions [29], and developed as a preoperative educational program for patients with lumbar radiculopathy [15].

Expert Panel

An expert panel was identified to evaluate the contents and statements of the two educational booklets. Considering the aim of the study was to examine the content of the booklets from a neuroscience perspective for lumbar surgery, experts were identified who teach postgraduate neuroscience classes or practice a neuroscience approach to spinal pain, with at least 5 years of clinical experience and have attended at least 30 hours of training in NE. A total of 25 experts, representing 7 countries were identified for the study.

Examination of the Booklets

The narrative contents of the booklets were extracted and each booklet was typeset and formatted into a separate Word document (Microsoft Office), in Arial font size 12. All images and identifiable materials were removed so that expert reviewers were blinded to authorship of the booklets. Following a simple coin toss, 'Your Back Operation', (4684 words/ 17 pages) was designated Booklet A; and 'Your Nerves are Having Back Surgery', (3169/ 14 pages) was Booklet B. The two appropriately labeled Word documents were attached to emails sent to the review team by an independent research assistant and collected by the same assistant, to rule out potential bias.

Also attached was a form to be completed by each reviewer, seeking information regarding their age; gender; highest academic degree; publications in peer-reviewed journals; years of experience; allocation of clinical, teaching or administrative time; active involvement in research; and their exposure to patients after spinal surgery. Reviewers were e-mailed an invitation letter to participate in the study and provided with specific instructions for their task:

"We are asking an expert panel to read through the attached documents and highlight all words (not sentences, but single words) that may be deemed 'provocative'. Provocative terms are defined (from a neuroscience perspective) as words that will likely increase threat to the brain and nervous system, rather than calm the nervous system down. An example may be the word 'pain'. It could be argued that, based on the neuromatrix of processing threat, a word such as 'pain' may "activate" the neuromatrix, rather and help a patient 'calm down.' Research in the orthopedic domain has found that words such as 'tear', 'rupture', 'herniated', and 'deteriorated' are perceived as threatening by patients in spinal pain.

Please read the narrative provided in Documents A and B, and as you encounter a word you deem 'provocative', highlight it (highlighter or bold/color). Once completed, you are asked to please e-mail it back to the research team. In pilot trial, the average time it took to complete this task was 20 minutes. There are no correct or incorrect answers and you will not be scored on your performance.

We would greatly appreciate it if you could send us your completed documents in 3 weeks."

Two days prior to the completion of the data collection, a reminder e-mail was sent to reviewers thanking them for their participation in the study and reminding them to complete the study if they have not already done so.

Data Extraction and Analysis

Completed demographic information and highlighted words were entered into an Excel spread sheet for analyses. This study was to a large degree a descriptive study, and therefore descriptive statistics such as means, total scores and descriptive analyses were used.

Results

Expert Panel

Seventeen of 25 expert reviewers (68%) completed the study with no missing data and represented seven different countries (Table 1).

Table 1: Summary of the Demographics of the Expert Review Panel

| Description | Results |
|---|-----------------------|
| Female: Male | 3 (17.6%): 14 (83.4%) |
| Average age (years) | 47.2 |
| PhD or doctoral degree | 10 (58.8%) |
| Master's degree | 5 (29.4%) |
| Bachelor's degree | 2 (11.8%) |
| Average years of clinical experience (years) | 22.18 |
| Published in peer-reviewed journals | 10 (58.8%) |
| Percentage of time spent on clinical work | 55% |
| Percentage of time spent on teaching | 41% |
| Average estimated weekly time actively involved | 15 hours |
| in treating spinal surgery patients | |

Booklet Evaluation

Booklet A ('Your Back Operation') was determined to have almost three times as many provocative terms as Booklet B ('Your Nerves are Having Back Surgery'). Booklet A was found to have an average of 67.2 provocative terms per expert review, whereas booklet B had an average of 22.6 provocative terms. The tabulation of the 15 highest rated individual words per booklet can be found in Table 2.

Table 2: Tabulation of the 15 Highest Rated 'Provocative' Terms Per Booklet as Noted by the Entire Expert Review Panel

| | Booklet A | | Booklet B | |
|------|---------------|-----|------------|----|
| Rank | Word | # | Word | # |
| 1 | pain | 203 | surgery | 91 |
| 2 | sciatica | 92 | pain | 85 |
| 3 | operation | 74 | alarm | 18 |
| 4 | wound | 72 | stress | 14 |
| 5 | disc | 48 | dangers | 11 |
| 6 | surgery | 32 | anxious | 7 |
| 7 | painkillers | 27 | fear | 4 |
| 8 | bulge | 26 | back | 3 |
| 9 | pressure | 24 | nerves | 3 |
| 10 | damage | 23 | anesthesia | 2 |
| 11 | complications | 22 | blood | 2 |
| 12 | claudication | 20 | clots | 2 |
| 13 | surgeon | 20 | dry | 2 |
| 14 | prolapse | 19 | failed | 2 |
| 15 | disability | 17 | problem | 2 |

Discussion

The primary hypotheses of McGregor et al. [24,26] were that the addition of an evidence-based educational booklet to a postoperative rehabilitation program would result in superior results and that the booklet itself would result in a meaningful change. Their results failed to support either hypothesis. The premise of the booklet was that well-designed and evidence-based information [6] would ease patient fears, increase knowledge, and thus result in improved function. The FASTER study was comprehensive and published in a journal with strong readership within the spine surgery and physical therapy professions. The outcomes of the FASTER study may suggest to spine surgeons, physical therapists and their patients that pre- and post-operative education is not an effective tool.

An expert panel in clinical application of NE found that the booklet, 'Your Back Operation', contains three times as many terms that could be associated with increased anxiety and fear, compared to a booklet utilizing the latest evidence for neuroscience education (NE).

The findings from our expert reviewers may allow us to consider the results of the FASTER program from a neuroscience education perspective. These findings suggest that the higher proportion of potential 'provocative' orthopedic terms such as 'sciatica', 'operation', 'wound', 'disc' and 'bulge' as well as the symptomatic description of 'pain' may have been a factor as to why use of the FASTER booklet resulted in outcomes similar to usual care and rehabilitation-only groups. It is clear that terms such as 'pain' and 'surgery' (ranked high in both booklets) are inevitable when describing the experience to the patient. Therapeutic neuroscience education (TNE) is in essence a neurobiological explanation of pain science [29,30], hence the regular use of the word 'pain' in the text. However, even when the words 'pain' and 'surgery' were omitted from the analysis, 'Your Back Operation' contained a higher proportion of provocative terms (4.5 times more).

Language is an input to an individual's pain construction in the pain neuromatrix [20]. This information will further be modulated by the patient's memories, thoughts and emotions [20,16]. Pain neuroscience education should be redefined as 'the delivery of healthcare information to a patient's neuromatrix in an attempt to de-threaten the medical procedure or injury experience'. The 'Your Back Operation' booklet used in the FASTER program, utilizing terminology associated with a biomedical model of tissue pathology may not have succeeded in decreasing that threat. In contrast, therapeutic neuroscience education has been shown to produce changes in patients with spinal pain associated with de-threatening the pain experience [29], improving catastrophization and physical movement in the absence of physical treatments [31], function and disability [30,31] and pain ratings.

Conclusion

The perioperative period is filled with stress and anxiety. Simple, well-meaning words, aimed at helping patients prior to lumbar surgery should be carefully examined by all healthcare providers as it may have the potential to decrease fear, anxiety and the patient's pain experience. This is especially true in orthopedic-based professions following a biomedical model of education.

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