

# From the Patient's Point of View: Patient-Centered Outcomes in Spine Surgery

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## Abstract

**Introduction:** A patient-centered approach to outcomes assessment necessitates knowledge of the outcomes that patients deem most important for their quality of life and overall health. To assess patient expectations with regard to seeking spine care, we conducted a prospective study of what outcome metrics were deemed most valuable to patients seeking evaluation at a tertiary spine surgery center.

**Materials & Methods:** Patients seeking evaluation at an academic spine surgery practice at Thomas Jefferson University in Philadelphia were offered a survey at intake. The two-question survey explored the issues most important for consulting a neurosurgeon. Survey data was acquired over three months in early 2010. Of the surveys distributed, 335 responded, with 147 patients completing the full survey and 188 responding to the first question alone.

**Results:** Pain was the primary impetus for patients seeking evaluation: 73.4% of the total surveyed group reported that pain in the back or neck was one of the major concerns for their visit. Similarly, 51% of responders indicated that pain in the back or neck was the single most important issue they wanted addressed. Frequency of responses dropped significantly for the next responses, including weakness/numbness in the leg (39.7%), problems walking (39.7%), pain shooting down the leg (30.7%), and problems sleeping (30.1%).

**Conclusions:** It is possible that current outcomes measures for spine surgery, including the VAS, ODI, SF-36, and EQ-5D, are either excessive or insufficient and should be adjusted to reflect patient concerns. Changing these measures, enforcing conformance with patient-centered choices of which outcome measures are most valuable, would be one approach to producing patient-specific outcomes measures in spine surgery. Alternatively, present measures may be more comprehensive, and by reducing measures to what patients care about, the quality of data captured may be limited. To determine future directions for patient-centered care, similar surveys should be rigorously conducted, reviewed, and compared to validated outcomes.

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**Categories:** Miscellaneous, Neurosurgery

**Keywords:** Outcomes, practice science, quality, registry, value

## Introduction

Efficient and affordable access to medical knowledge is now a reality for physicians and patients

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alike [1]. The emergence of electronic medical records (EMR) and the ubiquity and power of computing have increased the prospects for mass collection and analysis of healthcare data. Computer database systems have been established within institutions for the efficient accumulation and translation of patient data into meaningful statistics that impact the process of patient care and clinical decision-making [2]. The World Wide Web increasingly provides patients with affordable access to medical knowledge, though often of variable quality and navigability.

With a myriad of healthcare data readily available for both patients and physicians, physicians remain responsible for the meaningful synthesis and interpretation of patient data. Recent interest in patient centered outcomes and a patient-centric approach to outcomes assessment suggests that the flow of data compilation and interpretation may be reversed.

Rather than attempting to derive meaning from broadly collected outcomes data and wide-range outcome metrics, physicians may begin an approach to outcomes assessment by determining what outcomes are most important to their individual patients. Data can then be centralized according to the outcomes that patients deem most important for their quality of life and overall health.

While numerous outcome measures have been reported in the literature, minimal effort has been directed at determining whether or not these measures actually capture the specific outcome metrics most valuable to patients. To begin assessing patient expectations with regard to seeking spine care, we conducted a prospective study of what outcome metrics were deemed most valuable to patients seeking evaluation at a tertiary spine surgery center.

## **Abbreviations**

AAOS = American Academy of Orthopaedic Surgeons

ACA = Patient Protection and Affordable Care Act

ACO = Accountable Care Organizations

CDOSD = Chronic Disabling Occupational Spinal Disorders

EMR = electronic medical records

EQ-5D = EuroQOL-5D

ICCER = Institute for Comparative Clinical Effectiveness Research

ODI = Oswestry Disability Index

PCORI = Patient-Centered Research Outcomes Institute

SF-36 = Short Form Health Survey

VAS = Visual Analogue Scale of Spinal Pain

VSC = Vanderbilt Spine Center

## Materials And Methods

### Population

This study accrued patients from an academic spine surgery practice at Thomas Jefferson University in Philadelphia. The survey was offered to all patients in intake, irrespective of previous diagnoses, therapy, or stage. There were no negative sequelae for not filling out the survey and no incentives for filling out the survey. Survey data was acquired over three months in early 2010. Of the surveys distributed, 335 responded, with 147 patients completing the full survey and 188 responding to the first question alone. The Institutional Review Board of Thomas Jefferson University reviewed the experimental protocol and provided appropriate sanction for performing the study. Informed consent was waived. The investigators complied with ethical guidelines for research involving human subjects.

### Measures

The researchers developed a list of separate elements from outcome metrics widely used in spine surgery. These elements comprise the foundation measures used in compiling the Visual Analogue Scale of Spinal Pain (VAS), Oswestry Disability Index (ODI), Short Form Health Survey (SF-36), and EuroQoL Five Dimension questionnaire (EQ-5D). These common measures are widely reported in the literature for the evaluation of spine patients and have been validated in a variety of spine surgery conditions.

The two-question survey explored the issues most important for consulting a neurosurgeon (Table [1](#)). The first question prompted respondents to "circle the top five concerns and/or complaints that you would like addressed through your visit to our clinic." The second question asked patients to "pick the single most important issue you would like addressed and underline it."

1) Please circle the top 5 concerns and/or complaints that you would like addressed through your visit to our clinic

2) From these, pick the single most important issue you would like addressed and underline it

Pain in my back/neck	Limitations with traveling
Pain shooting down my leg	Problems participating in sports
Weakness/Numbness in my leg	Problems climbing stairs
Amount of pain medications I am taking	Problems bending over
Overall General Health	Problems doing normal housework
Problems with personal grooming/hygiene	(making bed, washing dishes, vacuuming)
Problems with dressing myself	Problems doing my job due to pain
Putting on shoes and socks	Relationships with
Problems lifting light objects	co-workers/supervisor/family/friends
Problems lifting heavy objects	due to my pain
Problems walking (distance, speed)	Depression or anxiety
Problems sitting	Irritability or becoming easily angered
Problems standing	Feeling exhausted or tired
Problems sleeping	Problems with normal social activities
Problems with sex life	Problems with bladder control

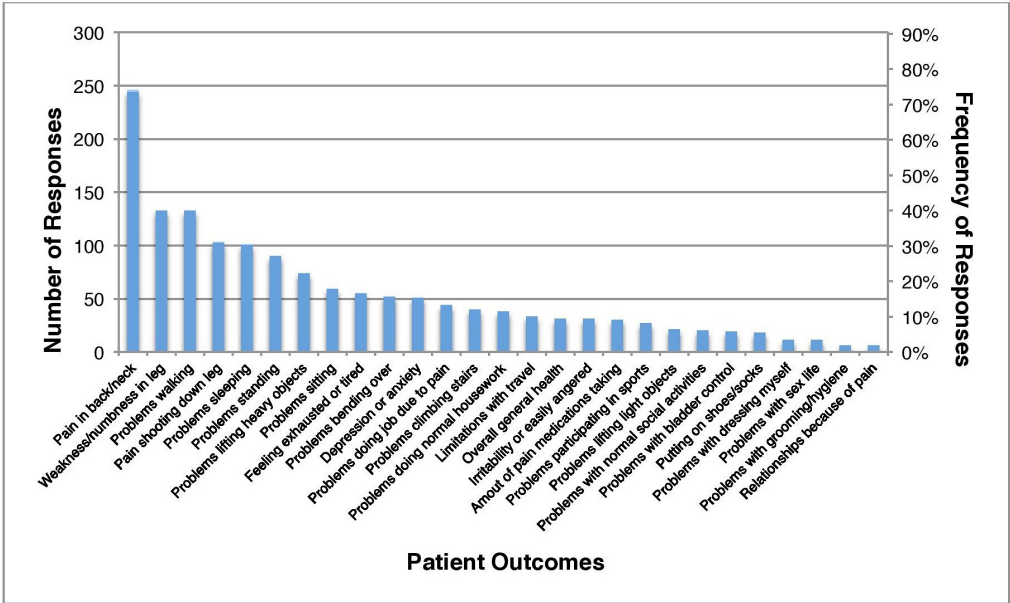
TABLE 1: Questions asked and possible responses in survey offered to patients in intake.

Statistical analysis

Categorical data were summarized with frequency/percentage and compared.

Results

Initial survey of a patient’s motivations for consulting a neurosurgeon elicits a distribution of concerns with moderate consensus (Figure 1). Pain was the primary impetus for seeking evaluation: 73.4% of the total surveyed group reported that pain in the back or neck was one of the major concerns for their visit (Table 2). Similarly, this was the primary concern affecting the majority of patients. Frequency of responses dropped significantly for the next responses, including weakness/numbness in the leg (39.7%), problems walking (39.7%), pain shooting down the leg (30.7%), and problems sleeping (30.1%). For the remaining options, about a quarter or less of patients indicated that one was among his or her major concerns. Sexual and social issues and return to work were of very low frequency, with such activities selected by less than 15% of patients.



**FIGURE 1: Top concerns and/or complaints patients wanted addressed during visit**

Outcome	Responses (N=335)	Frequency (%)
Pain in back/neck	246	73.4
Weakness/numbness in leg	133	39.7
Problems walking	133	39.7
Pain shooting down leg	103	30.7
Problems sleeping	101	30.1
Problems standing	90	26.9
Problems lifting heavy objects	74	22.1
Problems sitting	59	17.6
Feeling exhausted or tired	55	16.4
Problems bending over	52	15.5

**TABLE 2: Most common responses selected by patients when asked to indicate top five concerns and/or complaints to be addressed.**

When considering which issue was the primary concern for a patient, the highest cited

responses were similar (Figure 2). As before, pain in the back or neck was a dominating issue as indicated by 51% of responders (Table 3). Weakness/numbness in the leg (13.6%), pain shooting down the leg (6.1%), and problems with walking (5.4%) contributed to the top four issues. These last three lower limb concerns compose approximately one-quarter (25.1%) of the available responses. None of the remaining individual options assumed more than 5% of the total responding sample.

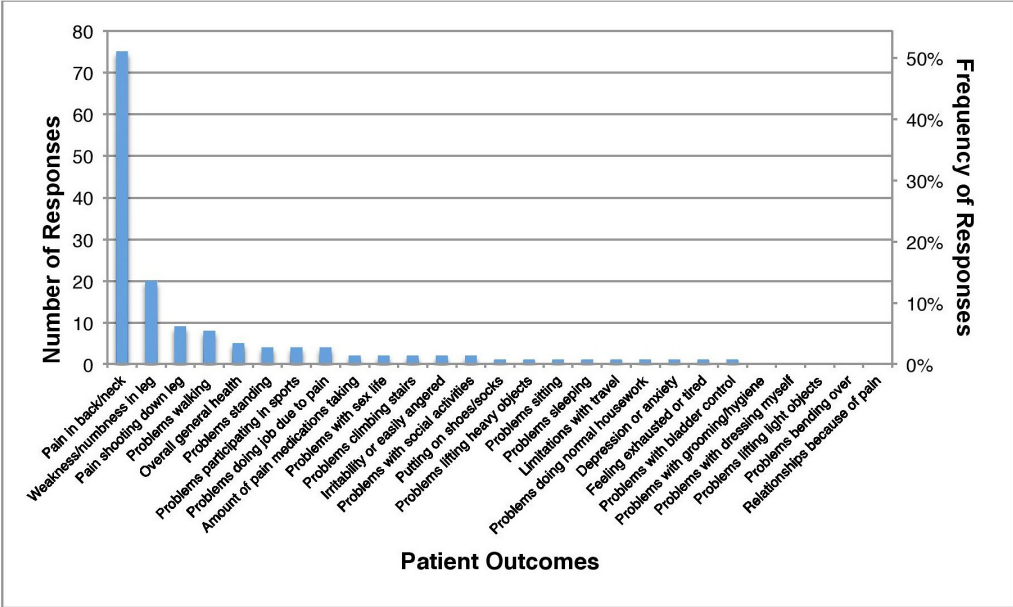


FIGURE 2: Single most important issue

Outcome	Responses (N=335)	Frequency (%)
Pain in back/neck	75	51
Weakness/numbness in leg	20	13.6
Pain shooting down leg	9	6.1
Problems walking	8	5.4
Overall general health	5	3.4
Problems standing	4	2.7
Problems participating in sports	4	2.7
Problems doing job due to pain	4	2.7
Amount of pain medications taking	2	1.4
Problems with sex life	2	1.4

**TABLE 3: Most common responses selected by patients when asked to indicate single most important issues for consulting neurosurgeon.**

Pain was consistently the most common complaint voiced by patients. Axial neck or back pain was the most common complaint offered for both the top five issue and single issue questions. Radicular pain was the third most common single complaint and fourth most common complaint from the multiple issue question.

Job problems were not a common complaint for this cohort of patients. Only 13.1% of patients noted that problems doing their job due to pain were among the top five issues prompting evaluation at a spine center. Only 2.7% noted this was the most important issue for which they sought evaluation.

Notably, only 43.8% of the total patient sample ultimately provided a submission for the survey's second question. The implications of this partial response rate are uncertain and varied, as this could reflect a patient's unwillingness or inability to provide a single answer, or could represent a deficiency in survey design or execution. While the number of responses tallied for the single most important issues are deflated, the true percentage distribution cannot be determined.

## Discussion

### Patient-centered outcomes

The results of this study indicate that pain in the back or neck is the single most important issue that prompts a patient to consult a spine surgeon. This may suggest higher utility for pain-centered validated outcomes measures, such as the VAS. Pain is included in the SF-36, EQ-5D and ODI as well, though it is only one of eight dimensions that contribute to the total score for the SF-36, only one of five for the EQ-5D, and distributed throughout the sections of the ODI. In the results of both survey questions, the three concerns that followed pain in the

back or neck in importance to patients involved both pain and the functional consequences of their pathology: weakness/numbness in the leg, pain shooting down the leg, and problems with walking. Only walking is addressed in the SF-36 and EQ-5D, while all these specific measurements are incorporated within the ODI.

It is possible that other outcomes measured by spine surgeons (ex: self-care, daily activities, and anxiety/depression) are not patient-centered as the majority of patients did not indicate that these issues were of primary concern. Therefore, this survey raises the question of whether neurosurgical outcomes assessments should be moved closer to assessments of the issues identified as most important to patients. This may enable physicians to quantify patient expectations without relying on previously validated outcomes measurements that over- or underemphasize concerns.

## The Patient Protection and Affordable Care Act

The Patient Protection and Affordable Care Act (ACA) was signed into law March 23, 2010 and will be fully implemented on January 1, 2014 [3]. Since the creation of the ACA, the emphasis of health care reform has shifted considerably from quantity to quality [4-7]. Present efforts seek to link physician reimbursement to "value measures" which take into account both quality and cost variation [8]. ACA legislation will invest nearly \$1.1 trillion between 2012 and 2021 in an attempt to make coverage affordable—an investment hoped to be offset in part by a reduction in Medicare and Medicaid spending through an emphasis on high quality and low cost care [9]. Therefore, data on effectiveness of care in everyday practice will be imperative to ensure that patients receive the highest quality rather than simply the lowest-cost care in the future.

The ACA introduces several changes pertinent to the present shift in focus on quality of care, three of which include the creation of Accountable Care Organizations (ACOs), a National Quality Strategy, and the Institute for Comparative Clinical Effectiveness Research. The first, ACOs, include a group of physicians and hospitals that will take responsibility for an expressed population of patients [10]. ACOs will provide physicians and hospitals with incentive to improve integration and increase quality measurement and reporting, ultimately leading to improved outcomes and a reduction in healthcare cost. A central measurement of performance in ACOs is the patient-reported outcome, which further incentivizes physicians to focus patient care and quality measures on patient-specific concerns.

The second, the development of a multi-payer National Quality Strategy, aims to generate multi-payer quality and efficiency measures to promote value purchasing, improve safety, and provide increased health information to private and public insurers [3]. In addition to the drive for increased comparative effectiveness research, The National Quality Strategy encourages increased performance reporting to increase patient's access to information about their care and about the quality of their care.

Lastly, the Institute for Comparative Clinical Effectiveness Research (ICCER) was established by the ACA "to assist consumers, clinicians, purchasers, and policy makers to make informed decisions that improve health care at both the individual and population levels" [3, 11]. This builds on the American Recovery and Reinvestment Act of 2009 that allocated 1.1 billion dollars for new comparative effectiveness research in the U.S [12].

## Patient-Centered Outcomes Research Institute

The Patient-Centered Research Outcomes Institute (PCORI) was created as part of the ACA effort to foster research on informed decision-making, patient care, and re-directing research efforts to be patient-centered. The PCORI has led to an increased focus on patient-centered outcome measures and on framing research in a fashion immediately applicable to patients.



The foundation of the PCORI approach may ultimately move outcomes assessment away from previously validated outcome measures. While many outcomes projects have been completed in spine surgery, limited research has been directed at understanding patient expectations and ensuring that outcome metrics appropriately capture the goals of patients in seeking care.

Outcome metrics in spine surgery

Spine surgery serves as an appropriate model for patient centered outcomes in neurosurgery as it is an elective procedure performed for a degenerative process. Patient outcomes are therefore of utmost importance in a patient's decision to proceed with surgery.

Current validated measures for patient outcomes in spine surgery include the VAS [13], ODI [14-16], SF-36 [17], and EQ-5D [18-20] (Table 4). The VAS is a self-reported, one-dimensional pain rating scale. In contrast to the VAS, the ODI is a self-reported questionnaire with seven (AAOS version 1.0) sections. The ODI measures condition-specific disability and focuses on pain and can be used for both assessment and outcomes data collection. A more general measure of quality of life, the SF-36, is a multipurpose, short-form health survey with 36 items that yields an eight-scale profile of scores as well as overall physical and mental health summary measures [17]. Similarly, the EQ-5D is a two-part self-reported multi-dimensional questionnaire that generates 243 possible health states based on three possible answers for five dimensions [19]. The EQ-5D also measures general quality of life and yields a single utility score of 0-1: 0 representing death and one representing full health.

	VAS	ODI	SF-36	EQ-5D
Pain	Pain	*	Bodily Pain	Pain/Discomfort
Functionality		Walking, Sitting, Standing, Sleeping, Lifting, Traveling, Personal Care	Physical Functioning, Role-Physical, General Health, Social Functioning,	Mobility, Daily Activities, Self-Care
Mental Health			Role-Emotional, Mental Health, Vitality	Anxiety/Depression

TABLE 4: Validated measures for patient outcomes in spine surgery

\* Incorporated throughout the Measure

These measures are frequently used in conjunction to report patient outcomes pre- and post-surgery. However, they may not all represent the outcomes most important to patients themselves.

Study limitations

The external validity of the study is limited by the fact that it is a single-institution study with a small cohort. Limiting the study to a single institution yields optimal data for the institution itself. However, to obtain more generalizable data, future multi-institutional studies should be performed. Additionally, the generalizability of this study is limited by the high prevalence of psychiatric disorders amongst spine patients. Dersh et al. have reported that a majority (65%) of patients with chronic disabling occupational spinal disorders (CDOSD) were diagnosed with at least one current disorder (not including Pain Disorder), compared with only 15% of the

general population [21]. While the patient population in this study is composed of all patients at an academic spine surgery practice with no inclusion criteria based on diagnosis, the potential increase in psychiatric disorders amongst this population must be considered as a variable affecting patient centered outcomes.

Furthermore, lack of an overall calculated response-rate yields high response bias and a lower response-rate for question two [188/335 (56.1%)] limits the internal validity of this study. A more rigorous approach to survey administration and collection should be applied in future studies to maximize internal and external validity and minimize response bias.

Collecting both admission and follow-up data may yield more information as to the benefits/constraints of patient-centered outcomes in the future. To obtain this data, the stringent methodology utilized by Berkowitz et al. in developing a Gamma Knife radiosurgery registry could be applied [2]. Berkowitz *et al.* ensure 100% patient inclusion in studies by monitoring their 11,738 member patient registry through the use of clerical staff checks, server data back up, and quality assessment in six-month intervals via built-in software. Similarly, the Vanderbilt Spine Center (VSC) includes all patients undergoing spine surgery in a prospective longitudinal spine registry, regardless of diagnosis or surgical treatment through the use of registry associates, Web-based Research Electronic Data Capture, and EMR [22]. The VSC employs validated outcomes measures to capture baseline, three month and 12 month outcomes data. Such strict forms of data-collection will be critical in developing accurate data to provide true patient-centered outcomes on an institution basis in the future. Cost and infrastructure development remain the largest drawbacks to this methodology.

## Results of this study

Knowing the issues of greatest concern to patients seeking evaluation for spinal disease will provide clinicians with the opportunity to reassess measurements of surgery outcomes. Assessment of patient expectations in seeking spine care may offer a valuable means to ensure that patients have appropriate expectations in seeking surgical treatment.

In this survey, the majority of patients seeking evaluation at a spine surgery center did so for complaints of pain. Some concerns that are focused upon by outcome metrics used in spine surgery were not listed as primary concerns by patients. Functional deficits, as outlined by the SF-36 measure, were not commonly noted to be primary issues for which individual patients sought treatment. Similarly, return to work is often reported as a proxy for recovery after spine surgery procedures. However, this patient cohort did not note that workplace concerns were significant to their seeking evaluation. This may, in part, explain the results of a study by Hodges et al. that found no correlation between OSW, VAS and SF-36 and return-to-work rates in 87 workers' compensation patients who underwent lumbar spine surgery [23].

Present approaches to outcome measures in spine surgery may not be entirely representative of patient expectations. Reviewing the commonly used outcome measures and comparing them to patient choices for most important issues for consulting a spine surgeon, the VAS is the single most valuable outcome metric. The ODI, similarly through relating pain to functional level, captures many issues deemed important by patients.

## Conclusions

It is possible that measures used today are insufficient and should be adjusted to reflect patient concerns. Some present, widely-used outcomes measures report elements that patients may not find valuable. Changing these measures, enforcing conformance with patient-centered choices of which outcome measures are most valuable, would be one approach to producing patient-specific outcomes measures in spine surgery.

Alternatively, present measures may be more comprehensive, and by reducing measures to what patients care about, the quality of data captured may be limited. Routinely used and validated outcome measures may be providing a broader measure of patient outcomes. By focusing solely on what patients are interested in, physicians may be limiting their opportunity to improve patient health across multiple measures.

Both possibilities have implications for the future of patient-centered care in neurosurgery. As healthcare transforms under reform efforts, it is important for physicians and patients alike to recognize that what makes patients happier does not necessarily make them healthier. The goals of health care need to be defined on a national, institutional and individual basis.

To determine future directions for patient-centered care, similar surveys should be rigorously conducted, reviewed, and compared to validated outcomes. A survey of both patients and surgeons should be performed to determine whether patients and health professionals differ in their perspectives with respect to quality in spine surgery.

## Additional Information

### Disclosures

**Human subjects:** Consent was obtained by all participants in this study. The Institutional Review Boards of Thomas Jefferson University issued approval N/A. **Animal subjects:** All authors have confirmed that this study did not involve animal subjects or tissue. **Conflicts of interest:** In compliance with the ICMJE uniform disclosure form, all authors declare the following: **Payment/services info:** All authors have declared that no financial support was received from any organization for the submitted work. **Financial relationships:** All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work. **Other relationships:** All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

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