

Beyond the Treatment:

Interactive Tools for QOL Data Collection

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22 March, 2013

Outline

- Purpose
- Methods
- Results
- Limitations

Quality of Life Data

Why Collect It?

Quality of Life Data

- Evaluate treatment
- Monitor disease
- Facilitate communication

Why Collect It?

Quality of Life Data

Criticisms:

- Subjective
- Unreliable

Quality of Life Data

Precision of Health-Related Quality-of-Life Data Compared With Other Clinical Measures

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SPECIAL ARTICLE

Precision of Health-Related Quality-of-Life Data Compared With Other Clinical Measures

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Clinical Significance Consensus Meeting Group

Reliable?



Yes.

Quality of Life Data

Criticisms:

- Subjective
- Unreliable
- Improves Care?**

Quality of Life Data

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ORIGINAL REPORT

Measuring Quality of Life in Routine Oncology Practice Improves Communication and Patient Well-Being: A Randomized Controlled Trial

*Galina Velikova, Laura Booth, Adam B. Smith, Paul M. Brown, Pamela Lynch, Julia M. Brown,
and Peter J. Selby*

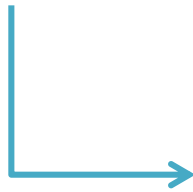
Improves Care?

Yes.

Quality of Life Data

Methods.

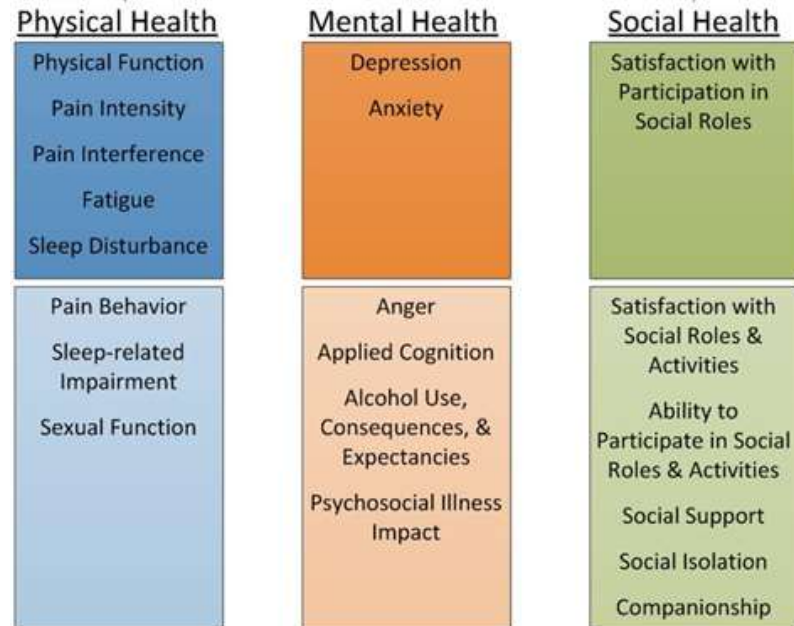
Quality of Life Data



Quality of Life Data



Adult Health



Database Development

What Data do we Collect?

Database Development

Quality of Life

- PROMIS Surveys
- EQ -5D
- Oswestry Disability Index
- Neck Disability Index
- DASH

Clinical Information

- Diagnosis
- Treatment
- Follow-up

Database Development

Quality of Life

Clinical Information



Began 1970's – Henry Mankin MD

Database Development

Quality of Life

Clinical Information



Began 1970's – Henry Mankin MD



Current Total: 21,000 Patients

Database Development

Quality of Life



Began 2011

Clinical Information



Began 1970's – Henry Mankin MD



Current Total: 21,000 Patients

Database Development

Quality of Life



Began 2011



Current Total: 1,200 Patients

Clinical Information



Began 1970's – Henry Mankin MD



Current Total: 21,000 Patients

Database Development



Database Development



- Customizable
 - Survey capture
 - Data Entry
- HIPPA compliant
- Ease of use
- Free

Oncology Database

Quality of Life

The screenshot shows the 'Orthopaedic Oncology Questionnaires' form. At the top left is the MGH 1811 logo. The title is 'Orthopaedic Oncology Questionnaires'. Below the title, it says 'Please complete the survey below. Thank you!'. The form is divided into sections. The first section is 'Demographic Information' and contains the following fields: 'Today's Date' (with a calendar icon and a 'Today' button), 'First Name', 'Last Name', 'Medical Record # (Blue Card #)', 'Date of Birth' (with a calendar icon and a 'Today' button), 'Sex' (radio buttons for Male and Female), 'Race' (radio buttons for Caucasian, African American, Hispanic, Asian, Middle Eastern, and Other), and 'Physician's Name' (radio buttons for Dr. Hornick, Dr. Razin, Dr. Schwab, Dr. Springfield, and Dr. DeLaney).

Clinical Information

The screenshot shows the 'Orthopaedic Oncology Surgeon's Notes' form. At the top left is the REDCap logo. The title is 'Orthopaedic Oncology Surgeon's Notes'. Below the title, it says 'Surgeons Notes' and 'View my responses'. There is a 'Download PDF of' button and a dropdown menu for 'select PDF downloaded option'. The form is divided into sections. The first section is 'Adding new Study ID 104'. The second section is 'Patient Information' and contains the following fields: 'Study ID' (value: 104), 'Today's Date' (with a calendar icon and a 'Today' button), 'Patient's Last Name', 'MRN', 'DOB' (with a calendar icon and a 'Today' button), and 'Gender' (radio buttons for Male and Female). The third section is 'Tumor Diagnosis' and contains the following fields: 'Tumor Location' (with a dropdown menu), 'Tumor Diagnosis by WHO Classification' (checkboxes for Spine, Upper Extremity, Lower Extremity, Pelvis, Joint, Soft Tissue Tumor, Bone Tumor, Metastatic Disease, and Other). The fourth section is 'Treatment Information' and contains the following field: 'Surgery performed?' (radio buttons for Yes and No).

Oncology Database

Quality of Life

The screenshot shows a web-based form titled "Orthopaedic Oncology Questionnaires" with the MGH 1811 logo. It includes a "Demographic Information" section with fields for "Today's Date", "First Name", "Last Name", "Medical Record # (Blue Card #)", "Date of Birth", "Sex" (Male/Female), "Race" (Caucasian, African American, Hispanic, Asian, Middle Eastern, Other), and "Physician's Name" (Dr. Hornick, Dr. Razin, Dr. Schwab, Dr. Springfield, Dr. DeLaney).

Clinical Information

The screenshot shows the REDCap interface for "Orthopaedic Oncology Surgeon's Notes". A central text box states "Completed by provider". The form includes sections for "Surgeons Notes", "Adding new Study ID 114", "Gender" (Male/Female), "Tumor Diagnosis" (Spine, Upper Extremity, Lower Extremity, Pelvis, Joint), "Tumor Location", "Tumor Diagnosis by WHO Classification" (Soft Tissue Tumor, Bone Tumor, Metastatic Disease, Other), "Treatment Information", and "Surgery performed?" (Yes/No).

Oncology Database

Quality of Life

MGH 1811

Orthopaedic Oncology Questionnaires

Please complete the survey below.

Thank you!

Demographic

Today's Date

First Name

Last Name

Medical History

Date of Birth

Sex

Race

Physician's Name

Completed by patient at home or in clinic

Clinical Information

REDCap

Orthopaedic Oncology Surgeon's Notes

Surgeons Notes

Adding new Study ID 104

Study ID: 104

Today's Date

Patient Information

Patient's Last Name

MRN

DOB

Gender

Tumor Diagnosis


Tumor Location

Tumor Diagnosis by WHO Classification


Treatment Information

Surgery performed?

Oncology Database



MGH
1811

Resize font:  [Returning?](#)

Orthopaedic Oncology Questionnaires

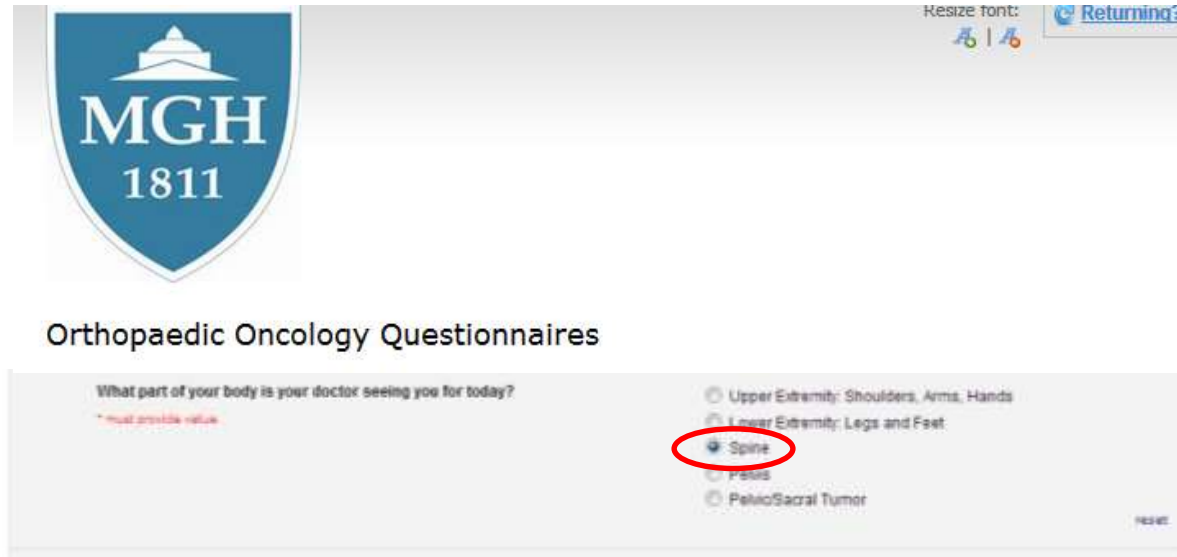
What part of your body is your doctor seeing you for today?
* must provide value

- Upper Extremity: Shoulders, Arms, Hands
- Lower Extremity: Legs and Feet
- Spine
- Pelvis
- Pelvic/Sacral Tumor

Reset

Quality of Life

Oncology Database



MGH
1811

Resize font: [A](#) | [A](#) [Returning?](#)

Orthopaedic Oncology Questionnaires

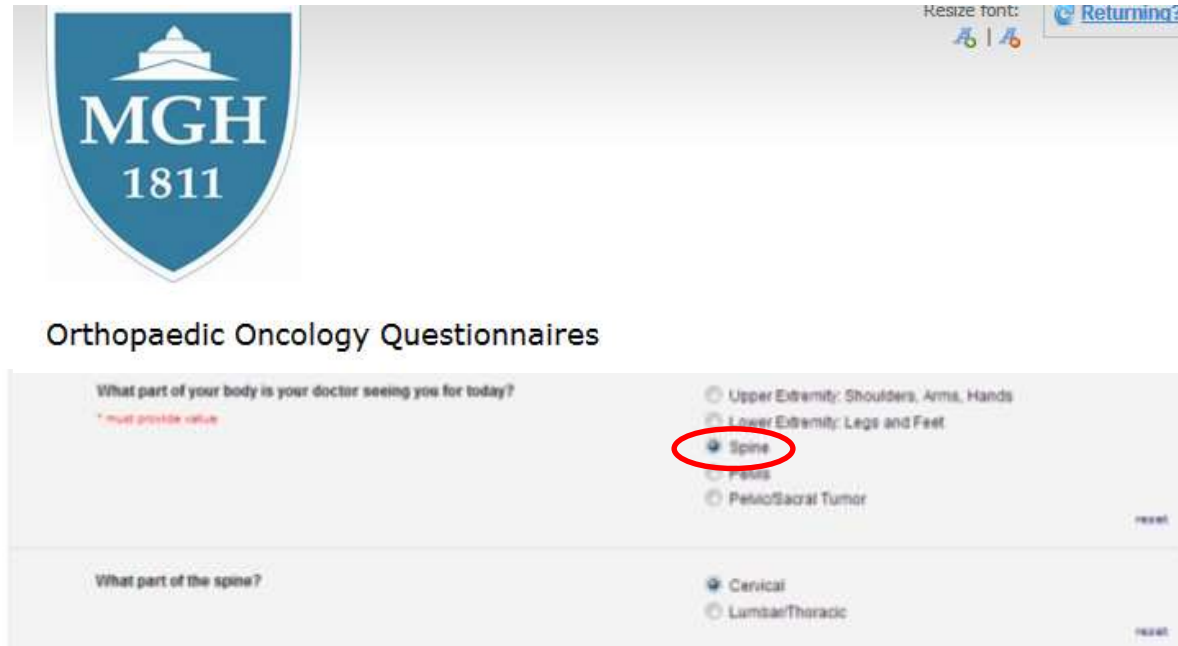
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- Upper Extremity: Shoulders, Arms, Hands
- Lower Extremity: Legs and Feet
- Spine
- Pelvis
- Pelvic/Sacral Tumor

Reset

Quality of Life

Oncology Database



MGH 1811

Resize font: [A](#) | [A](#) [Returning?](#)

Orthopaedic Oncology Questionnaires

What part of your body is your doctor seeing you for today?
* must provide value

- Upper Extremity: Shoulders, Arms, Hands
- Lower Extremity: Legs and Feet
- Spine
- Hands
- Pelvic/Sacral Tumor

[reset](#)

What part of the spine?

- Cervical
- Lumbar/Thoracic

[reset](#)

Quality of Life

Oncology Database

MGH 1811

Resize font: [A](#) | [A](#) [Returning?](#)

Orthopaedic Oncology Questionnaires

What part of your body is your doctor seeing you for today?
* must provide value

Upper Extremity: Shoulders, Arms, Hands
 Lower Extremity: Legs and Feet
 Spine
 Hands
 Pelvic/Sacral Tumor

What part of the spine?

Cervical
 Lumbar/Thoracic

Quality of Life

Oncology Database



MGH
1811

Resize font:  [Returning?](#)

Orthopaedic Oncology Questionnaires

What part of your body is your doctor seeing you for today?
* must provide value

Upper Extremity: Shoulders, Arms, Hands
 Lower Extremity: Legs and Feet
 Spine
 Pain
 Pelvic/Sacral Tumor

What part of the spine?

Cervical
 Lumbar/Thoracic

NDI: Neck Disability Index

1. Pain intensity:

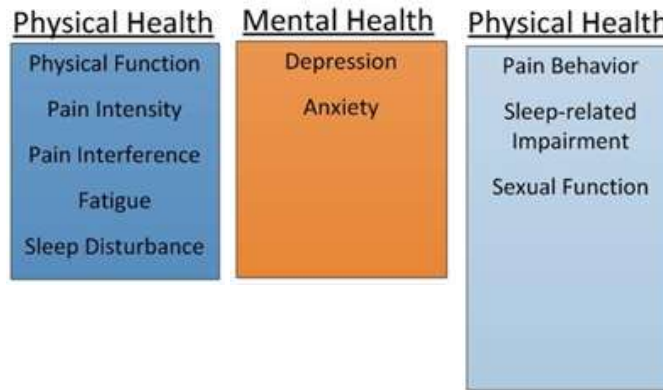
I have no pain at the moment.
 The pain is very mild at the moment.
 The pain is moderate at the moment.
 The pain is fairly severe at the moment.
 The pain is very severe at the moment.
 The pain is the worst imaginable at the moment.

2. Personal Care (Washing, Dressing, etc.):

I can look after myself normally, without causing extra pain.
 I can look after myself normally, but it causes extra pain.
 It is painful to look after myself and I am slow and careful.
 I need some help, but manage most of my personal care.
 I need help every day in most aspects of self-care.

Oncology Database

PROMIS



Quality of Life

Oncology Database

Started in late 2011



Results

1,200 Patients

Results

The Sacral Tumor Study Group

Massachusetts General Hospital

The Mayo Clinic

Memorial Sloan-Kettering

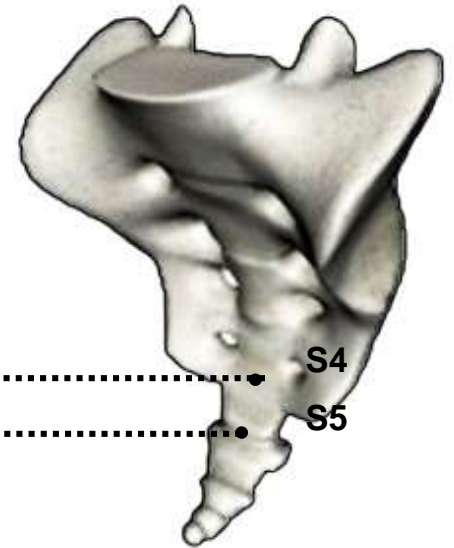


THE FOUNDERS OF THE SACRAL TUMOR STUDY GROUP: *Back row (left to right):* Peter Rose, MD; Peter Bergh, MD, PhD; John Healey, MD; Francis Hornicek, MD, PhD. *Front row (left to right):* Guo Wei, MD; Patrick Boland, MD; Björn Gunterberg, MD, PhD; Joseph Schwab, MD, MS; Franklin Sim, MD; Michael Yaszemski, MD, PhD

Sacral Chordoma



Treatment



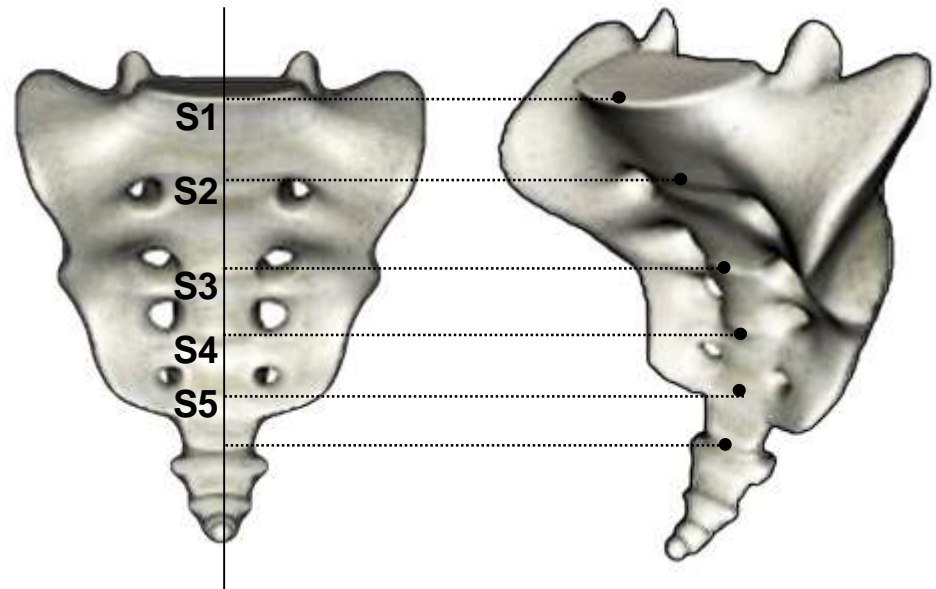
Sacral Chordoma

Quality of Life

- General Health
- Pain
- Bladder Function
- Bowel Function
- Sexual Function

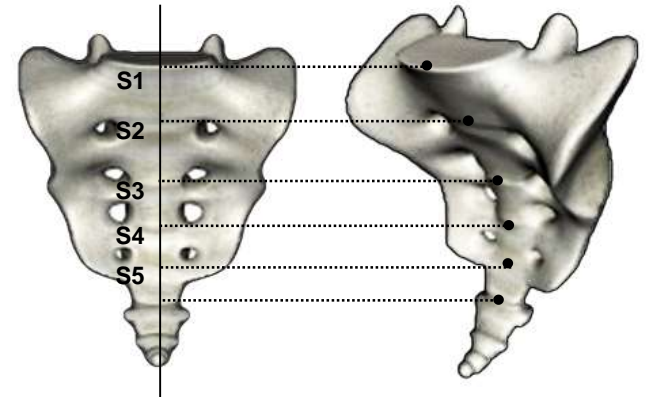
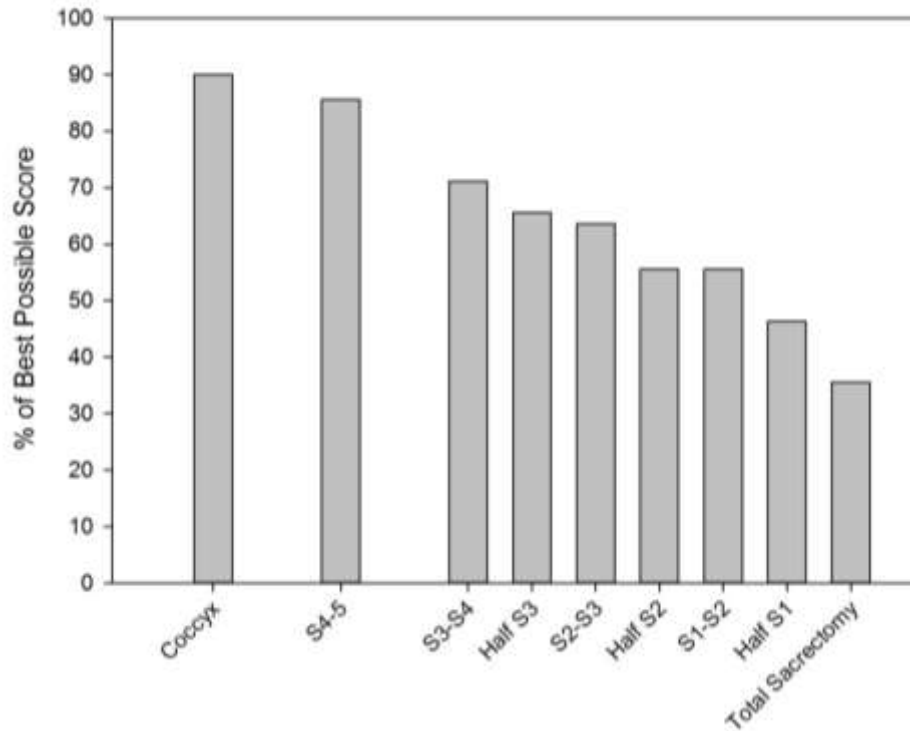
Clinical Information

- Level of Surgical Resection



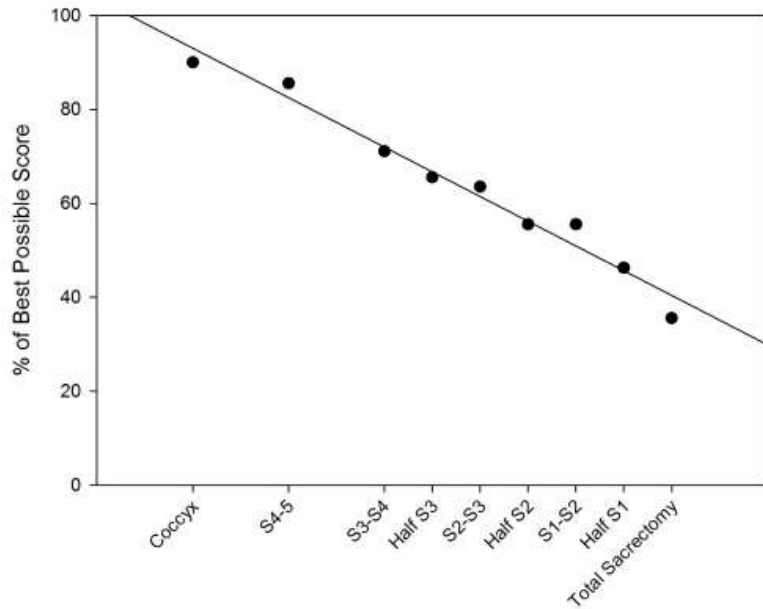
Results

General Health Score vs Resection Level



Results

Linear Regression - General Health Score vs Resection Level

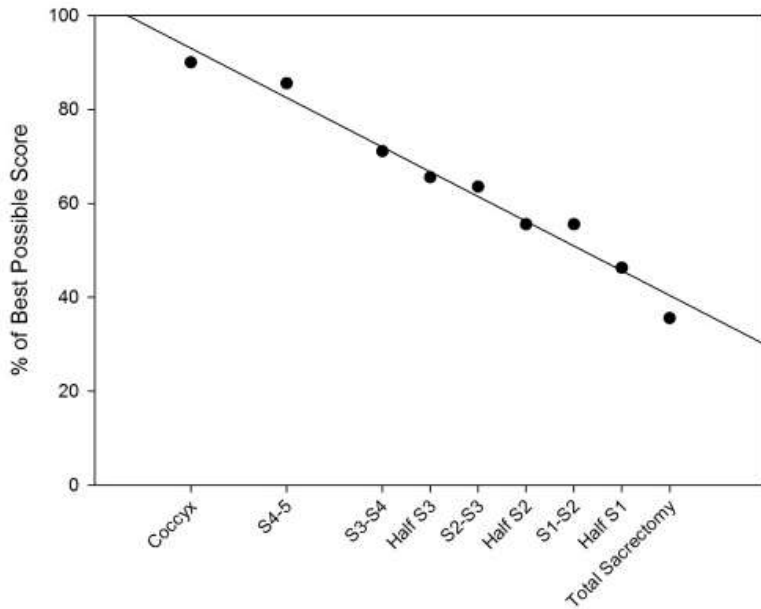


General Health

R = 0.985
Rsqr = 0.971
Adj Rsqr = 0.967

Results

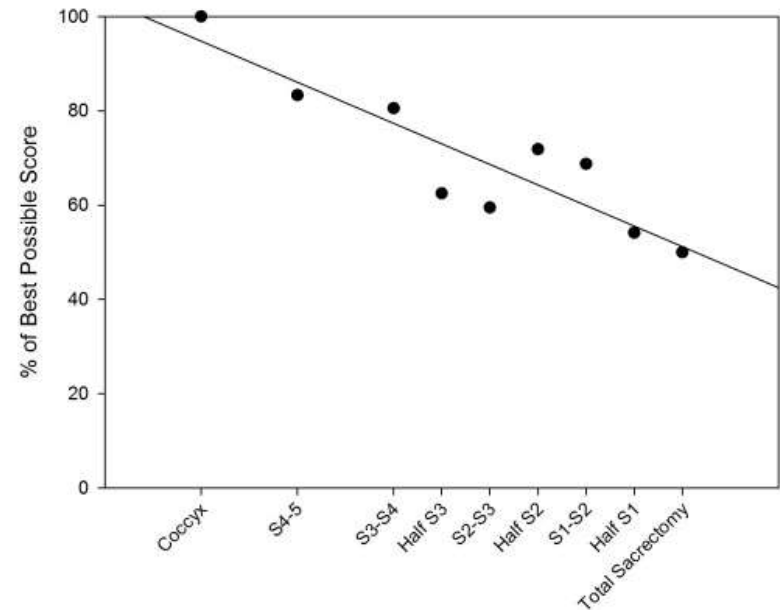
Linear Regression - General Health Score vs Resection Level



General Health

R = 0.985
Rsqr = 0.971
Adj Rsqr = 0.967

Linear Regression - Pain Score vs Resection Level



Pain

R = 0.901
Rsqr = 0.812
Adj Rsqr = 0.786

Limitations

Limitations

Lumbar Spine

EQ-5D

This is the EQ-5D, a questionnaire that helps us get a better idea of your health in general.



Instructions: By placing a checkmark in one box in each group, please indicate which statement best describes your own health state today.

Mobility:

- I have no problems in walking about.
- I have some problems in walking about. — uphill better - down hill - Extreme Pain
- I am confined to bed. — Couch on Rt Side Pillow Back, Knee + Feet

Self Care:

- I have no problems with self-care.
- I have some problems washing or dressing myself.
- I am unable to wash or dress myself.

Usual Activities (e.g. work, study, housework, family or leisure activities):

- I have no problems with performing my usual activities.
- I have some problems with performing my usual activities.
- I am unable to perform my usual activities. — No thinking - walking - riding in

Pain/Discomfort:

- I have no pain or discomfort.
- I have moderate pain or discomfort.
- I have extreme pain or discomfort.

Anxiety/Depression:

- I am not anxious or depressed.
- I am moderately anxious or depressed.
- I am extremely anxious or depressed.

To Date (month/year) 10/2012

Just took over from...

Car - Fed every 2 hrs
 in roads - 3 hrs
 max in the car - 3-4 hrs
 Totalled - just keep
 trying to get along - Life
 has been useless - last
 3 x 5 yrs - Compared to
 Active outdoorsman -
 SK; Instructor - etc

ADHD as well as
 Live Extreme - Reimburse
 About Socialization of wanting to
 Taking Care of 2 - Elder Call it quits - But
 Paralysis + I 86 yr old Refuse + keep Seeking help - Thus I'm having
 Gentleman - who has NO family that
 Keeps up w/ him + Macular Degeneration + Hardly works and has to
 Like - they Broke the Mold After him - only vacation 1952-1956

Limitations

If you were given the option would you choose to have this surgery again?

Yes

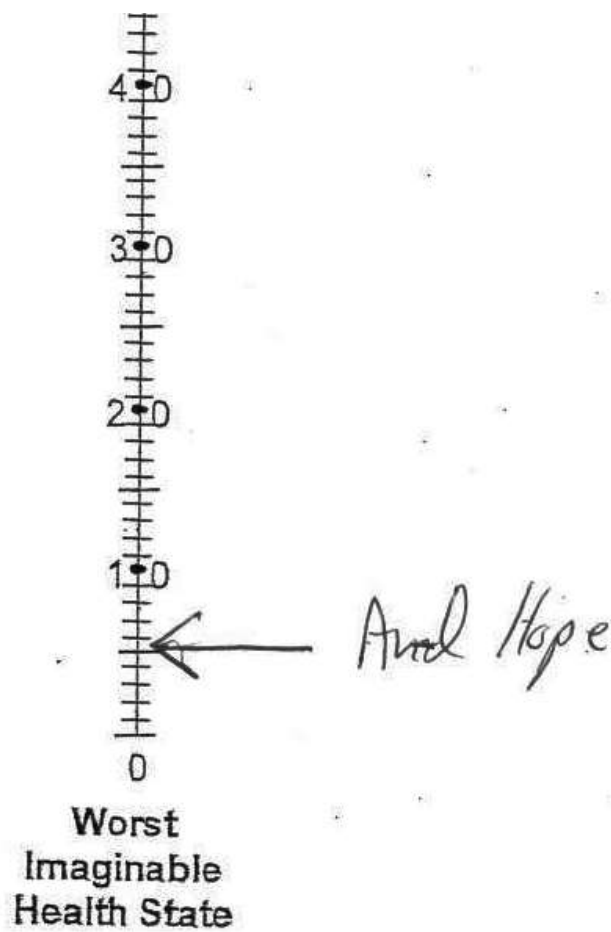
or I'd be ~~dead~~



No

Recovery was unexpectedly horrible.
Took months to feel normal
again. But since then, not
too bad. Dr. Hornick, Yun,
& Delaney are awesome gentlemen.

Limitations



Conclusions

- Unique clinical measurement
- Accessible instruments
- MGH Oncology Database
- Benefits patients
- Continued improvement

Acknowledgements

Stephen L. Harris Center for Chordoma Care

Massachusetts General Hospital

Sacral Tumor Study Group



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Al Ferreira RN,
Anne Fiore NP,

*Kevin Raskin MD, Thomas DeLaney MD, Yen-Lin Chen MD,
Dempsey Springfield MD*

Francis Hornicek MD, PhD,
Joseph Schwab MD, MS



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