Beyond the Treatment: Interactive Tools for QOL Data Collection

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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

Reliable? Yes.
Quality of Life Data

Criticisms:

- Subjective
- Unreliable
- Improves Care?
Quality of Life Data

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

PROMIS® Dynamic Tools to Measure Health Outcomes from the Patient Perspective

Adult Health

Physical Health
- Physical Function
- Pain Intensity
- Pain Interference
- Fatigue
- Sleep Disturbance

Mental Health
- Depression
- Anxiety

Social Health
- Satisfaction with Participation in Social Roles

Pain Behavior
- Sleep-related Impairment
- Sexual Function

Anger
- Applied Cognition
- Alcohol Use, Consequences, & Expectancies
- Psychosocial Illness Impact

Satisfaction with Social Roles & Activities
- Ability to Participate in Social Roles & Activities
- Social Support
- Social Isolation
- Companionship
Database Development

What Data do we Collect?
Database Development

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<tr>
<th>Quality of Life</th>
<th>Clinical Information</th>
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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

REDCap
Research Electronic Data Capture
Database Development

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

Quality of Life

Clinical Information
Oncology Database

Quality of Life

Clinical Information

Completed by provider
Oncology Database

Quality of Life

Completed by patient at home or in clinic

Clinical Information
Oncology Database

Orthopaedic Oncology Questionnaires

What part of your body is your doctor seeing you for today?
- Upper Extremity: Shoulders, Arms, Hands
- Lower Extremity: Legs and Feet
- Spine
- Pelvis
- Pelvis/Sacral Tumor

Quality of Life
Oncology Database

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Selected: Spine

Quality of Life
Oncology Database

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What part of the spine?
- Cervical
- Lumbar/Thoracic

Quality of Life
Oncology Database

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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 cautious.
- I need some help, but manage most of my personal care.
- I need help every day in most aspects of self-care.
Quality of Life

Oncology Database

PROMIS

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Mental Health
- Depression
- Anxiety

Physical Health
- Pain Behavior
- Sleep-related Impairment
- Sexual Function
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

S4
S5
Sacral Chordoma

Quality of Life
• General Health
• Pain
• Bladder Function
• Bowel Function
• Sexual Function

Clinical Information
• Level of Surgical Resection
Results
General Health

R = 0.985
Rsqr = 0.971
Adj Rsqr = 0.967
Results

General Health

R = 0.985
Rsqr = 0.971
Adj Rsqr = 0.967

Pain

R = 0.901
Rsqr = 0.812
Adj Rsqr = 0.786
Limitations
Limitations
Limitations

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

Yes [X] or I'd be dead [X]

No [ ]

Recovery was unexpectedly horrible. Took months to feel normal again. But since then, not too bad. Dr. Horning, Guns, and Delaney are awesome gentlemen.
Limitations

[Graph showing a vertical scale labeled "Worst Imaginable Health State" with an arrow pointing to the "And Hope" label at the bottom of the scale.]
Conclusions

- Unique clinical measurement
- Accessible instruments
- MGH Oncology Database
- Benefits patients
- Continued improvement
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Francis Hornicek MD, PhD,
Joseph Schwab MD, MS
References