Session Objectives

1. Briefly describe the most common impairments among those with urogenital cancers that contribute to lower extremity and genital lymphedema, and urinary incontinence and sexual dysfunction.
2. Identify selected assessment techniques and outcome measures that can appropriately be used to assess this population.
3. Recognize the role of consistency in outcomes measures to monitor patient status and demonstrate intervention effectiveness in individual and patient groups.
4. Discuss the relative merits of presented outcome tools based on psychometric properties, administration issues, and limitations.

History of EDGE

“"The bottom line is that evidence of intervention effectiveness depends on, among other things, common use of valid and reliable tests/measures that reflect clinically important outcomes and are responsive to change."”

Field-Fote E, Levangie P, Craik R. Towards Optimal Practice – How Can Students Contribute? Student Assembly Pulse (Newsletter of the Student Assembly of the APTA), March 2007, p. 4

Disclosure

No relevant financial relationship exists
EDGE Purpose

• Standardize outcome measures
  • To support/refute effectiveness of intervention strategies
• Determine outcome measures which are
  • Reflective of important outcomes
  • Valid
  • Reliable
  • Responsive to change

EDGE Goals

1. Establish a framework to facilitate the evaluation of outcome measures
2. Assist stakeholder groups in evaluating outcome measures reflective of specialty practice
3. Assist in promoting the use of a core set

EDGE Form

• Developed by consensus of experts to assess outcome measures
• Numerous iterations
• Informed by other test/measure assessment strategies in the literature

EDGE Ratings

• Neurology Section developed a Utility Scale Score
• Oncology Section
  • Created a task force in 2010
  • Identified measurement tools for breast cancer survivors
  • Identification of Domains and Subdomains in ICF based on literature review and expert panel
  • Body Structure and Function: 8 subdomains
  • Activity and Participation: 11 subdomains
• Adopted most of the documents/processes utilized by Neurology Section

ONCÖLOGY EDGE Rating Scale

<table>
<thead>
<tr>
<th>Highly Recommend</th>
<th>Highly recommended; the outcome measure has excellent psychometric properties and clinical utility; the measure has been used in research on individuals with or post cancer.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommend</td>
<td>Recommended; the outcome measure has good psychometric properties and good clinical utility; no published evidence that the measure has been applied to research on individuals with or post cancer.</td>
</tr>
<tr>
<td>Unable to Recommend at this time</td>
<td>Unable to recommend at this time; there is insufficient information to support a recommendation of this outcome measure; the measure has been used in research on individuals with or post cancer.</td>
</tr>
<tr>
<td>Do not Recommend</td>
<td>Poor psychometrics &amp;/or poor clinical utility (time, equipment, cost, etc.)</td>
</tr>
</tbody>
</table>

Target Client Population

The population which the outcome measure (OM) is validated

ICF Domain

The domain (body structure function, activities, participation) in which the OM is meant to capture

Instrument components

Aspects of the domain captured by the OM

Instrument properties

Validity for intended purpose

Instrument measures what is intended to measure
Instrument identifies a true change when a change has occurred

Sensitivity to change

Responsiveness. Instrument identifies a change in score when true change has occurred
MOD: Change in a measure that is considered to be clinically relevant to the patient
MDC: Estimates of error reported in same units as the toll from which they are derived

Ceiling/floor effect consideration

Ceiling effect: A measurement can not take on a value higher than some limit because of the finite nature of the instrument
Floor effect: Opposite of the ceiling effect

Reference values for interpretation in target population

Normative values or values known to be predictive
Oncology EDGE Work to Date: Breast cancer

- Shoulder function: scapular assessment; ROM and muscle length; self-reported functional scales for the shoulder
  - Presented at CSM ’12 - Chicago
  - Published in Rehabilitation Oncology, Vol. 31:1
- Pain; fatigue; lymphedema
  - Presented at CSM ’13 – San Diego
  - Published in Rehabilitation Oncology, Vol 32:1 and 32:3
- Strength, endurance, quality of life (QOL)
  - Presented at CSM ’14 – Las Vegas
  - Published in Rehabilitation Oncology, Vol 32:4, 33:1, 33:2
- Neuropathy, balance, functional mobility measures
  - Presented at CSM ’15 – Indianapolis
  - Published in Rehabilitation Oncology, Vol 33:1 and 33:3

Oncology EDGE Work to Date: Head and Neck cancer

- Patient-reported outcome measures for shoulder and neck dysfunction
  - Presented at CSM ’14 – Las Vegas
  - Published in Rehabilitation Oncology, Vol 32:3
- Temporomandibular-related dysfunction and Quantifying external lymphedema
  - Presented at CSM ’15 – Indianapolis
  - Published in Rehabilitation Oncology, Vol 33:2

Oncology EDGE Work to Date: Prostate cancer

- Strength and Muscular Endurance Measures
  - Presented at CSM ’15 – Indianapolis
  - Published in Rehabilitation Oncology, Vol 33:2
- Quality of Life
  - Presented at CSM ’15 – Indianapolis
  - Published in Rehabilitation Oncology, Vol 34:1
- Functional Mobility Measures
  - Presented at CSM ’15 – Indianapolis
  - To be submitted to Rehabilitation Oncology, Spring 2016

Oncology EDGE Future Work

- Steering Committee formed (subcommittee of Research Committee)
- Constructs similar to all cancers will be covered together
- Topics specific to particular cancers will be covered as required
- CSM 2017 – across cancers
  - Cancer-related fatigue
  - Cancer-related pain
- Contact Laura Gilchrist - lsgilchrist@stkate.edu

Oncology Section EDGE Task Force on Urogenital Cancer:
A Systematic Review of Clinical Measures for Lymphedema

Joy Cohn, PT, CLT-LANA

Contributors

- Hannah Geyer, BS, SPT
  – University of Dayton
- Jet Lee, PT, PhD
  – San Francisco State University/UCSF
- Mary I. Fisher, PT, PhD, OCS, CLT
  – University of Dayton
What is Lymphedema?

- An abnormal accumulation of protein rich fluid in the epifascial soft tissue with accompanied tissue fibrosis due to chronic inflammation
- Secondary lymphedema in many patients after cancer treatments is seen in the lower half of the body:
  - Lower extremities,
  - Abdomen,
  - Buttocks and genitals

Common Cancer Diagnoses with LE or Genital Involvement

- All gynecological cancers: uterine, cervical, ovarian, vulvar, endometrial
- Prostate CA
- Bladder CA
- Melanoma
- Colorectal CA
- Lymphoma

Risk Factors for Developing Lymphedema

- # of nodes dissected
- Radiation Therapy
- BMI
- Co-morbidities

Impairments Associated with LE and Genital Lymphedema

- Limb Volume
- Scrotal Volume
- Increased risk of cellulitis
- QOL Issues
  - Sexuality
  - Emotional health
  - Infertility
  - Function across domains
- Pain

Timeline for Lymphedema Urogenital Cancer EDGE Review

- Literature search and article review completed October-November 2015
- Review, rating, and consensus of identified outcomes completed December 2015

Search Strategy

<table>
<thead>
<tr>
<th>Databases and Sites Searched</th>
<th>Search Terms/Strings</th>
<th>Limits Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Google Scholar</td>
<td>Lower extremity/leg, genital, abdominal</td>
<td>English 1995 or newer</td>
</tr>
<tr>
<td>Ovid</td>
<td>Psychometric properties/clinimetrics</td>
<td></td>
</tr>
<tr>
<td>Pubmed/Medline</td>
<td>Swelling</td>
<td></td>
</tr>
<tr>
<td>CINAHL</td>
<td>Lymphedema/lymphoedema</td>
<td></td>
</tr>
<tr>
<td>Sports Discus</td>
<td>Limb volume</td>
<td></td>
</tr>
<tr>
<td>Web of Science</td>
<td>Cancer</td>
<td></td>
</tr>
<tr>
<td>Cochrane Review</td>
<td>Inguinal node dissection</td>
<td></td>
</tr>
<tr>
<td>PEDro</td>
<td>Node sampling</td>
<td></td>
</tr>
<tr>
<td>Academic Search</td>
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<td></td>
</tr>
</tbody>
</table>
Article Selection

Inclusion Criteria
- Measures of limb volume of the lower extremity, genitals, or abdomen
- Measures of QOL for those with lymphedema
- Adults, (human subjects)
- English language
- Clinically feasible methods
- Psychometric properties reported

Exclusion Criteria
- Non-clinical measures of lower extremity and genital edema measures

Initial Search of Articles = 347,180
Final Articles Included for Initial Review = 66
Articles not Meeting Criteria = 29
Articles Reviewed = 37

Each outcome measure was reviewed and rated independently by 2 reviewers
Any measure with discrepancies in ratings was discussed by Task Force to reach consensus

Outcome Measures Selected

Limb volume measures
- Bioimpedance
- Tape measure
- Perometer
- Ultrasound
- Water displacement

LLIS
- Lymphedema Life Impact Scale
FLQA-1
- Freiberg Life Quality Assessment
Lymph-ICF-LL
- Lymphoedema Functioning, Disability and Health Questionnaire for Lower Limb Lymphoedema

Outcome Measures Selected

Quality of Life
- LLIS
- FLQA-1
- Lymph-ICF-LL

LYMQOL
- Quality of Life Measure for Limb Lymphoedema
LyQLI
- Lymphedema Quality of Life Inventory

Summary
Limb Volume Measures

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Water Displacement</td>
<td>4</td>
</tr>
<tr>
<td>Tape Measure</td>
<td>4</td>
</tr>
<tr>
<td>Perometer</td>
<td>3</td>
</tr>
<tr>
<td>Bioimpedance</td>
<td>3</td>
</tr>
<tr>
<td>Ultrasound</td>
<td>1</td>
</tr>
</tbody>
</table>

Summary
Quality of Life

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>LLIS - Lymphedema Life Impact Scale</td>
<td>3</td>
</tr>
<tr>
<td>FLQA-1- Freiberg Life Quality Assessment</td>
<td>2A</td>
</tr>
<tr>
<td>Lymph-ICF-LL</td>
<td>2A</td>
</tr>
<tr>
<td>LYMQOL</td>
<td>2A</td>
</tr>
<tr>
<td>LyQLI - Lymphedema Quality of Life Inventory</td>
<td>2A</td>
</tr>
</tbody>
</table>

Highly Recommended Measures

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Water Displacement</td>
<td>4</td>
</tr>
<tr>
<td>Tape Measure</td>
<td>4</td>
</tr>
</tbody>
</table>

Water Displacement

Strengths
- Gold Standard for volume assessment
- Equipment inexpensive - <$400
- Utilized primarily for lower leg/foot volumes

Weaknesses
- Infection Control issues
- Limb Size vs Volumeter Size
- Time constraints

Tape Measure

Strengths
- Reliability
  - Test-retest Reliability: ICC = 0.82-0.89
  - Inter-rater Reliability: r = 0.78-0.98
  - Intra-rater Reliability: r = 0.94-0.97

- Validity
  - With Water Displacement: r = 0.80-0.91
  - With Perometer: r = 0.96-0.97

INEXPENSIVE! (equipment and time)
Tape Measure

Weaknesses
- Calculations of volume require spreadsheet or calculator
- If leg volume difference is >11%, tape measurement slightly overestimates
- In the leg: if the edema is primarily distal, a full limb calculation 'dilutes' the calculated change in volume

Recommended Measures

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perometry</td>
<td>3*</td>
</tr>
<tr>
<td>Bioimpedance</td>
<td>3</td>
</tr>
</tbody>
</table>

*with reservations; see weaknesses

Perometry

Strengths
- Reliability:
  - Test-Retest Reliability: ICC = 0.99
  - Intra-rater Reliability: ICC = 0.99
    - Tan, 1997; Stranton, 2011
- Validity
  - With Water Displacement:
    - \( r = 0.97 \)
  - With Tape Measure:
    - ICC = 0.99
    - Tierney, 1996
- Utilized regularly in centers of excellence

Weaknesses
- Expensive - $16,000-$26,000
- Pero System GmbH info@pero-system.de
- Available in horizontal and vertical configurations- neither easy to use for BOTH UE and LE
- Requires dedicated space and computer
- Not portable

Perometry

Weaknesses
- Expensive - $16,000-$26,000
  - Pero System GmbH info@pero-system.de
- Available in horizontal and vertical configurations- neither easy to use for BOTH UE and LE
- Requires dedicated space and computer
- Not portable
Bioimpedance

**Strengths**
- Reliability
  - Intra-tester Reliability using Concordance Statistic
    - Intra-tester Reliability: 0.88
  - Gordon, 2011
- Validity
  - With Water Displacement
    - $r = 0.62-0.85$
  - Schoeller, 2012
- Reference Range Values Available for LEs
- Allows for early diagnosis

**Weaknesses**
- Useful for early stage lymphedema only as progressive fibrosis replaces free fluid in limb with later stage lymphedema
- Recommended for unilateral lymphedema measurements only
- Pre treatment BIS values helpful, often not available
- Electrodes expensive and not reimbursed

Recommended QoL Measure

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>LLIS</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Test-Retest Reliability</th>
<th>Internal Consistency</th>
</tr>
</thead>
<tbody>
<tr>
<td>$r = .96$</td>
<td>$\alpha = .926$</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Construct (heaviness, stiffness, tightness)</td>
</tr>
<tr>
<td>$r = .706 - .830$</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MDC</th>
<th>MCID</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.53</td>
<td>7.31</td>
</tr>
</tbody>
</table>

Unable to Recommend at this Time

*Note: All are self-reported QoL questionnaires*

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>FLQA-1</td>
<td>2A</td>
</tr>
<tr>
<td>Lymph-ICF-LL</td>
<td>2A</td>
</tr>
<tr>
<td>LYMQOL</td>
<td>2A</td>
</tr>
<tr>
<td>LyQLI</td>
<td>2A</td>
</tr>
</tbody>
</table>

LLIS

**Strengths**
- Validated in population of interest
- Comprehensive
- 18 items only
- Responsiveness to change established

**Weaknesses**
- Cost to obtain from commercial entity
- New
- Not tested in a diverse population
- Still in development

FLQA-1

**Strengths**
- Validated in large population of patients at Foeldi Klinik
- Comprehensive

**Weaknesses**
- 92 items - Time to complete not noted but likely long
  - Shorter version also exists
- Not obtainable in English
- Primary validation in breast cancer related lymphedema
### Lymph-ICF-LL

**Strengths**
- Validated in population of interest
- Short, easily completed in 5 min and scored quickly
- Subscales follow ICF taxonomy
- English Translation done with WHO guidelines

**Weaknesses**
- Though translated into English, it has not been validated in English speakers

### LYMQOL

**Strengths**
- Developed and validated in the target population in English

**Weaknesses**
- Poor psychometrics

### LyQLI

**Strengths**
- Reliability - good
- Reduced from 188 item Swedish version to 45 items
- English version available

**Weaknesses**
- Validation in English lacking
  - Appendix provides English version of questionnaire
- Correlations only moderate to SF-36
- Responsiveness to Change not established

### GENITAL LYMPHEDEMA

**Genital Lymphedema**
- Difficult to treat
- Outcomes of treatment have not been researched
- Difficult to Assess?
- Functional limitations:
  - Sitting/standing/sleeping tolerance
  - Lymphorrhea
  - Difficulty with urination
  - Incidence of cellulitis
  - Many clinicians utilize LEFS

**Measurement of Genital Lymphedema**

---

*Scrotum*

Prepares for the surgery from the sides of the penis anteriorly to where the perineum posteriorly.

By Permission: BSN Medical
Summary of Measures

<table>
<thead>
<tr>
<th>Limb Volume Measure</th>
<th>Rating</th>
<th>Clinical Utility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Water Displacement</td>
<td>4</td>
<td>Inexpensive, relatively easy to perform</td>
</tr>
<tr>
<td>Tape Measure</td>
<td>4</td>
<td>Inexpensive, easy to perform</td>
</tr>
<tr>
<td>Perometry*</td>
<td>3 (with reservations)</td>
<td>Expensive, easy to perform</td>
</tr>
<tr>
<td>Bioimpedance</td>
<td>3</td>
<td>Expensive (electrodes), relatively easy to perform</td>
</tr>
</tbody>
</table>

Summary of Measures

<table>
<thead>
<tr>
<th>QOL</th>
<th>Rating</th>
<th>Clinical Utility</th>
</tr>
</thead>
<tbody>
<tr>
<td>LLIS</td>
<td>3</td>
<td>Responsive to change and discriminant validity; cost to use</td>
</tr>
</tbody>
</table>

Further Research

- Develop and validate a method for measuring genital lymphedema
- Further development and testing of QOL measures
- Develop and validate a lower cost perometer
- Utilize the Lower Extremity Functional Scale (LEFS) in oncology/lymphedema research

References

References

Contributors
• Shana E Harrington, PT, PhD, SCS, MTC
  – Creighton University
• Alexandra Hill, PT, DPT, CLT
  – Duke University
• Alicia Jeffrey, SPT
  – University of Florida
• Amanda Roscow, PT, DPT
  – Santa Fe College

Background
• Urinary incontinence
  – Any involuntary loss of urine
    • Urgency
    • Stress
    • Mixed
    • Nocturnal enuresis
  – Post micturition dribble and continuous urinary leakage

Urinary incontinence
• Prevalence and QoL impact
  – Mixed and stress UI higher than urge UI
  – Over 50% of women and nearly 14% of men
  – Higher depression and anxiety
  – Diminished enjoyment and sexual activity
  – Significant economic burden

Urinary incontinence
• Cancer-specific
  – 347 patients with suspected gyn malignancy
    • Over 50% reported UI
    • 20% moderate-severe symptoms
    • No difference b/w types of malignancy
  – 187 patients with gyn malignancy
    • 40.9% reported UI
    • 33% reported stress UI, 25% reported urge UI

Copyright Pfalzer, Cohn, Alappatu, 2016
Background

• Fecal incontinence (FI)
  – Any involuntary loss of fecal material
• Prevalence
  – 11-15% community dwelling adults
  – Combined UI and FI occurs in 10% of men and women
  – Risk of FI increases with age

Abrams et al 2009
Macmillan et al 2004
Whitehead et al 2009

Fecal incontinence

• Cancer-specific
  – 71 patients with colorectal cancer who underwent resection
    • Over 40% reported liquid stool incontinence
    • 10% reported solid stool incontinence
  – 89 patients who underwent transanal endoscopic microsurgery
    • 36% reported FI

Lin et al 2015
Restivo et al 2016

Background

• Sexual dysfunction
  – Disturbances in sexual desire and in the psychophysiological changes that characterize the sexual response cycle and cause marked distress and personal difficulty
    • Sexual desire, sexual arousal, orgasmic, sexual pain
  – Prevalence
    • Affects up to 40% of women in US

Basson et al 2000
Laumann et al 1999

Sexual dysfunction

• What about in people with cancer?
  – 40-100% affected after cancer treatment
  – WOMEN
    • 50% of women with breast and urogyn cancers
  – MEN
    • 60-90% of men report erectile dysfunction (ED) following prostatectomy
    • 25% of patients with testicular cancer or Hodgkin’s lymphoma experience long-term sexual issues

Ganz et al 1998
Robinson et al 2012
Aria 1997

Background

• Let’s stop and think about this…

• Sexual dysfunction extends beyond just urogynecological/ pelvic cancers

• Urinary and fecal incontinence are also prevalent in general population

• What does this mean for your patients?

Aim

• Systematic review of measures related to sexual function and urinary and fecal incontinence
  – Identify psychometric data and applicability to cancer population
  – Evaluate clinical utility of measures
    • Can and should you use these measures in your clinic on Monday morning?
### Search Strategy - CANCER

<table>
<thead>
<tr>
<th>Databases Searched</th>
<th>Search Terms/Strings</th>
<th>Limits Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medline</td>
<td></td>
<td></td>
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<tr>
<td>PsycInfo</td>
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### Search Strategy - INCONTINENCE

<table>
<thead>
<tr>
<th>Databases Searched</th>
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<th>Limits Used</th>
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<tbody>
<tr>
<td>CINAHL</td>
<td>&quot;Incontinence+&quot;, &quot;Urinary Incontinence+&quot;, &quot;Fecal Incontinence&quot;, incontinence, urinary dysfunction, urinary function, fecal function</td>
<td>Used, English and 1995</td>
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<tr>
<td>Medline</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PsycInfo</td>
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### Search Strategy - SEXUAL FUNCTION

<table>
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<tr>
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<th>Limits Used</th>
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<td></td>
<td></td>
</tr>
<tr>
<td>PsycInfo</td>
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<td></td>
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</tbody>
</table>

### Search Strategy - OUTCOME MEASURES

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<th>Search Terms/Strings</th>
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</tr>
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<td></td>
<td></td>
</tr>
<tr>
<td>PsycInfo</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Article Selection

#### Inclusion Criteria
- Text available in English
- Related to sexual function, urinary, or fecal incontinence

#### Exclusion Criteria
- Text not available in English
- Measure not related to sexual function, urinary incontinence, or fecal incontinence
**Article Selection**

- Initial Search of Articles = 1118
- Articles not Meeting Criteria = 890
- Final Articles Included in Primary Review = 228
- Outcome Measures Reviewed = 37

- Each outcome measure reviewed and rated independently by 2 reviewers
- Any measure with discrepancies in ratings was discussed by Task Force to reach consensus

**Scoring Scale**

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Highly Recommend</td>
</tr>
<tr>
<td>3</td>
<td>Recommend</td>
</tr>
<tr>
<td>2A</td>
<td>Unable to Recommend at this time</td>
</tr>
<tr>
<td>2B</td>
<td>Unable to Recommend at this time</td>
</tr>
<tr>
<td>1</td>
<td>Do not Recommend</td>
</tr>
</tbody>
</table>

**PART I: SEXUAL DYSFUNCTION**

(4) Highly Recommended Measures

- Sexual Function- Vaginal Changes Questionnaire
- International Index of Erectile Function
- Erection Hardness Score

(3) Recommended Measures

- Sexual Interest and Desire Inventory for Females

(2A) Unable to Recommend

- PROMIS-Sexual Function
- Female Sexual Function Index
- Arizona Sexual Experience Scale
- Golombok-Rust Inventory of Sexual Satisfaction
- Psychological Impact of Erectile Dysfunction
- Sexual Function Questionnaire
- Changes in Sexual Functioning Questionnaire

(2B) Unable to Recommend

- Female Sexual Distress Scale

(1) Not Recommended Measures

- Dyadic Adjustment Scale
- Brief Sexual Function Questionnaire for Men
- Sexual Concerns Questionnaire-Gynecological Cancer
- Watts Sexual Function Questionnaire
- Sexual Problems Scale
- Sexual Health Inventory for Men
- Brief Index of Sexual Functioning for Women
- Brief Sexual Function Inventory for Men
- Radiumhemmet Scale of Sexual Function
• Sexual Function- Vaginal Changes Questionnaire (SF-VCQ)
  • Designed to assess sexual and vaginal problems in patients with gyn cancers
  • Consists of 20 core items
  • 7 additional items assessing current levels of sexual and vaginal problems compared to pre-diagnosis
  • High test-retest reliability and internal consistency
  • Specific to females

Jensen et al 2004
Jensen et al 2014

• International Index of Erectile Function (IIEF)
  • 15-item self report covering 5 domains
    • Erectile function (max score 30)
    • Orgasmic function (max score 10)
    • Sexual desire (max score 10)
    • Intercourse satisfaction (max score 15)
    • Overall satisfaction (max score 10)
  • Total score ranges from 0-75
  • MCID of 4 for erectile dysfunction domain
  • Specific to males

Rosen et al 1997

• Erection Hardness Score (EHS)
  • Single item self report using a Likert scale
    • 0: Penis does not enlarge
    • 1: Penis is larger but not hard
    • 2: Penis is hard but not hard enough for penetration
    • 3: Penis is hard enough for penetration but not completely hard
    • 4: Penis is completely hard and fully rigid
  • MCID: 0.86
  • EHS<= 3 indicates ED

Mulhall et al 2007

• Sexual Interest and Desire Inventory for Females (SIDI-F)
  • 13-item clinician-administered measure used to quantify severity of symptoms in women dx with hypoactive sexual desire disorder (HSDD)
  • Total score 0-51
    • Scores less <= 33 indicate HSDD
    • High test-retest reliability and internal consistency
  • Specific to women; has not been validated in women with cancer

Clayton et al 2006

PART II: URINARY INCONTINENCE

(4) Highly Recommended Measures

<table>
<thead>
<tr>
<th>URINARY INCONTINENCE</th>
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</thead>
<tbody>
<tr>
<td>American Urological Association Symptom Index</td>
</tr>
<tr>
<td>Pelvic Floor Distress Inventory- Short Form</td>
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<tr>
<td>Pelvic Floor Impact Questionnaire- Short Form</td>
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(3) Recommended Measures

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<tbody>
<tr>
<td>Incontinence Quality of Life Questionnaire</td>
</tr>
<tr>
<td>International Consultation on Incontinence -Short Form</td>
</tr>
</tbody>
</table>
(2A) Unable to Recommend

**UROINARY INCONTINENCE**
- Urogenital Atrophy Questionnaire
- Incontinence Impact Questionnaire (IIQ-7)

(2B) Unable to Recommend

**UROINARY INCONTINENCE**
- 24 hour pad test

---

(1) Do Not Recommend

**UROINARY INCONTINENCE**
- 1 hour pad test
- Pelvic Floor Distress Inventory- Long Form
- Pelvic Floor Impact Questionnaire- Long Form
- Radiumhummet Scale of Disease Specific Symptom Assessment-Prostate Cancer

---

- **American Urological Association Symptom Index (AUA-SI)**
  - 7-item self report measure used to assess urinary urgency, frequency, and voiding symptoms
  - Total score 0-35 with higher scores indicative of higher symptom severity
    - Less than 8: mild sx; 8 to 19: moderate sx; 19+: severe sx
    - No established MCID
  - Validated in patients with prostate cancer (men) and also in women
  
  Barry et al 1992
  Scarperio et al 2003

- **Pelvic Floor Distress Inventory- short form (PFDI-20)**
  - 20-item self report measure examining 3 domains
    - Pelvic organ prolapse distress
    - Colorectal anal distress
    - Urinary distress
  - High internal consistency
  - Each domain score 0 (least distress)-100 (highest distress)
  - MCID 45 points
  - Validated in women with pelvic floor distress

  Barber et al 2005
  Kaplan et al 2012

- **Pelvic Floor Impact Questionnaire- Short Form (PFIQ-7)**
  - 7-item self report assesses the extent to which bladder, bowel or vaginal symptoms affect women’s activities, relationships and feelings
  - Each domain score 0-100; combine to calculate summary score (0-300)
  - Higher score indicates worse health status
  - High internal consistency
  - Specific to women
  - Validated in women with pelvic floor disorders but not necessarily in patients with cancer

  Barber et al 2001
  Barber et al 2005

- **Incontinence Quality of Life Questionnaire (I-QOL)**
  - 22-item self report measures effect of UI on quality of life
  - 3 subscales
    - Avoidance and limiting behavior
    - Psychosocial impact
    - Social embarrassment
  - High internal consistency for total score and subscale scores
  - MCID 4 points
  - Validated in a general population but not necessarily in patients with cancer

  Schurch et al 2007
PART III: FECAL INCONTINENCE

• International Consultation on Incontinence - Short Form (ICIQ-SF)
  • 6-item measure used to assess UI on quality of life and treatment outcomes over last 4 weeks
  • 2 demographic questions (unscored)
  • 3 scored questions
  • 1 self-diagnostic item (unscored)
  • Scores range from 0-21 with higher scores indicating increased symptom severity
  • High internal consistency and moderate-high test retest reliability
  • 12 mo MID: 5; 24 mo MID 4
  • Appropriate to use in males and females but not validated in patients with cancer

(4) Highly Recommended Measures

<table>
<thead>
<tr>
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(2A) Unable to Recommend

<table>
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<tr>
<th>FECAL INCONTINENCE</th>
<th>American Society of Colon and Rectal Surgeons Fecal Incontinence Questionnaire</th>
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(2B) Unable to Recommend

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<thead>
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(1) Do Not Recommend

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<td>Radiumhummet Scale of Disease Specific Symptom Assessment-Prostate Cancer</td>
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</tbody>
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Discussion

• What do I do with all of this information?
• Which measures are most appropriate for my patient?
• Timelines for re-administration of measures
Directions for Further Research

- Validation of measures in cancer population
- Is sexual dysfunction/incontinence “different” in people with cancer?

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- Creighton University Libraries
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