Non-Sexual Consequences of PD

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Grants

• NIH
• CIACT
• SMSNA

Consultant

• Pfizer
• Lilly
“It takes 50 years to get a wrong idea out of medicine and 100 years to get a right one into it”

John Hughlings Jackson
Neurologist
1835-1911
Peyronie’s Disease Intervention Trials: Methodological Challenges and Issues

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PD Trial Interpretation

• Patient population heterogeneity
  - Degree of curvature
  - Duration of Peyronie’s disease
  - Degree of calcification
  - Patient number

• Trial design issues
  - Randomization
  - Placebo control
  - Baseline and end of treatment assessment
  - Variability in Duration of treatment
  - Follow-up

• Variability in the Definition of Success
  - Pain
  - Plaque volume
  - Sexual function
  - Deformity
  - Bother, distress, satisfaction
Psychosocial Impact of PD
Clinical Experience

• Embarrassment

• Shame

• Anxiety

• Depression

• Failure to socialize (Isolation)

• Relationship discord
High Risk Populations (for Distress)

• Young men
• Single men
• Gay men
• Men with complex deformities
• Men incapable of sexual intercourse
Defining Psychosocial Impact

• Gestalt

• Specific complaints

• Speed of presentation

• Relationship discord

• Sexual satisfaction

• Questionnaires
Downward Spiral & Perpetual Cycle

Deformity  Constraint  Anxiety

Pain

Penetration difficulty  Communication difficulty

Physical Impairment  Psychological Bother

Sexual Dissatisfaction  Adrenaline

Psychogenic Sexual Dysfunction  Avoidance Behavior

Reduced QOL  Depression  Relationship discord
• Gelbard et al conducted a survey of 97 men with PD

• 77% of surveyed men indicated some degree of psychological effect from their disease (non-val instrument)

• 28% improved over time, 36% stayed the same, and 36% worsened.

• Among men who reported improvement in deformity over time, 48% stated that they “worry about their problem frequently or all the time”
• Sought to quantify the level and duration of depression and distress that men with PD experience

• 92 patients with PD from two centers in the US

• CES-D, and SF-36.

• 47% of men with PD reported clinically meaningful depression (26% moderate; 21% severe)

• Those men who were single and self-reported greater penile length loss were more likely to report depressive symptoms

• Additional analyses showed that depression remained consistently high over time, regardless of length of time elapsed since diagnosis of PD
• 81% of 245 men with PD reported emotional difficulties
• 54% reported relationship problems due to PD

Predictors of emotional problems
- Presence of relationship problems
- Loss of penile length were shown

Predictors of relationship problems
- Emotional difficulties
- Inability to have intercourse
13 focus groups composed of men with PD and controls

A total of 64 men (28 with PD, 36 without)

6 main areas of concern among men with PD
- Physical appearance
- Sexual self-image
- Loss of sexual self-confidence and attractiveness
- Sexual function and performance
- Performance anxiety
- Social stigmatization

Reported feelings of shame and inadequacy, problems with body image, diminution in their feelings of masculinity
110 PD patients completed questionnaires (4)

The predictor variables were the following: shame, body esteem, self-consciousness, genital self image, pain catastrophizing

Mean overall scores indicated mild impairment

Wide variation – 42-52% scoring in the clinical range

Catastrophizing and shame were major predictors of reduced relationship satisfaction and sexual satisfaction
MSK PD Depression Study
SMS Grant to Lawrence Jenkins MD

Ongoing longitudinal analysis of psychosocial aspects of PD

CES-D, PDQ, SEAR

Baseline, 3, 6 and 12 month FU

Baseline data @ SMS 2016
PDQ

• Validated instrument (15 questions)

• 3 domains (symptoms, penile pain, and symptom bother)

• Responsive (IMPRESS I & II)

• Correlation poor between deformity and degree of bother

• Correlation poor between deformity and bother change
**Effects on Partner**

- Unexplored in the literature
- 1/3 of posts on PD association site are from partners
- Commonest issue is communication difficulty
- Psychosocial effects less related to lack of sexual fulfillment
- More focused on emotional withdrawal and loss of intimacy
Health-Related Quality-of-Life Assessments and Patient-Physician Communication
A Randomized Controlled Trial

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Neil K. Aaronson, PhD

Context There has been increasing interest in the use of health-related quality-of-life (HRQL) assessments in daily clinical practice, yet few empirical studies have been conducted to evaluate the usefulness of such assessments.

Objective To evaluate the efficacy of standardized HRQL assessments in facilitating patient-physician communication and increasing physicians' awareness of their patients' HRQL-related problems.

All physicians and 87% of the patients believed that the instrument use facilitated communication.
Multi-Tiered Management

<table>
<thead>
<tr>
<th>Identify Patients with PD</th>
<th>Diagnose and Evaluate Patients</th>
<th>Interdisciplinary Treatment Plan</th>
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<tbody>
<tr>
<td>Increase physician awareness about PD</td>
<td>Medical evaluation should include physical, psychological, and psychosocial assessments</td>
<td>Team of physicians, appropriate specialists, and allied healthcare providers</td>
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<tr>
<td>Address common misconceptions regarding disease prevalence and progression</td>
<td>Develop validated screening tools</td>
<td>Implement effective interventions to assist with psychological and sexual challenges of patients and their partners</td>
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Nelson CJ, Mulhall JP. J Sex Med. 2013, 10:653
Role of Mental Health Professionals

• Clinically significant anxiety

• Frank depression (CES-D > 16)

• Partner communication issues

• Unrealistic expectations
Management Approach @ MSK

• Enhanced awareness & perspective (peyroniesassociation.org)
• Education (consultation, dispel myths, realistic expectations)
• Define psychosocial impact early (PDQ, SEAR, CES-D)
• Address negative psychological effects (Chris Nelson PhD)
• Multidisciplinary approach
The Future

• Longitudinal analysis of psychosocial impact

• Suicidality

• Better PD-specific instruments

• Evaluation of specific populations

• Partner impact evaluation
CREATE NEW PASSWORD?

'PENIS'

SORRY - YOUR PASSWORD ISN'T LONG ENOUGH