Endometriosis and quality of life

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Quality of life

Quality of life (QoL) is a broad multidimensional concept that assesses an individual’s daily well-being or lack thereof…

(It includes: physical, emotional, social, professional aspect)

Assessment of QoL is unrelated to a doctor’s clinical judgment and is only a patient-reported outcome.
Quality of Life measurements

• Quality of life in the evaluation of community support systems
  
  *Frank Baker & James Intagliata* 1982

• Quality of life in cancer patients--an hypothesis.
  
  *K C Calman*  J Med Ethics 1984

• Work Productivity and Activity Impairment (WPAI:GH)

  
  *The WHOQOL Group*
Quality of Life measurements

• Short Form 36 (SF36) is multipurpose generic measure of health status

• SF12

• These 12 items include one or two questions referring to eight health concepts commonly used in surveys

• Bodily pain, general health, vitality (energy/fatigue), social functioning, emotional problems, mental health (distress/well being)

• Questions are scored and analyzed by a statistical algorhythm to give two scores: physical and mental component
Quality of Life measurements

- **EuroQOL EQ-5D**
- Defines health status in terms of five dimensions:
  - Mobility, self-care, usual activity, pain/discomfort, anxiety-depression
  - Each dimension is subdivided in three levels: no problem, some problem, extreme problem
  - Each patient yields also her own health status on a numerical scale from 100 good to 0 worse state of health
Endometriosis

Endometriosis is a chronic disease associated with:

- chronic pelvic pain
- fatigue
- dysmenorrhoea
- deep dyspareunia
- infertility
Endometriosis prevalence

Prevalence in the general population is unknown, as a definitive diagnosis is established only at laparoscopy.

Based on community prevalence estimates, endometriosis probably affects 5-10% of all and 30-50% of symptomatic premenopausal women.

This represents ~176 million affected women worldwide.

Collecting evidence on QoL and endometriosis

Type of studies
- Qualitative: use interview data collection methods (based patient interviews)
- Quantitative (measure the effect of a condition by using specific questionnaires)
- Mixed method studies

Type of patient questionnaires
- Generic QoL questionnaires
  - Short Form–36
  - Work Productivity and Activity Impairment (WPAI:GH)
- Disease specific questionnaires
  - Endometriosis Health Profile-30 and -5
Quality of Life measurements-endometriosis

Quality of life i.e. physical performance and mental well being was decreased in several studies in women with endometriosis

- Qualitative interview-based studies on quality of life in small number of patients (<24) reveal that the experience of severe and chronic pain have a debilitating impact on all aspects of every day life

How could endometriosis affect QoL?

1. Impact of diagnostic delay
2. Impact on physical functioning and everyday activities
3. Intimate relationships
4. Mental health
5. Work productivity
Diagnostic delay – why?

- Diagnostic delay can range from **5 to 9 years** in symptomatic women
  
  **Sepulcri & do Amaral Eur J ObstGyn 2009; Fourquet et al Fertil Steril 2010**

- Mainly due to delays in referral from general practitioner to gynecologist, with women reporting an average of **seven visits** before specialist referral

  **Nnoahamet al Fertil Steril 2011**

**Diagnostic delay occurs for two reasons**
Delay at the patient level refers to the time between symptom onset and seeking medical help and could reach an average of 4 years.

Causes:
- Difficulty in distinguishing between normal and pathological symptoms
- Unawareness of the condition
- Women consider themselves ‘unlucky’ as opposed to ‘unwell’
- Fear that disclosure would result in embarrassment

2nd - Delay at the doctor level

- Lack of knowledge, awareness and sympathy
- Symptoms are often normalized or trivialized resulting in women feeling ignored and disbelieved
- Condition is often misdiagnosed as irritable bowel syndrome or pelvic inflammatory disease

Endometriosis and physical functioning

- 16% (Simoens et al) to 61% (Fourquet et al) of women experience difficulties with mobility and daily activities
  
  *Simoens et al Hum Reprod 2012; Fourquet et al FertilSteril 2010*

- 58% experience increased sleeping disturbances

- There is negative impact on childcare for 45% of women

*Fourquet et al FertilSteril 2010*
Endometriosis and physical functioning...

- SF-36 questionnaire physical scores for women with severe pelvic pain are similar to those reported in *women with cancer*

- This is supported by a cross-sectional study in 10 countries that recruited consecutive premenopausal women, aged 18–45 years, scheduled for a laparoscopy to investigate endometriosis-associated pelvic pain

*Nnoaham et al Fertil Steril 2011*
Intimate relationships

- Between 34% (Bernuit et al) and 71% of women (Fourquet et al) reported that endometriosis negatively affected their sex lives
  
  *Bernuit et al J Endom 2011; Fourquet et al FertilSteril 2011*

- The quality of sex life was affected in both women with minimal and with severe endometriosis

  *Chene et al J Endom 2012*
Women feel that the symptoms and experience of endometriosis (including but not limited to dyspareunia) have negative impact on their relationships and in some cases to relationship breakdown.

It is established that endometriosis, in all forms, has an adverse effect on fertility.

>50% of couples experience problems conceiving.

*Sepulcri & do Amaral 2009; Fourquet et al 2010*
Mental health and emotional wellbeing

- Higher rates of depression, anxiety and emotional distress than the general population
  
  *Fourquet et al 2011; Simoens et al 2012*

- The impact of endometriosis on mental health and emotional wellbeing may extend to partners

  *Butt and Chesla 2007*
To generate meaningful estimates, we need to consider both:

- **Presenteeism**: reduced productivity while at work
- **Absenteeism**: time lost from work
Endometriosis and work productivity

- The major driver of work productivity loss in endometriosis is pelvic pain
- Affected women reported greater absenteeism and preseenteism compared with non-affected women
- Presenteeism accounted for nearly 60% of total work productivity loss

Nnoahamet al Fertil Steril 2011
Impact on work productivity

- Work productivity loss was **10.8 h/wk** in women affected by endometriosis versus **8.4 h/wk** in the controls (P<.001)

- Absenteeism-related costs ranged from **1 US$ /wk** in Nigeria to **231 US$ /wk** in Italy

- Presenteeism costs ranged from **3 US$ /wk** in Nigeria to **US$ 250 US$ /wk** in the USA

*Nnoahamet al FertilSteril 2011*
Economic burden on Health Care

EndoCost study by the World Endometriosis Research Foundation

Calculated the cost of women treated in referral centres in 10 different countries

Simoens et al Hum Reprod 2012
EndoCost study

Annual health cost € 3113/woman

Similar to estimated annual (2009) health care cost for

- Diabetes (€ 2858)
- Crohn’s (€ 3100)
- Rheumatoid arthritis (€ 4284)
Endometriosis as a public health problem

The total (direct plus indirect) financial cost of Endometriosis in Europe has been estimated to be €30 billion/year

Simoens et al. Hum Reprod Update 2007
Methodology issues

- Most studies used generic questionnaires whose psychometric properties are not well established in endometriosis i.e. they exclude infertility.

- Very few studies accounted for social variables such as educational level, socio-economic status.

- The experience of endometriosis varies across an individual’s life course.
Methodology issues: Sample selection

Further...

Women with most severe cases are likely to have higher health care cost and more severe impairment of QoL. However, even for misdiagnosed ‘milder’ cases the cost is underestimated...due to the long diagnostic delays between symptoms and treatment and impact on productivity, social and health care.
In summary...

Endometriosis symptoms substantially impact QoL and daily activities such as household tasks, energy, vitality and socializing.

There is consistent evidence of a negative impact of endometriosis on women’s working lives and the difficulties they experience in disclosing information to employers.
Suggestions

- Clinicians need to make explicit, objective assessment of QoL using validated tools and instruments.
- **Heightened awareness** of the disease should lead to earlier diagnosis, less suffering, and improved work productivity.
- Support groups can be of value and help women interpret and share their experience.
Who is she?
Thank you
Suggestions for research

- Longitudinal cohort studies would enable to capture the changing nature of the impact of endometriosis on women’s lives.

- Future QoL research should utilize the EHP-30 or EHP-5 health questionnaires instead of generic ones.

- The impact of interventions i.e. surgery on QoL needs to be further assessed.
Short Form-36 questionnaire

Eight scaled scores that each one is transformed to a 0-100 scale

- vitality
- physical functioning
- bodily pain
- general health perceptions
- physical role functioning
- emotional role functioning
- social role functioning
- mental health
The endometriosis-specific questionnaires are specifically designed for the assessment of the impact of endometriosis on the QoL…

Available as either a long form 30-item instrument (EHP-30)
or the short 5-item form (EHP-5)

Five scale scores covering:

- Pain
- Control and powerlessness
- Social support
- Emotional well-being
- Self-image
Indirect cost

The indirect costs of loss of productivity were similar to

- ankylosing spondylitis (productivity loss 66%)
- rheumatoid arthritis (productivity loss 57%)

Franke et al 2009