



Paris 2015 - 1st SEUD Meeting

Endometriosis and quality of life

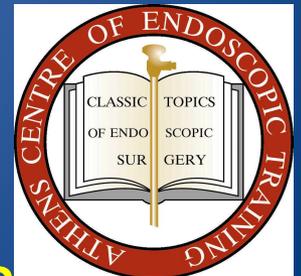
George A Pistofidis FRCOG

Clinical Director

Gynecologic Endoscopy

White Cross Hospital-Athens

Associated Centers Endoscopic Training



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 World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization* 1995

*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 algorithm 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**

Adamson GD, Kennedy SH, Hummelshoj L. Research Foundation. J Endometriosis. 2010

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 questionnaire*)

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*
- *Denny E et al 2004, Jones G et al 2004, Huntington A & Gilmour JA 2005, Gao X et al 2006*

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

1st - Delay at the patient level

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

Cox et al Int J Nurs Pract 2003; Ballard et al Fert Steril

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

Jones et al J Psychosom ObstGyn 2004 ; Ballard et al Fert Steril 2006

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 FertilSteril2010

➤ 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

Intimate relationships...

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

*Cox et al 2003; Jones et al 2004; Huntington 2005;
Fagervold et al 2009*

Fertility

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

Work productivity

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 presenteeism 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?

Hillary Clinton
2016





Thank you

December **13-14** 2008
Grande Bretagne Hotel • Athens, Greece

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

Endometriosis Health Profile-30 and -5

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