



ESHRE GUIDELINE coping with endometriosis

Lone Hummelshøj
Budapest, 26 February 2010

Disclosure

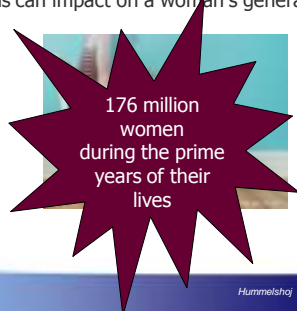
No conflicts to declare in relation to this talk.

Hummelshøj 02/2010

Endometriosis

Endometriosis symptoms can impact on a woman's general:

- physical
 - mental
 - social
- ...well being.



<http://guidelines.endometriosis.org>

Hummelshøj 02/2010

Endometriosis: challenge!



Pain symptoms may persist despite seemingly adequate medical and/or surgical treatment of the disease.

In such circumstances, a multi-disciplinary approach involving a pain clinic and counselling should be considered early in the treatment plan.

Kennedy et al, 2005

<http://guidelines.endometriosis.org>

Hummelshoj 02/2010

Endometriosis: chronic disease?



For many women, endometriosis becomes a chronic disease affecting quality of life due to incapacitating pain, emotional impact of sub-fertility, anger about disease recurrence, and uncertainty about the future regarding repeated surgeries or long term medical therapies and their side-effects.

There is a need to look at endometriosis, at least in a subset of highly symptomatic women, as a chronic disease.

Quality of life issues should therefore be addressed.

Colwell et al, 1998; Jones et al, 2001

<http://guidelines.endometriosis.org>

Hummelshoj 02/2010

Endometriosis: chronic disease?



For many women, endometriosis becomes a **chronic** disease affecting **quality of life** due to **incapacitating pain**, **emotional impact** of sub-fertility, **anger** about disease **recurrence**, and **uncertainty** about the future regarding **repeated surgeries** or **long term** medical therapies and their **side-effects**.

There is a need to look at endometriosis, at least in a subset of highly symptomatic women, as a **chronic** disease.

Quality of life issues should therefore be addressed.

Colwell et al, 1998; Jones et al, 2001

<http://guidelines.endometriosis.org>

Hummelshoj 02/2010

Endometriosis



Living with a chronic disease
Quality of life
Incapacitating pain
Emotional impact
Anger
Recurrence
Uncertainty
Repeated surgeries
Side-effect of medical treatments

COPING

Hummelshoj 02/2010

To cope



To deal successfully with; manage

The Collins Concise Dictionary of English Language, Glasgow: William Collins & Sons Co Ltd, 1988.

1. Carry on, get by, hold one's own, manage, rise to the occasion, struggle through, survive.
2. Contend, deal with, dispatch, encounter, grapple, handle, struggle, tangle, tussle, weather, wrestle.

The New Collins Thesaurus, Glasgow: Williams Collins Sons & Co, 1987

Hummelshoj 02/2010

To cope



To deal successfully with; manage

The Collins Concise Dictionary of English Language, Glasgow: William Collins & Sons Co Ltd, 1988.

1. **Carry on**, get by, hold one's own, **manage**, rise to the occasion, **struggle through**, **survive**.
2. Contend, **deal with**, dispatch, encounter, grapple, **handle**, **struggle**, tangle, tussle, **weather**, **wrestle**.

The New Collins Thesaurus, Glasgow: Williams Collins Sons & Co, 1987

Hummelshoj 02/2010

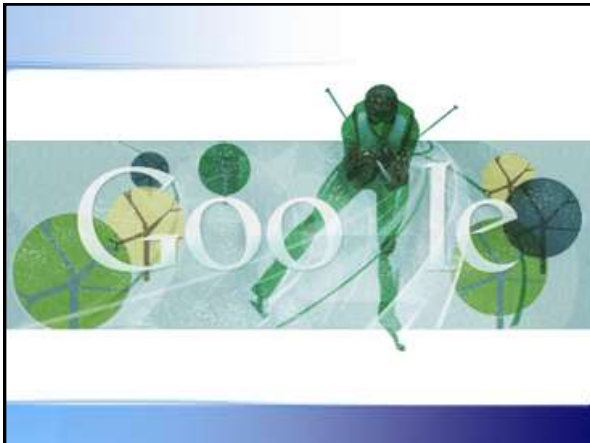
Endometriosis



Carrying on
Managing
Struggling through
Surviving
Dealing with
Handling
Struggling
Weathering
Wrestling

**POSSIBLE
WITH
ENDOMETRIOSIS?**

Hummelshoj 02/2010



ESHRE guideline: Coping with disease



C

There is evidence from two systematic reviews suggesting that high frequency TENS, acupuncture, vitamin B1 and magnesium may help to relieve dysmenorrhoea (Proctor and Murphy 2002; Proctor et al, 2001). One RCT has shown that vitamin E may relieve primary dysmenorrhoea and reduce blood loss (Ziaei et al, 2005). Whether such treatments are effective for endometriosis associated dysmenorrhoea and heavy bleeding is unknown.

Evidence
Level 4

<http://guidelines.endometriosis.org>

Hummelshoj 02/2010

Coping: TENS



A systematic review concluded that transcutaneous electrical nerve stimulation (TENS) can be effective in the treatment of dysmenorrhoea.

TENS represents a suitable alternative for women, who prefer not to use medication or wish to minimise their intake of NSAIDs.

Proctor et al, 2002

Coping: acupuncture (i)



Retrospective study of 47 families with paediatric pain patients:

- median age 16
- 6 diagnosed with endometriosis
- 70% felt the treatment helped their symptoms

Kemper et al, 2000

Coping: acupuncture (ii)



A randomised controlled trial of 90 women with endometriosis

- Shu-Mu acupuncture (n=30)
- routine needling acupuncture (n=30)
- oral Danazol (n=30)

The total effective rate was similar in the three groups.

Shu-Mu point combination group was superior for:

- improvement of dysmenorrhoea and irregular menstruation
- decreased serum CA125

Sun and Chen, 2006

Coping: vitamin B



Vitamin B1 plays an important role in metabolism and deficiency can result in fatigue, muscle cramps, various pains, and a reduced tolerance to pain.

Reavely, 1998

One large trial (n=556) showed a daily intake of 100mg of vitamin B1 for two months to be an effective treatment for dysmenorrhoea, with none of the women taking placebo experiencing complete pain relief.

Gokhale, 1996

Coping: magnesium (i)



Overproduction of PGF2 has been shown to be a substantial contributing factor to the painful cramps associated with dysmenorrhoea.

Magnesium inhibits the biosynthesis of PGF2- α as well as having a role in muscle relaxation and vasodilation.

Altura and Altura, 1985; Reavely, 1998

Coping: magnesium (ii)



Three double-blinded, but small, RCTs showed that magnesium was more effective than placebo for pain relief and the need for additional medication was less.

Davis, 1988; Fontana-Klaiber and Hogg, 1990; Seifert et al, 1989

Women taking the magnesium therapy:

- Had substantially lower levels of PGF2- α in their menstrual blood than those on placebo ($p < 0.05$)
- mirrored the therapeutic decrease in pain experienced by the participants

Seifert et al, 1989 (n=50)

Coping: vitamin E (i)



Vitamin E has an analgesic effect because it is able to inhibit pro-inflammatory prostaglandin production.

RCT of 278 girls aged 15-17 with primary dysmenorrhoea:

- 200 units of vitamin E or placebo twice a day
- two days before the expected start of menstruation and continued through the first three days of bleeding
- four consecutive menstrual periods.

Coping: vitamin E (ii)



At four months:

- vitamin E group had lower pain severity assessed by visual analogue scale (0.5 vs. 6, $p > 0.001$)
- shorter pain duration (1.6 hours vs. 17 hours, $p > 0.0001$)
- reduced blood loss assessed by pictorial blood loss assessment chart (46 vs. 70, $p > 0.0001$)

Ziaei et al, 2001

Coping: vitamin E (iii)



Two randomised, double-blinded, placebo controlled trials have demonstrated significant decrease in median pain scores in the groups treated with vitamin E compared to placebo for primary dysmenorrhoea.

Butler et al, 1955; Ziaei et al, 2005

ESHRE guideline: Coping with disease



C

There is evidence from two systematic reviews suggesting that high frequency **TENS**, **acupuncture**, **vitamin B1** and **magnesium may help to relieve dysmenorrhoea** (Proctor and Murphy 2004; Proctor et al, 2004). One RCT has shown that **vitamin E may relieve primary dysmenorrhoea and reduce blood loss** (Ziaei et al, 2005). Whether such treatments are effective for endometriosis associated dysmenorrhoea and heavy bleeding is unknown.

Evidence Level 4



ESHRE guideline: Coping with disease



GPP

Many women with endometriosis report that nutritional and complementary therapies such as homeopathy, reflexology, Traditional Chinese Medicine, herbal treatments, etc, do improve pain symptoms. Whilst there is no evidence from RCTs in endometriosis to support these treatments, they should not be ruled out if the woman feels that they could be beneficial to her overall pain management and/or quality of life, or work in conjunction with more traditional therapies.

Coping: nutritional therapies (i)



Nutritional therapy/dietary modification has shown promising effects on dysmenorrhoea in three small RCTs:

- supplementation with omega-3 fish oil combined with vitamin B12
- a diet high in vegetables and low in animal fats

Harel et al, 1996; Deutch et al, 2000; Barnard et al, 2000; Fjerbaek and Knudsen, 2007

Coping: nutritional therapies (ii)



- Intake of fruit and green vegetables decreased the risk of endometriosis
- Ham, beef and other red meat increased the risk

Parazzini et al, 2004

- Fibre intake is linked to an increased oestrogen excretion

Rose et al, 1997; Kaneda et al, 1997

Coping: nutritional therapies (iii)



A randomised comparative study evaluated:

- conservative surgery plus placebo
 - conservative surgery plus hormonal suppression treatment
 - conservative surgery plus dietary therapy (vitamins, minerals, lactic ferments, fish oil).
-
- hormonal suppression therapy and dietary supplementation were equally effective in reducing non-menstrual pelvic pain and improving quality of life compared with placebo in women with endometriosis stage III-IV.

Sesti et al, 2007

Coping: nutritional therapies (iv)



A randomised controlled trial of 80 women with endometriosis demonstrated that two months of high-dose vitamin E and C therapy was associated with significant improvement in endometriosis pain and a reduction in inflammatory markers.

Santanam et al, 2003

Coping: homeopathy



In a very small, non-randomised, study in eight patients diagnosed with endometriosis, five out of seven, who had dysmenorrhoea, reported relief from symptoms (and two had intermittent relief) following individualised homeopathic treatment.

Hunton, 1993

Coping: herbal medicine/TCM (i)



- A systematic review of clinical and experimental data on the use of medicinal herbs in the treatment of endometriosis suggest that medical botanicals may have anti-inflammatory and pain-alleviating properties.
- Medicinal herbs and their active components exhibit cytokine-suppressive, COX-2-inhibiting, antioxidant, sedative and pain-alleviating properties.
- Each of these mechanisms of action would be predicted to have salutary effects in endometriosis

Wieser et al, 2007

Coping: herbal medicine/TCM (ii)



An randomised controlled trial compared Yiweining (YWN) with Gestrinone post-operatively:

- YWN: recurrence rate of 5.0%
- Gestrinone: recurrence rate of 5.3%
- Placebo: recurrence rate of 30.7%

Yang et al, 2006

Coping: herbal medicine/TCM (ii)



An randomised controlled trial compared Yiweining (YWN) with Gestrinone post-operatively:

- YWN: recurrence rate of 5.0%
- Gestrinone: recurrence rate of 5.3%
- **Placebo: recurrence rate of 30.7%**
- Adverse reaction rate in the YWN was lower (10.0%) than that in the Gestrinone group (31.6%)

Yang et al, 2006

Coping: herbal medicine/TCM (iii)



Another randomised controlled trial also compared gestrinone, but this time with Quyu Jiedu Recipe (QJR) and showed a marked improvement of the symptoms of menorrhagia and menstrual disorders, speculating that its mechanism might be related with the lowering of eutopic endometrial VEGF expression.

Lian et al, 2007

Coping: herbal medicine/TCM (iv)



In endometriosis model rats the Chinese herb Yiweining (YWN) can prevent the growth of ectopic endometrium by inhibiting the synthesis and secretion of TNF-alpha, IL-6, and IL-8.

Qu et al, 2005

YWN can reduce the positive expressions of MMP-2 and COX-2 mRNAs.

Qu et al, 2006

Coping: exercise



Exercise releases endorphins, and can assist the body getting back into shape after surgery:

- > walking
- > swimming
- > pilates
- > yoga
- > physiotherapy

ESHRE guideline: Coping with disease



GPP

Many women with endometriosis report that **nutritional** and complementary therapies such as **homeopathy, reflexology, Traditional Chinese Medicine, herbal treatments**, etc, do improve pain symptoms. Whilst there is no evidence from RCTs in endometriosis to support these treatments, they **should not be ruled out if the woman feels that they could be beneficial to her overall pain management and/or quality of life, or work in conjunction with more traditional therapies.**



ESHRE guideline: Coping with disease

GPP Coaching and self-management programmes may prove beneficial in providing the woman with tools to enable her to make informed decisions and learn to live with a chronic disease. Patient self-help groups can provide invaluable counselling, support and advice. The website www.endometriosis.org/support.html provides a comprehensive list of all the self-help groups in the world.

<http://guidelines.endometriosis.org> Hummelshoj 02/2010

Coping with disease

Physical and psychological trauma can contribute to a negative self-image and negative internal dialogue
Stones, 2000

- counsellor/psychologist
- pain psychologist
- develop strategies on how to cope with endometriosis including breaking the pain cycle, dealing with stress and anxiety, and resolve feelings about infertility.

<http://guidelines.endometriosis.org> Hummelshoj 02/2010

Coping: coaching



An essential component of high quality clinical care is an informed and engaged patient

Coulter et al, 2007

Coaching used in chronic conditions:

- The clinician and patient work together to reach informed decisions about the plan of care on the basis of the patient's clinical needs, priorities, and values.
- Expressing treatment preferences increases satisfaction

<http://guidelines.endometriosis.org>

Hummelshoj 02/2010

Coping: self management



Expert Patients Programme (developed by Stanford University supported by Coventry University)

- Symptom/pain cycle
- Interaction between disease, fatigue, depression, anger/fear/frustration, stress/anxiety and tense muscles
- Provides tools to break the cycle at any given point through weekly sessions with tutors, who also have chronic diseases

<http://www.endometriosis.org/best-practise-falconer.html>

<http://guidelines.endometriosis.org>

Hummelshoj 02/2010

ESHRE guideline: Coping with disease



GPP

Coaching and self-management programmes may prove beneficial in providing the woman with tools to enable her to make informed decisions and learn to live with a chronic disease. Patient self-help groups can provide invaluable counselling, support and advice. The website www.endometriosis.org/support.html provides a comprehensive list of all the self-help groups in the world.

<http://guidelines.endometriosis.org>

Hummelshoj 02/2010

ESHRE guideline



It is important to:

- Maintain a good relationship with the woman
- Involve the woman in all decisions
- Be flexible in diagnostic and therapeutic thinking

Kennedy et al, 2005

ESHRE guideline



"Treatment must be individualised, taking the clinical problem in its entirety into account, including the impact of the disease and the effect of its treatment on quality of life"

Kennedy et al, 2005

ESHRE guideline



"...seek advice where appropriate from more experienced colleagues or refer the woman to a centre with the necessary expertise to offer all available treatments in a multi-disciplinary context, including advanced laparoscopic surgery."

Kennedy et al, 2005

Women with endometriosis



Living with a chronic disease
Quality of life
Incapacitating pain
Emotional impact
Anger
Recurrence
Uncertainty
Repeated surgeries
Side-effect of medical treatments

COPING

Hummelshoj 02/2010

Endometriosis: challenge!



Pain symptoms may persist despite seemingly adequate medical and/or surgical treatment of the disease.

In such circumstances, a multi-disciplinary approach involving a pain clinic and counselling should be considered early in the treatment plan.

Kennedy et al, 2005

<http://guidelines.endometriosis.org>

Hummelshoj 02/2010

Endometriosis: challenge!



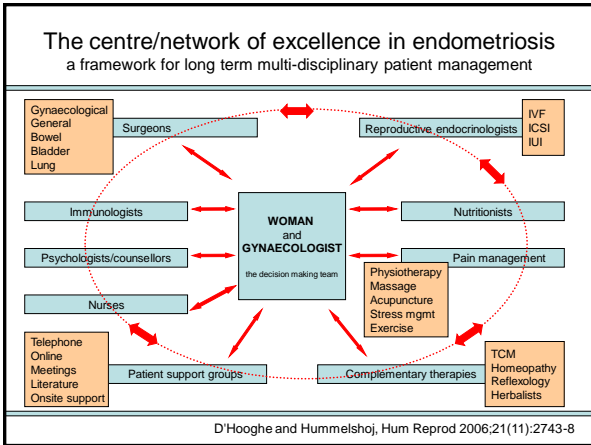
Pain symptoms may persist despite seemingly adequate medical and/or surgical treatment of the disease.

In such circumstances, a multi-disciplinary approach involving a pain clinic and counselling should be considered early in the treatment plan.

Kennedy et al, 2005

<http://guidelines.endometriosis.org>

Hummelshoj 02/2010



References

References are listed in:

<http://guidelines.endometriosis.org/references.html>

...with hyperlinks to abstracts in Medline.

<http://guidelines.endometriosis.org> Hummelshoj 02/2010

MARK YOUR CALENDAR NOW
XIth World Congress on Endometriosis

WCE 2011
TOWARDS EXCELLENCE

Montpellier, France 4 - 7 September 2011
