Endometriosis symptoms can impact on a woman’s general:

- physical
- mental
- social

...well being.

176 million women during the prime years of their lives
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

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
Endometriosis

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

COPING

To cope

To deal successfully with; manage


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
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
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

http://guidelines.endometriosis.org

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

http://guidelines.endometriosis.org

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

http://guidelines.endometriosis.org
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.

Gahala, 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; Solfert 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

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

Evidence Level 4

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

http://guidelines.endometriosis.org

Hummelshoj 02/2010

Coping: herbal medicine/TCM (ii)

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

http://guidelines.endometriosis.org

Hummelshoj 02/2010
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

Coping: herbal medicine/TCM (iv)

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ESHRE guideline: Coping with disease
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.

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.
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

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

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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

"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

"...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
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COPING

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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
The centre/network of excellence in endometriosis a framework for long term multi-disciplinary patient management

Surgeons Reproductive endocrinologists Immunologists Nutrionists Pain management

Patient support groups Complementary therapies PCP IVF, ICSI, IUI TCM, Homeopathy, Reflexology, Herbalists

References

References are listed in:

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

...with hyperlinks to abstracts in Medline.

http://guidelines.endometriosis.org

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Xth World Congress on Endometriosis
Montpellier, France 4 - 7 September 2011

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