

Meeting expectations in the chronically ill patient by extending the therapeutic network

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The challenge of chronic endometriosis symptoms

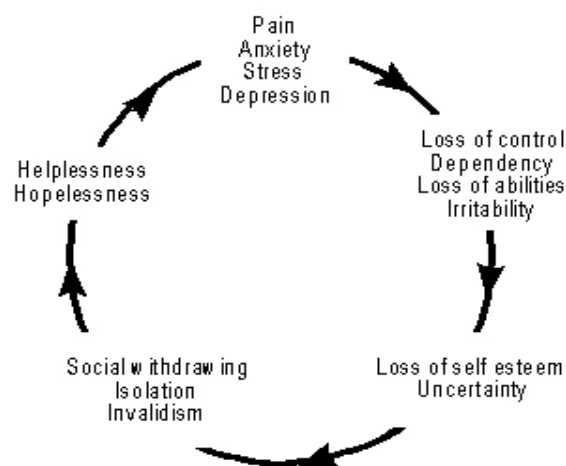
Dysmenorrhoea. Infertility. Bowel problems. Nausea. Dyspareunia. Vomiting. Fatigue. Pelvic pain.

These are all symptoms associated with endometriosis, and when any of these turn chronic, the treatment challenge is magnified. Furthermore, many of these women with endometriosis have been through a series of hit and miss treatments, including repeated surgeries and long-term medical therapies with their associated side-effects (and subsequent personal financial impact) that by now have contributed to a diminished quality of life.

Whilst the far-reaching consequences that endometriosis plays on quality of life and fertility, and the ramifications on general well-being are now well documented [1, 2], these issues remain to be addressed. Chronic pain in particular is challenging because it is something one wears on the inside, not on the outside. "You do not look as if you are in pain" is a common phrase – but what does pain look like?

How does one deal with a woman, who may now be deeply entrenched in an all consuming pain cycle, where it soon becomes difficult to tell which feeling leads to which or where one emotion stops and another begins? (See figure 1).

The pain cycle



How does one deal with a woman, who has high expectations for a cure, and every time these expectations are not met, she will be further disillusioned, and the negative cycle will continue to repeat itself?

Who is going to teach this woman how to live with and manage her pain, her grief, her loss, and how to increase her coping skills and in order to regain control of her life, and stop her from sliding back into the condition of poor health she has become so used to living with?

These are all questions that need to be asked, when we deal with the chronic aspect of endometriosis, and yet there is no "blue print" with which to answer these challenges, because there is no "blue print" treatment for the disease, which guarantees a cure or relief of symptoms.

The only thing that is becoming apparent is that effective management of endometriosis will require a multidisciplinary approach along with integration of all observations about the disease [3].

Information, communication, and expectations

The first step on this multi-disciplinary ladder is to communicate information and to set expectations. Information is the cornerstone for any patient to understand what is happening in her body, and it will enable her in the long term to cope with her symptoms. When the diagnostic news is first delivered, disbelief is often the first emotion to strike, followed rapidly by fear. Fear of the unknown. The woman will have lots of questions: Will she be able to have children? Will the disease lead to hysterectomy? Will the pain ever end? Will endometriosis lead to cancer? Will the disease recur? What will happen if she does not get treatment? Will it get worse? Will she pass it to her daughter? She may fear further tests and treatments, and experience anxiety when having to face unfamiliar medical tests or therapeutic procedures. And then comes the worry about possible side effects, which for some can be as bad, or worse, than the disease itself.

Reality is that most fears are due to a lack of information – as well as the way in which this information is communicated. "Let's see what happens" is potentially the most damaging phrase to patient confidence, and physicians sharing verbal uncertainty can be unnerving [4]. Thus the role of the communicator becomes extremely important. The physician has to explain what is happening, must be prepared to answer questions and provide information, and needs to listen! A patient has a great deal to tell about her health and specific concerns. She, above anyone else knows her pain, symptoms, and needs – she is the expert at having endometriosis, but not the expert at treating it. Thus, as part of effective communication, patients should also be encouraged to read medical literature and understand the current trends in the management of their condition, which will help them chose the options most appropriate to them. Being familiar with the medical terms makes the consultation with the physician more effective [5], when the physician and the woman set out – as a team – to develop a treatment plan for her.

The challenge with all this information, however, becomes that of maintaining realistic expectations, which can be difficult when dealing with a chronic condition. The resentment and frustration, which many with chronic diseases develop over time, more often than not, results from a mismatch between clinical management and the patient's expectations – a mismatch that leaves the patient unprepared for the possibility of recurrence after treatment. For example, if a patient has been promised a 100% cure, and yet she finds herself only 80% symptom free, the outcome is not successful. Conversely, if it has been communicated to her that any given treatment may only give 75% relief, and indeed it does – expectations have been met! (See figure 2).

Setting expectations

Expectation	Outcome	Successful?
100% symptom free	80%	NO
80% symptom free	75%	Maybe
75% symptom free	80%	YES

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Setting realistic expectations will be much more helpful in the long run than creating hopes that lead to a roller coaster of ups and downs of an unwarranted anticipation for a complete cure or a much longed for baby.

Evidence based medicine?

It is imperative that patients have the full support of their physician to ensure that science – not untested myths – determine treatment options. However, the evidence supporting the use of many medical therapies for endometriosis may not be as robust as we might wish to believe [6], and subsequently treatment failures within this field are common. Whilst clinical practice ideally aims to provide "best practice" (ultimately with the patient as the key stakeholder in the treatment and management process), this increasingly does not include only evidence based treatment pathways. An integrated approach involving a multidisciplinary team is needed [3, 7], with an open mind to explore a combination of therapies, even beyond the medical mainstream, based on patient outcome measures, to improve symptoms, alleviate side effects, and/or to assist recovery after surgery.

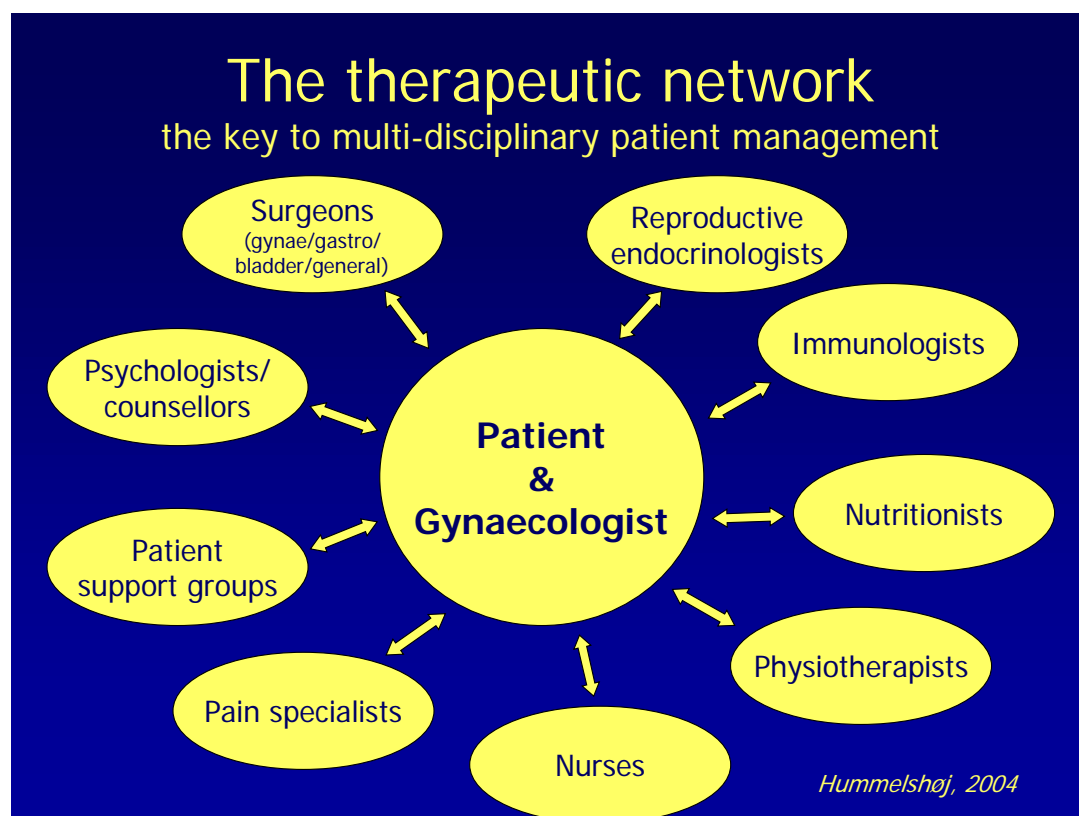
Extending the therapeutic network

Highly personal issues mean that the decisions involved in treatments are very individual, and the combination of potential therapies needs to be worked out bearing this in mind. The woman and her gynaecologist must approach this as a "team", and together tap into that therapeutic network, which can consist of:

- reproductive endocrinologists
- surgeons (from a number of disciplines)
- pain specialists
- nurses
- physiotherapists
- counsellors
- psychologists
- nutritionists/dieticians
- immunologists

- patient support organisations
- traditional Chinese medicine practitioners
- homoeopaths
- acupuncturists/reflexologists.

These therapists, with their different sets of skills, may all play an important role in providing a holistic, long-term, and individualised treatment plan for a woman or girl with endometriosis, depending on where she is in her treatment cycle, and which symptoms need to be managed at any given time. If all these cogs in this treatment and management wheel are well linked the outcomes for both the physician, the patient, and her family will truly deliver positive, long-term outcomes (see figure 3).



Talking it over and learning more

For some women, all they need is to talk to others with the disease – to share a mutual experience, coping techniques, and learn about treatment outcomes. This need may be covered through the resources of patient organisations [8] as adjuncts to the therapeutic management, or via peer reviewed internet-based resources for both physicians and patients. The emotional support provided through these global networks and the solid information in publications that these organisations provide will help build coping skills in patients and make the job of the physician so much easier [9].

References

1. Garry R, et al. The effect of endometriosis and its radical laparoscopic excision on quality of life indicators. *BJOG* 2000;107(1):44-54.
2. Grace VM. Problems women patients experience in the medical encounter for chronic pelvic pain: A NZ study. *Healthcare for Women International* 1995;16(6):509-519.
3. Metzger DA. Endometriosis. In: Glasser SR et al (eds). *The Endometrium*. Taylor & Francis, London 2002:626-641.
4. Ogden J, et al. Doctors' expressions of uncertainty and patient confidence. *Patient Education and Counselling* 2002; 48:171-176.
5. Donaldson L. Patients as health care consumers. *BMJ* 2003; 326:1279-1280
6. Prentice A. Medical advances in the treatment of endometriosis. Presented at the ESHRE Endometriosis pre-congress course, Bologna, Italy, 1 July 2001.
7. Martin DC and Ling FW. Endometriosis and pain. *Clin Obstet Gynecol* 1999; 42:664-686.
8. See www.EndoZone.org ("Support groups") for an up-to-date list of world wide patient organisations.
9. Hummelshoj L. Endometriosis: sharing resources and pooling knowledge. *Gynaecology Forum* 2003; 8(4):13-15.