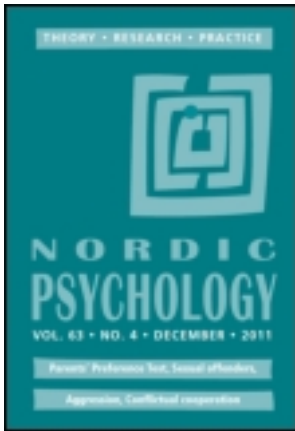


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Mindfulness-based psychological intervention for coping with pain in endometriosis

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Abstract

Endometriosis is an important cause of pain and fatigue in fertile women. The disease is often overlooked in general medical practice, and significant delay from onset of symptoms to diagnosis and treatment is common. Severe cases cause chronic pain and reduce work ability and quality of life even after optimal medical treatment. We suggest a psychological intervention based on mindfulness techniques for dealing with pain, and report results from a pilot study with 10 endometriosis patients with chronic pain problems. Participants' level of distress was measured with self-report questionnaires of general health status (SF-36) and endometriosis health profile (EHP-30) pre- and post-intervention and at six- and 12-month follow-ups. Results indicate significant and lasting effects on participants' pain level, well-being, and ability to function in daily life. Although conclusions remain preliminary until tested in a randomized controlled trial, it should be noted that our findings are in line with qualitative studies in women with endometriosis, and with data on the effects of mindfulness in other chronic pain domains. We encourage further studies on this kind of intervention for women with endometriosis.

Keywords: endometriosis, chronic pain, mindfulness.

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Introduction

Endometriosis denotes a condition where tissue similar to the mucosa (endometrium) of the uterus is found in the abdominal cavity and causes bleeding, local inflammation and adherence formation. The disease occurs in up to 10% of fertile women (Vigano et al., 2004) and represents a major cause of pelvic pain (Giudice & Kao, 2004). The main pathogenetic mechanism is probably retrograde menstruation through the oviducts with small fragments of endometrium implanting on the peritoneal surface (Bulun, 2009).

The disease is often overlooked and many patients experience a delay of several years from onset of symptoms to diagnosis and treatment (Denny, 2004; Husby, Haugen & Moen, 2003). Moreover, it is a general clinical experience that severity and objective findings are only weakly correlated in some patients (Whiteside & Falcone, 2003). Although recent findings of pathological local nerve growth within and around endometriosis lesions and changes in nociception pose a likely explanation (Howard, 2009), some clinicians are still reluctant to the diagnostic workup and specialized treatment.

On this background, symptoms of endometriosis are often dismissed as somatization or normal menstrual pain, which may aggravate the problem (Cox et al., 2003; Grace, 1995; Poulin, 2000) and enhance the risk of Central nervous system (CNS) sensitization (Evans, Moalem-Taylor & Tracey, 2007). Moreover, even combined medical and surgical therapy does not always prevent development of chronic pain (Vercellini et al., 2009a, 2009b).

Pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (IASP Taxonomy, Merskey & Bogduk, 1994). Women with pain from endometriosis are affected in several aspects of work and social life. In a postal survey conducted by the National Endometriosis Society in UK, 2463 women reported to have been diagnosed with endometriosis. Their main symptom was abdominal pain related to the menstrual cycle but not confined to the actual period of bleeding. Two-thirds of respondents reported that they had missed one or more work days (on average, 45 days per year) and one-third that their economic situation had changed due to endometriosis. Eleven per cent of all respondents were on welfare benefits. Furthermore, almost half of the respondents reported sexual intercourse to be painful, and more than one in four had reduced fertility (Carlton, 1996). These studies indicate that endometriosis is associated with both societal economical losses and severe distress for the patients (Cox et al., 2003; Whelan, 2007) and their families (Butt & Chesla, 2007; Fernandez, Reid & Dziurawiec, 2006).

In line with these findings, professionals from pain clinics insist that chronic pain hampers all aspects of life and requires more recognition and priority (Jensen & Frølich, 2006). Nevertheless, scientific data on the potential of psychological interventions are sparse, and the effect may be underestimated (Andersson, 1999; Astin et al., 2008). However, evidence in favour of this approach is beginning to accumulate. Thus, meta-analyses indicate positive effects of several mind-body techniques on headaches (Sierpina, Astin & Giordano, 2007) and chronic non-malignant pain (Morone & Greco, 2007).

The psychological approach should be based on the special background of patients with endometriosis. Some have been told that dysmenorrhoea was a fact of life they just had to live with, or it was implied to them that patience, marriage and children could make the problem go away. This might lead to secondary victimization or "blaming the victim" (Ballweg, 1997; Cox et al, 2003). Transferring emphasis to the psychological make-up, rather than the somatic

background, can also be found in studies on personality factors behind the continued distress. Results have been mixed at best (Low, Edelmann & Sutton, 1993; Peveler et al., 1996; Selfe, Matthews & Stones, 1998; for a discussion of dismissal by psychologization, see Ballweg, 1997).

Another approach focuses on coping styles. Nunnink & Meana (2007) found passive coping style to be a significant predictor for overestimating pain when recalled retrospectively, and one study found coping style to predict severity of symptoms (Poulin, 2000). This offers the conjecture that psychological intervention may be particularly helpful for women with passive coping styles.

In his advice to general medical practitioners, Frølich (1993, 2011) argued that the inherently subjective nature of any pain experience, as well as its dependence on many factors – both internal and external – necessitates acknowledgement of the patient's own interpretation. He saw this as a prerequisite for assisting his patient in separating emotional and derived components of chronic pain from the pain itself. If this effort succeeds, the patient might regain feelings of control and more active behavioural strategies.

Several studies on the mind–body approach have focused on *mindfulness*. For example, mindfulness training can increase pain tolerance (Kingston et al., 2007) and immunity system responses to influenza virus (Davidson et al., 2003). Some studies have linked mindfulness to changes at the brain level (Davidson et al., 2003; Lutz et al., 2004; Orme-Johnson et al., 2006; for an exception see Kingston et al., 2007).

Mindfulness originates in Eastern traditions of meditation. It is gaining popularity as a therapeutic and self help tool in the West, albeit with reduced reference to the spiritual dimension of mindfulness as originally conceived (Baer, 2003). In this context, a state of mindfulness can be characterized as having five dimensions (quoting from Carmody & Baer, 2008, p. 24):

1. observing (attending to or noticing internal and external stimuli, such as sensations, emotions, cognitions, sights, sounds and smells);
2. describing (noting or mentally labelling these stimuli with words);
3. acting with awareness (attending to one's current actions, as opposed to behaving automatically or absent-mindedly);
4. non-judging of inner experience (refraining from evaluation of one's sensations, cognitions and emotions); and
5. non-reactivity to inner experience (allowing thoughts and feelings to come and go, without attention getting caught up in them).

Used in this way, mindfulness can reduce illness, anxiety and pain related to stress (Carmody & Baer, 2008). Such effects seem to be effected through mechanisms involving the autonomous nervous system (Greeson, 2009), and might involve modification of stress-induced visceral hypersensitivity (Larauche et al., 2010)

A meta-analysis of 20 studies of mindfulness-based stress reduction found effect across a number of populations, including clinical samples with chronic pain, fibromyalgia, and cancer (Grossman et al., 2004). Greeson (2009) summarized 54 selected studies from 2003–2008 and suggested that mindfulness brings ability to adjust attention, thought patterns, mood states, and sleep in ways that may lead to improved somatic functions as well as feeling of well-being.

A clinical encounter launched adaptation of the mindfulness approach to women with endometriosis (Kold, Vedsted-Hansen & Hansen, 2011). The present prospective, observational

pilot study served to improve the intervention and evaluate the feasibility of this technique in patients with chronic pain secondary to endometriosis. We aimed to assess the feasibility and effects of this approach in a prospective observational pilot study.

Method

The study consisted of a 10-session intervention (five individual and five group sessions, 15 hours in total), monitored by standardized tests. The intervention was based on mindfulness and visualization techniques, supported by elements of psycho-education, counselling, and group support. The latter elements were included in addition to mindfulness due to the marked variation in individual needs of the participants in order to facilitate use of the mindfulness technique. The intervention was conducted by the first author who is an experienced clinical psychologist. For an overview of elements and time frame, see Figure 1.

Participants – selection and recruitment

At Aarhus University Hospital, Denmark, women who had received treatment according to the European Society of Human Reproduction and Embryology (ESHRE) guidelines for endometriosis (Kennedy et al., 2005) but still experienced pronounced pain were invited to participate in the study. The invitation offered

training mental techniques for coping with the pain. The participant will receive instructions and training both individually and in a group setting. Topics covered include fatigue, quality of sleep, job, relationship-issues, etc. The intervention focuses on dialogue, specific hints, methods and techniques to enhance quality of life.

Practice at home seems to improve the therapeutic effect of mindfulness training (Carmody & Baer, 2008). Thus, homework was a requirement for participation in this project, and women unwilling to make this commitment were excluded during the recruitment process.

Thirteen women followed the intervention. Three participants disclosed disease other than endometriosis during the study period (malignant disease: $n = 1$, borderline psychosis: $n = 1$,

Aug 2007	Dec 2007	May 2008	Dec 2008
Intervention: Group sessions, 5×1.5 hrs: - mindfulness techniques - establishing relationship - psycho-education - group counselling Individual sessions, 5×1.5 hrs: - mindfulness techniques - counselling/supportive therapy - one session includes partner Email contact availability			
Measures: <i>Pre-</i> SF-36 EHP-30 Field notes Emails <i>Post-</i> SF-36 EHP-30 <i>6-month follow-up</i> SF-36 EHP-30 <i>1-year follow-up</i> SF-36 EHP-30			

Figure 1: Timetable of intervention and measures

metroragia with need for hysterectomy: $n = 1$). For ethical reasons, these women were allowed to continue participation in the study group.

The result thus concerned 10 participants for whom endometriosis was the only known diagnosis. No dropouts occurred. Nine of our 10 participants lived with a partner when the investigation began; one partnership later dissolved.

The intervention

The intervention employed three types of interaction: (a) mindfulness training (body scan, sensory training, breathing techniques, music and bio-feedback support), (b) psycho-education and group dialogue, and (c) individual sessions, whose themes were adapted to the individual client's personal goals and challenges.

Mindfulness training

Mindfulness training was performed according to Kabat-Zinn (2004), with the following modification. Visualization, as described by Zachariae (1993) was used in individual cases when direct registration of the pain problem was considered too problematic.

Body-scan is a form of meditation aimed at developing awareness of one's body while experiencing mind-body connection and achieving a relaxed state of both (Kabat-Zinn, 2004). This exercise was guided by the therapist during group sessions, and was also performed at home between sessions.

Breathing techniques include making participants' aware of their own respiration, and making them consciously change its pattern according to instruction. Breath therapy aimed at somatic benefits has been compared to physiotherapy and was found efficient in a randomized controlled trial (RCT) study with chronic low back pain patients (Mehling et al., 2005).

Respiration has a natural pattern variation with physical and emotional levels of arousal. This is under autonomous CNS control but may also be altered voluntarily (Davidson et al., 2003; Ditto, Eclache & Goldman, 2006). The intervention trained participants to notice their own breathing, and to voluntarily change it from patterns associated with tenseness towards patterns associated with relaxation. Theoretically, this allows a relaxed but alert awareness, a state of mindfulness.

To assist participants' training efforts, a simple version of *bio-feedback* was provided. The tool used continuously measures and graphically displays heart rate and skin conductance levels based on electrodes attached to three fingers (manufacturer Wild Divine®). Bio-feedback was used because Hawkins & Hart (2003) argued that a vicious cycle exists for chronic pain patients – from chronic pain to emotional distress to increased arousal to increased pain – and suggested that relaxation and bio-feedback might break the cycle. With a quote from Rock (1998 p. 950, in Hawkins & Hart, 2003, p. 280): "Depression may 'open the gate' to allow the pain to intensify despite stable disease". Relaxation intervenes at the physiological arousal stage, and bio-feedback lets participants monitor immediate effects during training, which enables more efficient training. Since bio-feedback shows a physiological effect of a mental effort, it should also decrease distress caused by feelings of helplessness towards the pain.

Music was used to aid relaxation. Music has been found to alter physiological measures such as blood pressure, heart rate, respiration, body temperature, galvanic skin response, and brain waves monitored by electroencephalography (EEG) (Snyder & Chlan, 1999). An effect of music on chronic pain has been suggested and discussed by several studies (e.g. Mitchell et al., 2007;

Siedliecki & Good, 2006), including a single-case study with a woman whose pain was caused by endometriosis (Colwell, 1997).

Other intervention elements

Women with endometriosis have typically been met with disregard of their bodily perceptions and possibly internalized such disbelief in own sensory experience (cf. Grace, 1995). The group sessions therefore provided psycho-education and collective counselling, and facilitated mutual support among the women.

The psycho-education focused on six themes: (1) psychological challenges: grief processes, emotions associated with adapting to chronic pain, (2) stress and pain, (3) work issues, (4) healthy habits including food and exercise, (5) social network in a challenging situation, and (6) mind–body interaction.

Individual sessions provided support by targeting each participant's main goal, which she chose during the first session. All sessions focused on this and related goals with reference to the woman's particular resources and needs. Most participants chose pain relief as their main goal. One session included the client's partner.

Measures and statistical analysis

Participants' pain level, sleep quality, symptom prominence, general health, physical impairment, social life, emotional condition (anxiety and depression), emotional reaction to the disease, work capacity, and sex life were assessed before and after the intervention and at the six- and twelve-month follow-ups by means of two questionnaires, SF-36 (general health, generic) and EHP-30 (endometriosis specific).

Both are standardized self-report tools. SF-36 measures health related quality of life by eight sub-scales, also condensed into two summary-scales of physical and mental health, and is widely used (Ware, 2000; Danish standardization by Bjørner et al., 1997). The 36 questions are answered with reference to the preceding four weeks, using yes/no or Likert-type scales.¹

The 30 items of EHP-30 are derived through in-depth interviews with 24 British women with endometriosis (Jones, Jenkinson & Kennedy, 2004b) and measure endometriosis-related quality of life problems by 11 scales, covering frequently affected domains. The form's psychometric properties have been evaluated in the United Kingdom and the United States (Jones, Jenkinson & Kennedy, 2004a; Jenkinson, Kennedy & Jones, 2008), and it is increasingly used in the international literature on health-related research in endometriosis (Khong, Lam & Luscombe, 2010; Van de Burgt, Hendriks & Kluivers, 2011). Items for five scales are to be answered by all participants on all occasions. For the remaining six scales (called 'modular'), relevance varies with current context of the participant; for example, participants without a job are instructed to skip the items belonging to the *work life* scale. Our study used the English Manual (Jones, Jenkinson & Kennedy, 2001). The questionnaires underwent translation to Danish and back to English by two independent translators, with approval of the final version by Stephen Kennedy (the senior scientist of the group behind the EHP-30 form). As far as can be judged with the small amount of Danish data yet available, scale-consistency seemed acceptable in this version.²

The principal investigator (first author) was not involved in the collection or analysis of data. SF-36 and EHP-30 forms were sent to the participants by a secretary. The forms were completed by the participants in their home. Data were entered by an independent contractor, and

analyses were conducted by the second author using the IBM SPSS version 19 packages Base statistics and Advanced statistics. Before analysis, items were recoded and scales derived according to the manuals³ (Bjørner et al., 1997; Jones, Jenkinson & Kennedy, 2001).

We expected that measures improved after the intervention relative to before the intervention. The design allows testing for differences over time, although the absence of a control group prevents causal conclusions. Repeated measures ANalysis Of VAriance between groups (ANOVAs) with time of measurement as within-subject factor (four levels) were computed for all SF-36 scales and for EHP-30 when a scale had at least five identical participants at all levels. Pairwise comparisons were made between the before-intervention level and each subsequent level, using Bonferroni significance level adjustment for multiple comparisons.

Results

Participants in this study were between 14 and 37 years old ($Md = 23$) when experiencing the first symptoms of endometriosis, and between 25 and 47 years ($Md = 31$) before diagnosed. Within-subject analysis revealed that the slip between onset and diagnosis ranged from one to 20 years ($Md = 9$ years).

Prior to the intervention, participants scored below national average on all SF-36 scales, and the scales for *bodily pain*, *role-physical*, and *role-emotional* were particularly low (Table 1). Bottom score on the *bodily pain* scale indicates very strong pain that causes severe difficulties for daily life (Bjørner et al., 1997, p. 9). Bottom score on the *role-physical* scale indicates problems with work or other daily activities for physical reasons, and bottom score on the *role-emotional* scale indicates the problems for psychological reasons (Bjørner et al., 1997)

Bodily pain significantly and consistently improved from pre- to post-intervention and follow-up measures (Table 1). Improvement was also seen in the scales for *physical functioning*, *role-physical* and *role-emotional*, although with some fluctuation over time. At its best, *physical functioning* even approached the national average. Paradoxically, a decline was also seen in some scales (*social functioning* and *general health*), albeit of comparatively limited magnitude and only statistically significant at few data points.

For endometriosis-interventions, EHP-30 may be a better test of effect than SF-36. Thus, EHP-30 zooms in on areas that are specifically relevant to women with endometriosis and detects change over time (Jones, Jenkinson & Kennedy, 2004a). However, its structure allows for non-reports on several scales, and there is no general population baseline for comparison.

Results on EHP-30 are shown in Table 2. Of the five scales that could be measured for all participants on all occasions, four suggested lasting improvement: the *pain* scale, and the scales for *control and powerlessness*, *emotional well-being*, and *social support*. A transient effect was found on the fifth scale, *self image*.

Most participants ($n = 8$ or 9 depending on time slot) also answered the modular scale *sexual intercourse*; no significant difference from pre-test was found on this scale at any measurement point. The *work life* scale showed significant improvement on all measurement points. However, fewer participants answered the items at follow-up ($n = 6$, $n = 5$) than at pre- and post-test ($n = 7$). This suggests improved work ability but that drop-out from the work force also

Table 1: SF-36 comparison data, descriptive statistics, and tests for post-intervention change

	DK standard, women 16 +		T1 Pre intervention		T2 Post intervention		T1-T2 ^b		T3 6 mo follow-up		T1-T3 ^b		T4 12 mo follow-up		T1-T4 ^b		Repeated measures ANOVA		
	M	SD	M	SD	M	SD	p	M	SD	p	M	SD	p	M	SD	p	df	F	p
Physical functioning	86.40	21.23	69.34	14.62	77.00	18.14	ns	83.50	12.03	0.082	82.50	12.96	ns	50.00	39.09	.040	3,27	3.96	0.018
Role – physical	80.26	33.56	15.00	21.08	37.50	39.53	ns	47.50	41.58	ns	50.00	39.09	ns	59.00	7.38	.007	1,43, 12.87	3.95	0.019
Bodily pain	76.29	24.30	23.00	27.51	61.00	8.76	0.002	64.00	6.99	.004	59.00	7.38	ns	59.00	7.38	ns	3,24	3.80	0.023
General health	75.61	20.93	69.20	12.66	63.40	13.81	ns	^a 66.33	13.86	ns	59.40	9.81	ns	52.00	10.06	ns	3,27	1.37	ns
Vitality	67.43	20.55	55.50	4.97	53.00	7.15	ns	49.84	9.83	ns	50.00	10.21	ns	50.00	10.21	ns	2,00, 18.04	5.48	0.014
Social functioning	90.17	18.57	60.00	9.86	47.50	5.27	0.090	46.25	8.44	ns	63.33	36.68	ns	50.00	42.31	ns	3,27	5.48	0.005
Role – emotional	84.47	29.18	23.33	35.31	76.67	35.31	0.050	66.00	9.09	ns	68.00	10.33	ns	68.00	10.33	ns	3,27	0.15	ns
Mental health	79.98	16.03	65.80	8.56	66.40	3.37	ns	66.00	9.09	ns	68.00	10.33	ns	68.00	10.33	ns	3,27	0.15	ns
<i>Summary measures:</i>																			
1-item Health transition	–	–	3.30	0.48	2.40	1.07	ns	1.90	0.74	0.001	2.50	0.97	ns	2.50	0.97	ns	^c 2,10, 18.85	6.88	0.005
Phys. health composite	–	–	37.34	2.93	42.34	4.82	ns	^a 46.51	6.02	0.031	45.22	3.52	.001	41.11	5.52	ns	3,24	9.50	0.000
Mental health composite	–	–	42.62	4.82	44.89	4.34	ns	^a 41.68	5.09	ns	41.11	5.52	ns	41.11	5.52	ns	3,24	1.71	ns

Notes: For all means, higher is better.

N = 10 except ^aN = 9.^b Pairwise comparisons based on estimated marginal means; Bonferroni adjustment for multiple comparisons.^c Sphericity not assumed; Huynh-Feldt correction applied.

Table 2: EHP-30 descriptive statistics and tests for post-intervention change

	T1 Pre intervention		T2 Post intervention		T1-T2 ^b		T3 6 mo follow-up			T4 12 mo follow-up			T1-T4 ^b			Repeated measures ANOVA			
	N	M	N	M	N	SD	N	M	SD	N	M	SD	N	M	SD	df	F	p	
Pain	9	52.53	10	33.18	10	12.52	10	31.59	12.88	10	28.18	16.04	10	28.18	16.04	3,24	18.06	0.000	
Control and Powerlessness	9	65.28	10	37.50	10	18.98	10	38.33	11.42	10	35.42	22.50	10	35.42	22.50	3,24	15.64	0.000	
Emotional Well-being	10	52.08	10	34.17	10	16.23	10	29.58	13.81	10	34.17	19.02	10	34.17	19.02	3,27	16.22	0.000	
Social Support	10	52.50	10	31.25	10	25.89	10	38.75	17.38	10	31.88	20.72	10	31.88	20.72	3,27	4.89	0.008	
Self Image	10	41.67	10	25.83	10	21.52	10	26.67	21.08	10	30.00	22.64	10	30.00	22.64	3,27	2.59	ns	
<i>Modular scales^c:</i>																			
Work life	7	47.86	8	28.13	8	27.36	7	14.29	10.97	7	15.00	11.73	5	15.00	11.73	3,12	4.15	0.031	
Children	7	46.43	7	25.00	7	22.49	8	12.50	14.94	8	12.50	19.09	7	12.50	19.09	3,18	7.73	0.002	
Sexual intercourse	9	66.67	10	56.00	10	19.69	8	56.25	32.49	8	62.59	30.62	9	62.59	30.62	3,18	1.28	ns	
Medical profession	6	33.33	7	28.57	7	32.99	4	18.75	33.46	4	26.79	31.19	7	26.79	31.19	(n = 2)	-	-	
Treatment	6	69.44	5	26.67	5	21.52	5	41.67	28.26	5	47.92	24.88	4	47.92	24.88	(n = 3)	-	-	
Infertility	2	21.88	2	15.63	2	30.94	3	47.92	46.91	3	81.25	26.52	2	81.25	26.52	(n = 1)	-	-	

Notes: For all means, lower is better.

^a Modular scales comprise optional items; descriptive statistics are reported but caveat fluctuation over time of who responded; inferential statistics are only reported for scales with at least 5 consistent respondents.

^b Pairwise comparisons based on estimated marginal means; with Bonferroni adjustment for multiple comparisons.

occurred. The children scale ($n = 7$) also seemed to indicate declining distress, with significant improvement at the follow-up data points. Remaining scales were answered by few and results were unclear.

Discussion

In the present prospective, observational pilot study, a questionnaire about general health (SF-36) and a questionnaire with focus on the effects of surgical treatment of endometriosis (EHP-30) were used to objectively assess the effects of a 15 hours intervention with mindfulness techniques. The results showed a complex pattern, but positive effects on pain level and associated aspects were achieved. These results need confirmation in a randomized controlled study, but some conclusions and suggestions for future research may be justified.

Prior to this study, the situation of women with endometriosis was described and discussed in several articles (Ballweg, 1997; Brosens et al., 2004; Butt & Chesla, 2007; Carlton, 1996; Cox et al., 2003; Denny, 2004; Grace, 1995; Husby et al., 2003; Nunnink & Meana, 2007; Whelan, 2007), but data on the effect of psychological interventions are sparse.

In our study, the intervention was mindfulness-based and focused on pain. When effect was measured with the endometriosis specific questionnaire (EHP-30), all five standard scales responded positively, and four of them still indicated improvement at one-year follow-up: *pain*, *control and power(lessness)*, *emotional well-being*, and *social support*. Only one scale consistently failed to improve, i.e., the modular scale *sexual function*. The remaining modular scales suggested some improvement (*work life* and *children*), or were relevant to only few participants and inconclusive.

The pattern of findings with the general health and well-being questionnaire, SF-36, points in the same direction. Of the two summary measures, *physical health* consistently improved, whereas no effect was found for *mental health*. Four composite scales responded positively, of which three were *bodily pain*, *role-physical* and *physical functioning*. In his discussion of the psychometric properties of SF-36, Ware (2000, pp. 3131–3132) notes that these three scales correlate most strongly with the summary measure of physical health and adds that they are “most responsive to treatment that change the physical morbidity, whereas scales loading highest on the mental component respond most to drugs and therapies that target mental health”. From the mental domain, only the scale *role-emotional* responded positively in our study.

Of the remaining composite scales, *mental health* and *vitality* showed no effect whereas, unexpectedly, *general health* and *social functioning* indicated slightly negative effects, implicating a complex pattern. We cannot account for the negative findings, but it might be speculated that improved capability to define realistic limits and goals implied a decreased social function in parallel to enhanced physical well-being.

In summary, the intervention suggested here did, albeit psychological in its form, successfully target physical aspects of the participants' problems. Had the origin of their problem been a psychological one, or had the effect of the intervention merely been a general psychological effect of being cared about etc., the mental scales of SF-36 should have improved more than the physical scales. They did not, on the contrary.

With the uncertainties inherent in our study borne in mind, these aspects support a preliminary integration of our data and the literature on endometriosis, chronic pain and mindfulness.

Pain is a core problem of endometriosis (Carlton, 1996; Denny, 2004). Chronic (and recurrent) pain leads to a vicious cycle, where stress and despair increases while ability to sleep and function socially decreases. This in turn leads to more tenseness, which leads to more pain (Greeson, 2009). Thus, to help chronic pain patients, we must provide assistance to separate the pain itself from the above mentioned derivatives. Mindfulness techniques have been shown to help chronic pain patients in a number of domains (Baer, 2003; Grossman et al., 2004). Some participants in clinical trials report reduced pain, others report no reduction in pain level but help in increased ability to control and cope with it (Kabat-Zinn, Lipworth & Burney, 1985). Thus, mindfulness might act by breaking this vicious cycle. It helps distinguish the pain itself from its derivatives, and it lends tools to relax, which makes it easier to bear the pain when it comes, as well as to sleep, feel in control, and take on social tasks with less fear of failing (Greeson, 2009). This could be perceived as a good cycle of empowerment taking over, and may explain that in our study some of the measures continued to improve after termination of the intervention itself. Some endometriosis specific problems remained, such as infertility and hindered sexuality. However, the women became better at dealing with their pain, felt empowered and to have regained options.

In conclusion, the present study suggested that use of mindfulness techniques is feasible and might imply positive effects on some aspects of quality of life in patients with chronic pain secondary to endometriosis. Some of these effects might be durable, and our data motivate testing of this principle in randomized controlled studies.

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NOTES

- 1 For example, one of the three items comprising the *role-physical* scale reads: Within the last four weeks, have you had any of the following problems with your work or other daily activities because of your physical health: ... I have cut down on the time I spend on work or other activities. Answer options: yes or no.
- 2 All Cronbach's alphas within the present data set, by scale and time of measurement: pain, 11 items, $\alpha = 0.86, 0.92, 0.86, 0.94$; control and powerlessness, six items, $\alpha = 0.93, 0.77, 0.66, 0.91$; emotional well-being, six items, $\alpha = 0.89, 0.83, 0.79, 0.90$; social support, four items, $\alpha = 0.91, 0.74, 0.79, 0.91$; self, three items, $\alpha = 0.81, 0.84, 0.88, 0.91$; work life, five items, $\alpha = 0.90, 0.92, 0.55, 0.82$; children, two items, $\alpha = 1.0, 0.86, 0.51, 0.94$; sexual intercourse, five items, $\alpha = 0.84, 0.84, 0.96, 0.95$; medical profession, four items, $\alpha = 0.93, 0.98, 0.99, 0.93$; treatment, three items, $\alpha = 0.75, 0.34, 0.65, 0.06$; infertility, four items, $\alpha = 1.0, 1.0, 0.98, 1.0$.
- 3 For SF-36, means-substitution was used for single missing items (seven items in total), whereas more missing items led to the participant being discarded for that scale at that time of measurement (one case,

general health scale at the six-month follow-up; this also affects the two composite scales, which are weighted scores of all other scales). For EHP-30, only when no items were missing was a scale computed (except the modular scale 'sexual intercourse' which allow missing items). Please refer to the manuals for details.

REFERENCES

- Andersson, G. (1999). Om psykologins roll i den somatiska vården [The role of psychology in somatic care]. *Nordisk Psykologi*, 51(2), 128–134.
- Astin, J. A., Sierpina, V. S., Forsy, K., & Clarridge, B. (2008). Integration of the biopsychosocial model: Perspectives of medical students and residents. *Academic Medicine*, 83(1), 20–27.
- Baer, R. A. (2003). Mindfulness training as clinical intervention: A conceptual and empirical review. *Clinical Psychology: Science and Practice*, 10, 125–143.
- Ballweg, M. L. (1997). Blaming the victim. The psychologizing of endometriosis. *Obstetrics and gynecology clinics of North America*, 24(2), 441–453.
- Bjørner, J. B., Damsgaard, M. T., Watt, T., Bech, P., Rasmussen, N. K., Kristensen, T. S., et al. (1997). *Dansk manual til SF-36. Et spørgeskema om helbredsstatus*. Copenhagen: LIF.
- Brosens, I., Puttemans, P., Campo, R., Gordts, S., & Kinkel, K. (2004). Diagnosis of endometriosis: Pelvic endoscopy and imaging techniques. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 18(2), 285–303.
- Bulun, S. E. (2009). Endometriosis. *New England Journal of Medicine*, 360(3), 268–279.
- Butt, F. S., & Chesla, C. (2007). Relational patterns of couples living with chronic pelvic pain from endometriosis. *Qualitative Health Research*, 17(5), 571–585.
- Carlton, D. (1996). Awareness of endometriosis. *Practice Nurse*, 12, 513–515.
- Carmody, J., & Baer, R. A. (2008). Relationships between mindfulness practice and levels of mindfulness, medical and psychological symptoms and well-being in a mindfulness-based stress reduction program. *Journal of Behavioral Medicine*, 31(1), 23–33.
- Colwell, C. M. (1997). Music as distraction and relaxation to reduce chronic pain and narcotic ingestion: A case study. *Music Therapy Perspectives*, 15(1), 24–31.
- Cox, H., Henderson, L., Andersen, N., Cagliarini, G., & Ski, C. (2003). Focus group study of endometriosis: Struggle, loss and the medical merry-go-round. *International Journal of Nursing Practice*, 9(1), 2–9.
- Davidson, R. J., Kabat-Zinn, J., Schumacher, J., Rosenkranz, M., Muller, D., Santorelli, S. F., et al. (2003). Alterations in brain and immune function produced by mindfulness meditation. *Psychosomatic medicine*, 65(4), 564–570.
- Denny, E. (2004). Women's experience of endometriosis. *Journal of Advanced Nursing*, 46(6), 641–648.
- Ditto, B., Eclache, M., & Goldman, N. (2006). Short-term autonomic and cardiovascular effects of mindfulness body scan meditation. *Annals of Behavioral Medicine*, 32(3), 227–234.
- Evans, S., Moalem-Taylor, G., & Tracey, D. J. (2007). Pain and endometriosis. *Pain*, 132(Suppl. 1), S22–S25.
- Fernandez, I., Reid, C., & Dziurawiec, S. (2006). Living with endometriosis: The perspective of male partners. *Journal of Psychosomatic Research*, 61(4), 433–438.
- Frølich, S. (1993). Smertepsykologi [The psychology of pain]. *Månedsskrift for praktisk lægegerning*, 71(3), 169–176.
- Frølich, S. (2011). *Kroniske smerter – kan man lære at leve med det?* (3rd ed.). Copenhagen: Nyt Nordisk Forlag.
- Giudice, L. C., & Kao, L. C. (2004). Endometriosis. *Lancet*, 394(9447), 1789–1799.
- Grace, V. (1995). Problems women patients experience in the medical encounter for chronic pelvic pain: A New Zealand study. *Practice Nurse*, 16(6), 509–519.
- Greeson, J. M. (2009). Mindfulness research update: 2008. *Complementary Health Practice Review*, 14(1), 10–18.
- Grossman, P., Niemann, L., Schmidt, S., & Walach, H. (2004). Mindfulness-based stress reduction and health benefits: A meta-analysis. *Journal of Psychosomatic Research*, 57(1), 35–43.
- Hawkins, R. S., & Hart, A. D. (2003). The use of thermal biofeedback in the treatment of pain associated with endometriosis: Preliminary findings. *Applied Psychophysiology & Biofeedback*, 28(4), 279–289.
- Howard, F. M. (2009). Endometriosis and mechanisms of pelvic pain. *Journal of Minimally Invasive Gynecology*, 16(5), 540–550.
- Husby, G. K., Haugen, R. S., & Moen, M. H. (2003). Diagnostic delay in women with pain and endometriosis. *Acta Obstetrica et Gynecologica Scandinavica*, 82(7), 649–653.
- Jenkinson, C., Kennedy, S., & Jones, G. (2008). Evaluation of the American version of the 30-item Endometriosis Health Profile (EHP-30). *Quality of Life Research*, 17(9), 1147–1152.
- Jensen, N-H., & Frølich, S. (2006). Behandling af kroniske smerter – en underprioriteret samfundsopgave [Treatment of chronic pain – an under prioritized task for society]. *Ugeskrift for Læger*, 168(20), 1940.
- Jones, G., Jenkinson, C., & Kennedy, S. (2001). *The endometriosis health profile user manual*. Oxford: Nuffield Department of Obstetrics & Gynaecology & Health Services Research Unit, University of Oxford.

- Jones, G., Jenkinson, C., & Kennedy, S. (2004a). Evaluating the responsiveness of the endometriosis health profile questionnaire: The EHP-30. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 13(3), 705–713.
- Jones, G., Jenkinson, C., & Kennedy, S. (2004b). The impact of endometriosis upon quality of life: A qualitative analysis. *Journal of Psychosomatic Obstetrics & Gynecology*, 25(2), 123–133.
- Kabat-Zinn, J. (2004). *Full catastrophe living*. London: Piatkus.
- Kabat-Zinn, J., Lipworth, L., & Burney, R. (1985). The clinical use of mindfulness meditation for the self-regulation of chronic pain. *Journal of Behavioral Medicine*, 8(2), 163–190.
- Kennedy, S., Bergqvist, A., Chapron, C., D'Hooghe, T., Dunselman, G., Greb, R., Hummelshoj, L., Prentice, A., & Saridogan, E.; ESHRE Special Interest Group for Endometriosis and Endometrium Guideline Development Group. (2005). ESHRE guideline for the diagnosis and treatment of endometriosis. *Human Reproduction*, 20(10), 2698–2704.
- Khong, S. Y., Lam, A., & Luscombe, G. (2010). Is the 30-item endometriosis health profile (EHP-30) suitable as a self-report health status instrument for clinical trials? *Fertility and Sterility*, 94(5), 1928–1932.
- Kingston, J., Chadwick, P., Meron, D., & Skinner, T. C. (2007). A pilot randomized control trial investigating the effect of mindfulness practice on pain tolerance, psychological well-being, and physiological activity. *Journal of Psychosomatic Research*, 62(3), 297–300.
- Kold, M., Vedsted-Hansen, H., & Hansen, T. (2011). Mindfulness som smertehåndteringsredskab for kvinder med endometriose. Et spirende koncept og en faktisk case. *Psyke & Logos*, 32(1), 170–188.
- Larauche, M., Gourcerol, G., Million, M., Adelson, D. W., & Taché, Y. (2010). Repeated psychological stress-induced alterations of visceral sensitivity and colonic motor functions in mice: influence of surgery and postoperative single housing on visceromotor responses. *Stress*, 13(4), 343–354.
- Low, W. Y., Edelmann, R. J., & Sutton, C. (1993). A psychological profile of endometriosis patients in comparison to patients with pelvic pain of other origins. *Journal of Psychosomatic Research*, 37(2), 111–116.
- Lutz, A., Greischar, L. L., Rawlings, N. B., Ricard, M., & Davidson, R. J. (2004). Long-term meditators self-induce high-amplitude gamma synchrony during mental practice. *Proceedings of the National Academy of Sciences of the United States of America*, 101(46), 16369–16373.
- Mehling, W. E., Hamel, K. A., Acree, M., Byl, N., & Hecht, F. M. (2005). Randomized, controlled trial of breath therapy for patients with chronic low-back pain. *Alternative Therapies in Health and Medicine*, 11(4), 44–52.
- Merskey, H., & Bogduk, N. (Eds.). (1994). *IASP Task Force on Taxonomy*. Seattle, WA: IASP Press.
- Mitchell, L. A., MacDonald, R. A. R., Knussen, C., & Serpell, M. G. (2007). A survey investigation of the effects of music listening on chronic pain. *Psychology of Music*, 35(1), 37–57.
- Morone, N. E., & Greco, C. M. (2007). Mind-body interventions for chronic pain in older adults: A structured review. *Pain Medicine*, 8(4), 359–375.
- Nunnink, S., & Meana, M. (2007). Remembering the pain: Accuracy of pain recall in endometriosis. *Journal of Psychosomatic Obstetrics & Gynecology*, 28(4), 201–208.
- Orme-Johnson, D. W., Schneider, R. H., Son, Y. D., Nidich, S., & Cho, Z. -H. (2006). Neuroimaging of meditation's effect on brain reactivity to pain. *Neuroreport: For Rapid Communication of Neuroscience Research*, 17(12), 1359–1363.
- Peveler, R., Edwards, J., Daddow, J., & Thomas, E. (1996). Psychosocial factors and chronic pelvic pain: A comparison of women with endometriosis and with unexplained pain. *Journal of Psychosomatic Research*, 40(3), 305–315.
- Poulin, E. M. (2000). *Living with endometriosis: Women's experiences with disease stressors, coping, and medical support*. Abstract of unpublished dissertation, ProQuest Information & Learning, United States.
- Selfe, S. A., Matthews, Z., & Stones, R. W. (1998). Factors influencing outcome in consultations for chronic pelvic pain. *Journal of Women's Health*, 7(8), 1041–1048.
- Siedliecki, S. L., & Good, M. (2006). Effect of music on power, pain, depression and disability. *Journal of Advanced Nursing*, 54(5), 553–562.
- Sierpina, V., Astin, J., & Giordano, J. (2007). Mind-body therapies for headache. *American Family Physician*, 76(10), 1518–1522.
- Snyder, M., & Chlan, L. (1999). Music therapy. *Annual Review of Nursing Research*, 17, 3–25.
- Van de Burgt, T. J., Hendriks, J. C., & Kluivers, K. B. (2011). Quality of life in endometriosis: Evaluation of the Dutch-version endometriosis health-profile 30 (EHP-30). *Fertility and Sterility*, 95(5), 1863–1865.
- Vercellini, P., Crosignani, P. G., Abbiati, A., Somigliana, E., Viganò, P., & Fedele, L. (2009a). The effect of surgery for symptomatic endometriosis: the other side of the story. *Human Reproduction Update*, 15(2), 177–188.

- Vercellini, P., Somigliana, E., Viganò, P., Abbiati, A., Barbara, G., & Crosignani, P. G. (2009b). Endometriosis. Current therapies and new pharmacological developments. *Drugs*, 69(6), 649–675.
- Vigano, P., Parazzini, F., Somigliana, E., & Vercellini, P. (2004). Endometriosis: Epidemiology and aetiological factors. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 18(2), 177–200.
- Ware, J. E. Jr (2000). SF-36 health survey update. *Spine*, 25(24), 3130–3139.
- Whelan, E. (2007). "No one agrees except for those of us who have it": Endometriosis patients as an epistemological community. *Sociology of Health & Illness*, 29(7), 957–982.
- Whiteside, J. L., & Falcone, T. (2003). Endometriosis-related pelvic pain: What is the evidence? *Clinical Obstetrics and Gynecology*, 46, 824–830.
- Zachariae, B. (1993). *Visualisering og helbredelse*. Copenhagen: Munksgaard.