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Long-term Effects of Mindfulness-Based Psychological Intervention for Coping with Pain in Endometriosis: A Six Year Follow-up on a Pilot Study

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Long-term Effects of Mindfulness-Based Psychological Intervention for Coping with Pain in Endometriosis: A Six Year Follow-up on a Pilot Study

Abstract (250 ord)

Objective: Development of chronic pain problems in endometriosis is frequent. Until now there has been no alternative treatment offer when medical and surgical treatment has been unhelpful in relieving the pain. The aim of this study was to evaluate the long-term effects of a mindfulness-based psychological intervention on chronic pain and quality of life in endometriosis when conducting a six year follow-up on a pilotstudy.

Materials and methods: In the original study, participants were recruited through Aarhus University Hospital and included ten women with diagnosed endometriosis and chronic pelvic pain. The women participated in 10 sessions of mindfulness-based psychological intervention. When contacted after 6 years all ten women agreed to participate in the follow-up study. Quality of life was measured by the endometriosis specific questionnaire EHP-30 and the generic form SF-36. **Results:** When comparing data from the 12 months follow-up with data from the six year follow-up, results showed no significant differences in mean scores on all scales of the EHP-30 and almost all scales of the SF-36 scale scores. The results indicate lasting improvement on almost all scales of the EHP-30 and the SF-36.

Conclusion: Although conclusions remain preliminary until tested in a randomized controlled trial, results presented in this article indicate that mindfulness-based psychological treatment of chronic pain seems very relevant to women with endometriosis with the potential to improve quality of life.

Keywords (3-6 stk): endometriosis, mindfulness, chronic pain, psychological intervention, quality of life

Introduction

Endometriosis is a chronic and painful gynecological disease defined as the presence of endometrium-like tissue elements outside the uterus, usually in the abdominal cavity. These elements cause bleeding, adhesions and inflammatory reactions with development of symptoms like cyclical and chronic pelvic pain, dyspareunia, pain at defecation and urination, constipation, diarrhea, abnormal bleeding, fertility problems and fatigue. Estimated prevalence among women of reproductive age is 5-10 % (Hansen, Kesmodel, Baldursson, Kold, & Forman, 2014; Viganò, Parazzini, Somigliana, & Vercellini, 2004). Despite a biological explanation of these symptoms endometriosis is often overlooked, and it is associated with a diagnostic delay of 7-9 years from symptoms onset to diagnosis and treatment (Hudelist et al., 2012; Husby, Haugen, & Moen, 2003; Nnoaham et al., 2011). Despite optimal treatment, development of chronic pain with the risk of reduced quality of life, work absence and job loss is frequent. Estimated socioeconomic costs in DK amount to more than 500 million EUR per year, and new intervention strategies are therefore needed (De Graaff et al., 2013; Hansen, Kesmodel, Baldursson, Schultz, & Forman, 2013; Lemaire, 2004; Simoens et al., 2012).

Mindfulness-based treatments seem to have a positive impact on quality of life in patients with other chronic pain syndromes (Garland et al., 2012; Garmon et al., 2014; la Cour & Petersen, 2015), but previous studies are limited by short follow-up periods, and the long-term effects of mindfulness-based interventions are unknown.

Mindfulness originates from Eastern traditions of meditation and is used in the West as a therapeutic and self-help tool to enhance physical and psychological well-being (Kabat-Zinn, 2013). From a treatment perspective mindfulness is conceptualized as a set of skills. The skills training approach suggests that with a regular praxis of different mindfulness exercises, people can learn to be more observant of inner experiences, describe them without reacting on or judging them and act with awareness in daily life. This will help people to be more acceptant of unpleasant inner experiences (Baer et al., 2008; Kabat-Zinn, Lipworth, & Burney, 1985).

In 2007 we performed an observational pilot study on mindfulness-based psychological intervention with a view to coping with endometriosis-related pain (Kold, Hansen, Vedsted-Hansen, & Forman, 2012). Health related quality of life was measured by the endometriosis specific questionnaire Endometriosis Health Profile 30 questionnaire (EHP-30) and the general questionnaire Short Form 36 (SF-36) before intervention, after intervention and at six and twelve months' follow-up. Repeated measures analysis showed significant improvements in four out of five standard scales of EHP-30: "pain", "control and powerlessness", "emotional well-being" and "social support". From the modular questionnaire two out of three scales showed significant improvements: "work-life" and "relationship with children. In according SF-36 showed significant improvements in all eight scales. The intervention thus seemed to improve short-term quality of life but the long-term effects are not known. The purpose of this study was therefore to perform a six-year follow-up of these patients before running a randomized controlled study.

Materials and methods

Participants and recruitment

In 2007, in the original study, ten participants were recruited at Aarhus University Hospital, which represents one of two national centers for treatment of severe endometriosis (Kold et al., 2012). Only patients with endometriosis and chronic pain despite treatment according to the European Society of Human Reproduction and Embryology (ESHRE) guidelines for endometriosis were included. Patients had to commit themselves to practice mental techniques at home and women unwilling to make this commitment were excluded. The ten participants were contacted by e-mail in 2013, six years after the intervention, for the purpose of participating in the follow-up study. After written consent self-administered questionnaires were sent out by postal mail, filled out at home and returned to the department.

Psychological intervention

The original study consisted of 10 sessions of mindfulness-based psychological intervention (five individual and five group sessions) over a period of 10 weeks. The intervention included mindfulness training, visualization techniques, counselling, group support and patient-education focusing on fatigue, quality of sleep, job, relationship- and family-issues etc. (Kold et al., 2012). The intervention has been fully described elsewhere.

Measurement

In both the original and the follow-up study health related quality of life was measured by EHP-30 and SF-36. The EHP-30 questionnaire has been shown to be more sensitive to change among women with endometriosis than SF-36 (Jones, Jenkinson, & Kennedy, 2004).

The patient generated questionnaire EHP-30 relates specifically to quality of life among women with endometriosis (Jones et al., 2004; Jones, Jenkinson, Taylor, Mills, & Kennedy, 2006; Jones, Kennedy, Barnard, Wong, & Jenkinson, 2001). It consists of a core questionnaire containing 30 items applicable to every woman with endometriosis. Supplementary questions only relevant to some women with endometriosis can be added by means of a modular questionnaire. The core questionnaire concerns the influence of endometriosis on daily life as categorized in five standard scales: "pain", "control and powerlessness", "emotional wellbeing", "social support" and "self-image". The modular questionnaire concerns the influence of endometriosis on "work life", "relationship with children", "sexual intercourse", "medical profession", "treatment" and "infertility".

SF-36 is widely used and measures health related quality of life in general (Bjorner, Damsgaard, Watt, & Groenvold, 1998; Bjorner, Thunedborg, Kristensen, Modvig, & Bech, 1998). It consists of eight subscales that represent important aspects of general health, including: "physical functioning", "role – physical", "bodily pain", "general health", "vitality", "social functioning", "role – emotional" and "mental health".

Together with EHP-30 and SF-36 participants answered some general questions and a retrospective transition question about their subjective judgment of changes in health status and

pain level from pre-intervention till today. Respondents could choose between five response categories: “much worse”, “worse”, “the same”, “better” or “much better”. The study also includes qualitative data on which techniques are used and how they are implemented in daily life.

The study was approved by the Danish Data Protection Agency (J.no. 2013-41-2607).

Statistical methods

EHP-30 and SF-36 scale scores are standardized on a range from 0-100. Better quality of life is indicated by lower scores for EHP-30 and higher scores for SF-36. Differences in scale scores were calculated by paired t-test. The level of statistical significance was set at $p < 0.05$ in all analyses. Statistical analysis was performed using SPSS version 21.

Results

All ten participants in the original study agreed to answer the follow-up questionnaires. At the six year follow up the women were between 33 and 68 years (mean = 48.00, standard deviation = 10.00). During the follow-up period one woman had entered natural menopause, three had had endometriosis lesions removed surgically, and two of these had had a hysterectomy.

Differences in EHP-30 scale scores

EHP-30 scores are presented in table 2. The modular scales “medical profession”, “treatment” and “infertility” were excluded from the analyses since only 1-3 of the participants found these aspects relevant.

Results showed that all significant improvements from the original study 12 months after the intervention (four out of five scales on the core questionnaire) remained during the following five years: “pain”, “control and powerlessness”, “emotional wellbeing” and “social support”. Also the modular scales “work life” and “relationship with children” indicated lasting improvement from twelve months’ follow-up till six years’ follow-up. All scales improved further during the twelve months’ to six years’ follow-up, but the improvement did not reach statistical significance.

Differences in SF-36 scale scores

SF-36 scores are presented in table 3. Results showed that significant improvements from the original study remained during the five year period from 12 months after the intervention. Improvements remained on all eight scales: “physical functioning”, “role – physical”, “bodily pain”, “general health”, “vitality”, “social functioning”, “role – emotional” and “mental health”. In addition the scale “social functioning” improved significantly during the five year period from 12 months follow-up.

Use of mindfulness techniques and quality of life today

Six years after completed intervention, nine out of ten still used the mindfulness-techniques and other mental techniques learned during the intervention. Seven of these nine women experienced benefits from these techniques to a great or very great extent.

The body scan and breathing meditation were the most used mindfulness techniques among the women at follow-up (table 4). Body scan was often used for dealing with pain and problems falling asleep. Some women used the technique almost every night. The breathing meditation was primarily used for pain relief during the day both at home and at work.

One participant wrote “I use the body scan when I am in pain and when I go to sleep. The course has helped me to a great extent also the day today.” Another participant wrote “When I am sleepless I lie on the back and I do a body scan. I use this technique almost every day. The breathing techniques have been the most helpful techniques. They are a major help in my everyday life. In the beginning it was difficult, but now I just do it. All in all the course has been very useful to me”. A third participant wrote “Breathing meditation helps me relax my abdomen”, and a fourth wrote “I use the body scan and breathing meditation when in pain during menstruation or at bed time together with meditation music. This helps me endure the pain and makes it go away faster – and I sleep better.”

The patient’s subjective judgment of quality of life six years after completed intervention compared to pre-intervention levels was a better or much better quality of life in all cases, and eight of ten participants also experienced a better or much improved pain level (table 4).

Discussion

This pilot series represents the first data on the potential long term effects of mindfulness-based psychological intervention for chronic pain in endometriosis. With reservation for the weaknesses, our results may suggest a lasting positive effect on health related quality of life of women with endometriosis six years after the end of treatment.

The patient generated questionnaire EHP-30 represents different life-areas affected by endometriosis and endometriosis-related pain. Together these life-areas comprise a measure of the quality of life in women with endometriosis. These life-areas include daily activities, work-life, relationship with children, sexual activity, social relationships, emotional wellbeing, self-image and the feeling of control or powerlessness in one’s life. Detailed results of the EHP-30 questionnaire suggested that mindfulness-based psychological treatment could have lasting positive effects on these life areas except for “sexual activity” and “self-image” in women with endometriosis-related chronic pelvic pain. The “self-image” scale improved during the study- and follow-up period, but the difference was not significant.

Also results of SF-36 suggested that mindfulness-based psychological intervention could have lasting positive effects on general health-related quality of life. A lasting effect was found on all scales of SF-36 and in addition we found another significant improvement in “social functioning” during the time from 12 month follow-up till six years follow-up. There is a possibility that this continued improvement in social functioning could be the result of continued mindfulness-training, where the patient learns to accept the pain and live with it. She could have learned to be present without letting the pain get in her way, and if accepting the pain she would possibly find it

easier to talk about. Hence, endometriosis will not have that much of an influence of her social relations anymore. It could also be due to the fact that people learn to live with chronic conditions along the way.

We actually observed a small continued improvement of the quality of life in all endometriosis-specific scales and almost all general scales in the period from 12 months follow-up till six years follow-up, but the differences were not significant.

Unfortunately our study did not include a control group and the sample is very small. However patients included had chronic pain despite previous medical and surgical treatment, probably due to persistent changes in the peripheral and central nervous system (Stratton & Berkley, 2011). Three cases had repeat surgery during the follow-up period, but available data indicate that pain recurrence is frequent in such cases (Vercellini et al., 2009). Only one had entered the menopause during the follow-up period, and decreased ovarian function did not seem to play a major role for the persistent improvement in quality of life seen in our study.

Continuing improvements in quality of life during the period after the end of mindfulness-based psychological treatment could to some extent be facilitated by the mindfulness treatment in which the goal is to learn to observe and describe the pain without evaluation or judgement of the pain and without reacting on the inner experience. The purpose is to learn to accept the pain and live life in a valuable way despite the pain. Learning mindfulness techniques could make the woman independent of her practitioner, because she can continue the praxis on her own and in time get more and more experienced. This is supported by the qualitative data in which the women describe what techniques they use and how they implement them in their daily lives. Also the quantitative data suggest that nine out of the ten women still uses the mindfulness techniques learned during the treatment period at six years follow-up. Seven of them experienced a great or very great extent of benefits from the techniques, which could suggest that independent, continuous use of mindfulness is realistic and feasible.

When comparing the women's own subjective evaluation of their quality of life and the more objective measurements by EHP-30 and SF-36 from pre-intervention till six years follow-up, there seems to be consistence between the results. On the contrary some women have evaluated the difference in quality of life higher than the difference in pain level from pre-intervention till six years follow-up. The reason that some women experience higher quality of life despite some persistent pain could come from a mindfulness facilitated change in acceptance of the pain or a change in the pain experience. Pain is defined as "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (International Association for the Study of Pain) (Merskey & Bogduk, 1994, pp. 209-214). One could envisage that the difference is due to a change in the quality of the pain in which the emotional aspect or the unpleasantness of the pain more than the sensory aspect or the intensity of the pain has changed. Since the study is limited by the absence of a control condition, we do not know if a change would have happened spontaneously anyway.

Many former articles have described the situation of women with endometriosis and the negative consequences of the disease. These include a diagnostic delay of 5-7 years, a feeling of being

ignored and stigmatized, reduced quality of life and work ability and billions in socio-economic costs every year due to loss of work ability and health care costs. So far research in the treatment of endometriosis has focused on medical and surgical treatment, but new strategies for rehabilitation of these patients such as mindfulness-based psychological pain treatment might imply both significant benefits to the patients as well as savings in the healthcare system. This study was limited by a small study-group, the lack of a placebo control group and a lack of a standardized pain measure. Future studies should focus on including more participants in a randomized placebo-controlled study including data on endometriosis-specific pain symptoms measured by standardized pain scores.

Despite the limitations the study suggests that this treatment could have potential benefits for women suffering from endometriosis related chronic pelvic pain.

Conclusion

Although conclusions remain preliminary until tested in a randomized controlled trial, the results presented in this article suggests that mindfulness-based psychological treatment of chronic pain seems relevant to women with endometriosis with the potential to improve quality of life.

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Table 1 Symptoms and endometriosis treatment of participants in the period from pre-intervention till six years follow-up.

	Pre- intervention N = 10	The time period between post-intervention till six years follow-up N = 10	Six years' follow-up N = 10
Symptoms because of endometriosis in the past 4 weeks			
Abdominal pain	8	-	5
Nausea or vomiting	3	-	4
Tiredness	10	-	7
Pain at urination	3	-	2
Pain at defecation	7	-	5
Constipation or diarrhea	8	-	7
Irregular bleeding	1	-	0
Menstruation pain	3	-	1
Have entered natural menopause			
Yes	2	-	3
No	8	-	7
Treatment for endometriosis			
Operation removing endometriosis lesions	-	3	-
Operation removing uterus	-	2	-
Operation removing ovaries	-	0	-
Hormonal treatment	-	5	3
Medical pain treatment	-	6	5
Physical treatment	-	4	1
Psychotherapeutic treatment	-	1	0
Alternative treatments	-	2	1
Pain Clinic	-	1	0
No treatment	-	1	3

Table 2. The difference in EHP-30 scale scores from 12 months' follow-up (T4) till six years' follow-up (T5).

	T1		T4		T5		T4 - T5	
	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	95 % CI	P-value
EHP-30 scales								
Pain	9	52,53 (12,52)	10	28,18 (15,9)	10	24,55 (11,97)	-10,83 – 18,1	0,583
Control and powerlessness	9	65,28 (18,98)	10	35,42 (22,5)	10	31,67 (14,46)	-12,24 – 19,74	0,609
Emotional Wellbeing	10	52,08 (16,23)	10	34,17 (19,02)	10	29,17 (16,2)	-8,09 – 18,09	0,41
Social support	10	52,50 (25,89)	10	31,88 (20,72)	10	25,63 (14,86)	-10,87 – 23,37	0,430
Self-image	10	41,67 (21,52)	10	30,00 (22,64)	10	25,00 (15,21)	-11,91 – 21,91	0,52
Work-life^a	7	47,86 (29,94)	4	13,75 (13,15)	4	3,75 (4,79)	-15,16 – 35,16	0,295
Relationship with children^a	7	46,43 (22,49)	7	12,50 (19,09)	7	5,36 (9,83)	-14,84 – 29,14	0,457
Sexual intercourse^a	9	66,67 (12,82)	8	59,79 (29,12)	8	58,13 (32,40)	-22,85 – 26,19	0,877
<p>^a = only patients who found answering the modular scale relevant at both measuring times were included in the analysis T1 = pre-intervention SD = standard deviation Lower means indicate better quality of life</p>								

Table 3. *The difference in SF-36 scale scores from 12 months' follow-up (T4) till six years' follow-up (T5).*

SF-36 scales	T1		T4		T5		T4 - T5	
	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	95 % CI	P-value
Physical functioning	10	69.50 (14.80)	10	82.50 (12.96)	10	78.50 (16.68)	-12.07 – 20.01	0.587
Role – physical	10	15.00 (21.08)	10	50.00 (39.09)	10	60.00 (35.75)	-45.97 – 25.97	0.545
Bodily pain	10	31.30 (14.39)	10	57.80 (12.52)	10	59.10 (24.96)	-22.82 – 20.22	0.894
General health	10	36.10 (14.08)	10	55.40 (22.25)	10	56.40 (20.35)	-12.45 – 10.45	0.848
Vitality	10	27.50 (17.83)	10	49.00 (20.11)	10	55.50 (24.55)	-23.28 – 10.28	0.404
Social functioning	10	47.50 (24.86)	10	70.00 (26.48)	10	83.75 (18.68)	-26.00 – (-1.50)	0.032
Role – emotional	10	23.33 (35.31)	10	50.00 (42.31)	10	76.67 (35.31)	-65.28 – 11.95	0.153
Mental health	10	59.20 (22.69)	10	69.60 (20.76)	10	75.60 (9.13)	-18.08 – 6.08	0.290
T1 = pre-intervention SD = standard deviation Higher means indicate better quality of life								

Table 4 Use of mindfulness techniques, benefits, quality of life and pain level of participants at six years' follow-up.

	Participants N = 10
Are you still using the mindfulness techniques learned at the intervention today?	
Yes	9
No	1
What mindfulness techniques are you using today?^a	
Bodyscan	5
Breathing meditation	6
Yoga	1
Mindful walking	1
Mindful music	3
Own meditation	1
To what extent do you benefit from these techniques today?^a	
No benefits	0
To a lesser extent	1
To some extent	1
To a greater extent	4
To a very great extent	3
How do you experience your general quality of life today compared with the time before the intervention?	
Much worse	0
Worse	0
The same	0
Better	5
Much better	5
How do you experience your general pain level today compared with the time before the intervention?	
Much worse	0
Worse	0
The same	2
Better	3
Much better	5

^a N = 9