

About me as a person not only the disease – piloting Guided Self-Determination in an outpatient endometriosis setting

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Introduction: Endometriosis is a chronic disease affecting 5–10% of women in the reproductive age. Despite surgical and medical treatment, many women struggle with pain, infertility, sexual dysfunction, depression, distress and reduced workability, affecting their overall quality of life. The usual follow-up procedures may not support the women's self-management of this condition. Therefore, person-centred empowerment-based approaches are needed.

Aim: To assess if the implementation of the Guided Self-Determination method targeted women with complex endometriosis appeared feasible and supported self-management.

Methods: Guided Self-Determination was offered to 10 out-patients with complex endometriosis. Each of the women had five conversations based on prefilled disease-specific reflection sheets. A qualitative evaluation was conducted in 2016–2017 covering semi-structured, telephone interviews and focus group interviews, which were analysed using thematic analysis. Additionally, we assessed if the women changed the self-reported

questionnaires, Endometriosis Health Profile 30 and the Patient Activation Measure from before and after the conversations.

Results: We identified four themes: feeling alone with the disease; establishing a meaningful relationship with healthcare professionals in a traditional hospital setting; person-specific knowledge facilitated new behaviours and; accepting a chronic condition – the beginning of a process. All dimensions of the Endometriosis Health Profile 30 and the Patient Activation Measure appeared to improve at two weeks and so did almost all the dimensions of Endometriosis Health Profile 30 after 1 year.

Conclusions: The implementation of the Guided Self-Determination method appeared feasible and the women developed self-management skills in relation to endometriosis and its symptoms. This was achieved by increasing insight into their needs and behaviours and gaining new knowledge about the disease itself. The before-and-after assessment suggested benefit of the intervention, but this should be further tested in a randomised trial.

Keywords: endometriosis, empowerment, self-management, nurse-led intervention, guided self-determination, life skills, follow-up, outpatient clinic.

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Introduction

Endometriosis is a gynaecological disease defined by the presence of endometrial-like tissue outside the uterus causing chronic inflammation (1). The prevalence is estimated to be about 5–10% of the general female

population of reproductive age but is much higher in women with infertility and chronic pelvic pain (2). Women with endometriosis experience a broad spectrum of symptoms including pelvic pain, dysmenorrhoea and dyspareunia (1). Sexual dysfunction is described as a multidimensional phenomenon which is associated with but not limited to deep dyspareunia and thus can have a great impact on those suffering from endometriosis (3). Women may also experience fatigue (4) psychological challenges (5) and psychopathological comorbidities such as somatisation, anxiety, sensitivity and depression (6–8)

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all of which can negatively impact their quality of life (QOL) (9,10), sleep, perceived stress (10) and perception of pain (7). Altogether endometriosis affects education and workability (5) with direct and indirect socio-economic costs (7,9).

The primary purpose of endometriosis treatment is to reduce pain and has traditionally focused on surgical and medical treatment. Even though these treatment options have been shown to reduce pain, women often still struggle with pain which ultimately affects their QOL (9,11). A Norwegian study reported that women with moderate to severe endometriosis had poorer mental HRQOL as compared to women with rheumatoid arthritis (12). Therefore, it is important to address psychosocial symptoms alongside physical symptoms. Usual follow-up procedures following treatment appear not to support the women's self-management of the condition. Therefore, person-centred interventions are needed to address all the aspects of women's lives suffering endometriosis and simultaneously support their self-management skills in relation to persisting symptoms. Searching the literature, we have not found such interventions.

In this study, we apply a person-centred empowerment-based method, 'Guided Self-Determination' (GSD), which was developed in diabetes care (13–16). It includes patient reflection sheets and conversations with health-care professionals (HCPs). It has successfully been transferred to other patient groups including parents to premature children (17), patients in dialysis (18) and patients with schizophrenia (19,20) and cancer (21,22). In diabetes, GSD improved glycemic control (23) and has reduced disease-related distress (24). Qualitative evaluations in the diabetes and dialysis settings have shown GSD to be a useful person-centred problem-solving tool that facilitates the development of life skills (18,25). In a nurse-led stepped-care intervention, GSD improved physical QOL (22) and the development of relational competencies and problem-solving skills in gynaecological cancer survivors (26).

In this study, we aimed to assess if the implementation of GSD was feasible in an outpatient setting treating endometriosis and if and how GSD impacted on the women's self-management of the disease. Additionally, we assessed changes in self-reported endometriosis-specific health-related quality of life (HRQOL) and confidence in managing health and care.

Methods

Design

We used both qualitative and quantitative methods. Thematic analysis was conducted according to Braun and Clarke (27) on data from semi-structured individual and focus group interviews to gain knowledge of the

women's experience of GSD targeted at women with endometriosis (GSD-endo). These were supplemented with before-and-after assessment on the self-reported measurements, Endometriosis Health Profile 30 (EHP-30) (28,29) and the Patient Activation Measure (PAM) (30).

Participants

From January 2016 to April 2017, women with endometriosis were invited to participate if they indicated complex symptoms by marking at least two of six questions in a short endometriosis screening tool developed for the study (Table 1). Development was inspired by the questionnaires SF 36 (31) and EHP 30 (28,29).

Additional inclusion criteria were age 18 years or above; pre-menopausal; diagnosed with endometriosis (histology) at least 4 months ago but not more than 10 years ago; and the ability to read and write in Danish. Exclusion criteria were participation in a prior GSD-endo pilot study; pregnancy or fertility treatment; pain due to other conditions; and psychological conditions including cognitive or psychiatric impairment, alcohol or drug abuse and surgery planned within the next year. After verbal and written information, women signed a written informed consent form to participate and answered the baseline questionnaires (Fig. 1) after which they were mailed the preparatory reflection sheets for the first conversation.

Fourteen women initially agreed to participate; however, four never received the intervention due to the following reasons: one became pregnant; one became divorced; one lived too far away; and one provided no reason for nonparticipation, leaving 10 participants to receive the intervention.

The intervention GSD

Guided Self-Determination supports reflection, collaboration and changes in the patients' lives facilitated by the development of life skills in dealing with the disease (18,25). Life skills are a comprehensive concept defined as: 'Those personal, social, cognitive and physical skills that enable a person to control and direct their lives and

Table 1 Screening questions

1	Are you worried about what the endometriosis will cause in the future?
2	Do you feel limited in your daily life due to endometriosis?
3	Does endometriosis keep you from doing things in your daily life?
4	Do you consider your quality of your life affected due to endometriosis?
5	Have you experienced pain due to your endometriosis within the past 4 weeks?
6	Do you feel more tired than your peers?

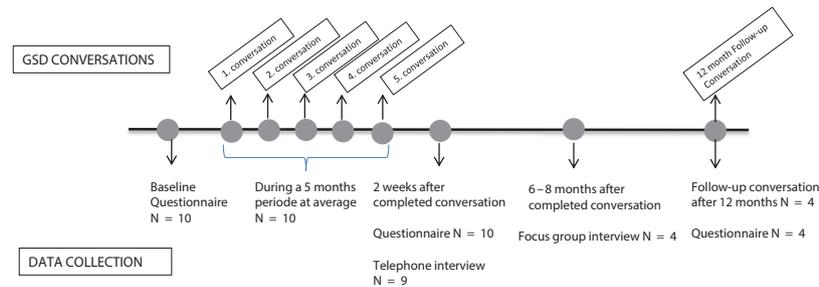


Figure 1 Overview of the intervention and the data collection.

develop the capacity to live with and produce change in their environment' (32).

The main features of GSD include preparatory semi-structured reflection sheets and conversations with an HCP certified in GSD. Different reflection sheets were completed by the patients before face-to-face conversations with the HCP. The sheets facilitate reflection and self-insight helping the patients to acknowledge and express their own specific needs, values and resources. The prefilled sheets constitute the starting point for face-to-face conversations, and during these, the patient and the HCP together create a common knowledge that provides the basis for further problem-solving of the issues that the patient considered to be particularly important in accordance with their values and needs.

Our study builds on a previously piloted GSD-endo study (unpublished, presented at the 11th World Congress on Endometriosis, 2011). In our study, a total of 20 disease-specific reflection sheets were used in five conversations. In addition, four women received a one-year follow-up conversation as a test. They were the first to complete the GSD course, and therefore, they participated in a focus group interview in which they suggested the follow-up conversation.

GSD certified nurses

Nurses were educated during a four-day course including theoretical and practical training with a final test. In this study, GSD-endo was facilitated by three nurses, who had at least 20 years of gynaecological experience, all employed at the Gynecological Outpatient Clinic at the Copenhagen University Hospital, Rigshospitalet. In addition to the certification in GSD, they received two group supervisions with a psychologist covering their experience with GSD and discussion about when to refer to a psychologist.

Interviews

Nine women were interviewed two weeks after the last conversation; one was not interviewed due to referral to

a psychologist. The individual interviews lasted 25–35 minutes and aimed to capture the women's immediate experience of GSD-endo and the feasibility of the intervention while the conversations were still remembered. The first question was: *Why did you choose to participate in the pilot study?* Thereafter, the focus was on four areas: *how they experienced the reflection sheets; the conversations with the nurse; GSD's contribution to the development of life skills; and the overall organisation of GSD-endo conversations.* After 8 months, a 50-minute focus group interview was conducted with four women to gain various perspectives on GSD and to assess the long-term durability of any changes. Knowledge from the single telephone interviews qualified the questions in the focus group interview guide. The patient trajectory and time points for data collection are presented in Fig. 1.

Analysis of interviews

Data from the two kinds of interviews were initially analysed separately but it became clear that the findings integrated and complemented each other. Therefore, we decided to analyse them together. We used thematic analysis (27) which was applied as a hybrid of inductive and deductive analysis. The inductive part considered how women with endometriosis experienced living with the disease and receiving GSD-endo. The deductive part referred to whether the women, like in previous qualitative evaluations of GSD, developed life skills enabling them to self-manage their disease in daily life.

The thematic analysis was carried out by three of the investigators (SMS, CS, MLO) in six phases: first, the transcribed interviews were read multiple times to become familiar with data; second, initial ideas about codes were noted; third, the interviews were coded independently by each investigator into codes and possible overall themes and discussed; fourth, codes and overall themes and their potential inter-relationship were visualised in several mind maps and were discussed; fifth, a consensus was reached on codes which were named and defined; and sixth, findings were reported in this article.

Questionnaires

Questionnaires were collected at three different time points: after informed consent at baseline (n = 10), two weeks after the last conversation (n = 10) and after one year (n = 4) to assess potential changes short term and long term in this particular patient group.

EHP-30. The EHP questionnaire is disease-specific and designed to measure the women's experience of their HRQOL regarding endometriosis. We used the long-form core instrument EHP-30 (28,29), which covers pain, control and powerlessness, emotional well-being, social support and self-image dimensions. Answers were given on a five-point Likert scale, and each dimension was calculated on a scale from 0 to 100 where 0 is the best possible health status and 100 is the worst. We were granted permission to use the Danish validated version by Isis Innovation Limited (www.isis-innovation.com).

PAM. The PAM measures the women's knowledge, skills and confidence in managing health and care (30). Based on their answers, they obtained a PAM score between 0 and 100 which classified the women on one of four levels of activation from being passive and overwhelmed at level 1 to having adopted behaviours to support their health though still being struggling to maintain them because of life stressors on level 4. A license was obtained to use the Danish validated version from Insignia Health (www.insigniahealth.com).

Data were entered into the software program Excel, and descriptive statistics were calculated according to the guidelines of the various scales including scores, medians, interquartile ranges and median changes.

Results

Baseline characteristics of the 10 participating women are shown in Table 2.

Table 2 Characteristics of participants

Women	Age	Number of births	Endometriosis stage based on ASRM score	Number of prior surgeries
1	25–30	0	2	2
2	35–40	0	4	1
3	20–25	0	1	1
4	40–45	0	3	2
5	25–30	0	4	1
6	25–30	2	2	4
7	30–35	0	4	1
8	40–45	2	4	1
9	35–40	0	4	3
10	25–30	0	4	8

The analysis generated four themes as shown in Table 3. The women experienced many challenges and felt lonely in dealing with the disease. GSD-endo became the turning point for a process where they developed life skills improving their ability to self-manage the disease in daily life. In the following, we describe the themes in detail.

Feeling alone with the disease

In the single interviews, all the women expressed that their motivation for participating was a feeling of loneliness. They described, trying different methods to receive help with their condition but had not succeeded in getting what they needed 'I had no life left in me, physically, mentally or socially. My illness continually consumed everything (Woman 7)'. They had several worries regarding fertility, sexuality, their relationship to their partner and having to take sick leave due to pain. The usual follow-up had not fulfilled their needs.

The women expressed that they did not share their problems with others because they felt that nobody understood 'I have never talked about my illness with anyone (Woman 8)'. A barrier for others to understand the disease and the related pain was that it was invisible 'There are many who say: 'You do not look like someone who has such a pain' but that is because I am used to having pain every day (Woman 5)'.

Establishing a meaningful relationship with HCPs in a traditional hospital setting

The women appreciated being invited to evaluate the new empowerment-based approach in the outpatient

Table 3 Themes and subthemes

Themes	Subthemes
Feeling alone with the disease	Not knowing what to do Difficult to explain to others Worried about the future Reduced expectations to the HCPs
Establishing a meaningful relationship with HCPs in a traditional hospital setting	Equality Different expectations to the HCPs Seen as a person A feeling of being acknowledged Increasing trust
Person-specific knowledge facilitated new behaviours	Gaining insight into themselves and their previous behaviour Gaining knowledge about the disease and treatment Developing life skills in relation to endometrioses
Accepting a chronic condition – the beginning of a process	Not feeling abnormal anymore Increased self-confidence Increased quality of life In short term and long term

clinic that normally represented a biomedical approach to them. They experienced that the GSD-endo conversations differed from the dialog they usually had with professionals 'It has been very different from other conversations. I have gotten more in-depth answers and much deeper talks (Woman 4)'. They pointed out that these conversations were focused on their personal needs and preferences. They experienced it was an advantage that the nurses had both communicative competences, disease-specific knowledge and time for conversations was prioritised 'Nice that it [the GSD conversations] was held in the outpatient clinic and good that the outpatient clinic also created something good and positive because the visits usually caused something negative and frustrating (Woman 1)'.

During the GSD-endo conversations, the women expressed having a more equal dialog with the nurses than normally and they also began to have new expectations to the collaboration with all the HCPs in the multidisciplinary endometriosis team. 'It has been exciting and rewarding. I didn't expect to gain so much from this. It made so much sense to me and the outcome has been good in terms of the future and myself (Woman 1)'.

They described that the prefilled reflection sheets offered structure and reflection. It helped them to organise their thoughts and challenges and prepared them for the conversations 'Words put on the sheets helped to prepare and set structure and direction (Woman 6)'. This preparation provided insight into challenges and actions in relation to their disease which they were previously not aware of. The new insight led to a deeper and more focused subsequent conversation 'the sheets helped to get around difficult things (Woman 3)'. They experienced that the GSD-endo conversations had a positive focus on what they could do to manage the disease themselves 'I have learned more about myself. It is okay to ask for help and I have greater care for myself' (Woman 3).

They appreciated the focus on their whole life situation with endometriosis 'I was seen as a person. It was about me and not just about the disease (Woman 10)'. They emphasised that a prerequisite for the conversations was mutual trust enabling them to share intimate concerns and dare to talk about things that they found were difficult. 'The nurse had the knowledge and understood... I felt very safe. I am usually very cautious and quiet, and I don't simply talk to others (Woman 9)'. They also appreciated the time for GSD-endo conversations 'During these conversations there was time and 100% focus (Woman 6)'.

Person-specific knowledge facilitated new behaviours

The women gained new disease-specific knowledge about endometriosis, treatment and symptoms as well as personal knowledge about themselves and their way of managing endometriosis in daily life. 'I have become

more aware of my thinking patterns. When I get sad and frustrated, I can better understand it and I have a better insight (Woman 1)'. The new personal knowledge made it easier to deal with the symptoms.

It has given me more knowledge, and my boyfriend also knows more now because we can talk about things based on the sheets. It's the same at work, because I'm more open and can tell them more about it (Woman 3).

Their personal knowledge was obtained by awareness and insight into their previous way of thinking and dealing with the disease, and they developed a more positive mindset. New actions and behaviours were described which provided the women with a sense of being in control.

I have gotten new and better thinking patterns and a more positive view. I have become better at taking pain medication and dare to connect my disease to my emotions. I have obtained tools for problem-solving. I still have the same emotions, but they are easier to handle (Woman 5).

They received support to change inappropriate ways in which they had previously managed the disease: 'I took pain medications – both Dolol and Oxycontin. I have now been drugfree for a month and a half and only take medicine when needed. The nurse believed in me and was certain that I could get off the pain relief medication... we fought together (Woman 9)'.

It was a common theme that they became better at communicating needs. They began to explain endometriosis and their challenges to friends, family and colleagues: 'I ask for help, and they [GSD-endo conversations] have helped me with being more open to everyone. My work [colleagues] had no knowledge about the disease, and therefore I have been able to educate them about it. I realized that it is about me (Woman 3)'.

Accepting a chronic condition – the beginning of a process

The women became better at prioritising which problems to address and solve and accepting that not all could be solved 'I have gained greater acceptance [after the GSD conversations] and I'm in a process of gaining complete acceptance (Woman 3)'. They started to accept living with endometriosis and the inescapable and persistent symptoms. 'I have gained a much greater emotional acceptance of the disease. I want to be healthier and I found out that I need to accept my body. I have gone from frustrations to actions (Woman 5)'.

This process of acceptance seemed to be initiated by the knowledge about their reactions and the new disease-specific knowledge 'I've got a lot out of talking to someone who has a lot of knowledge and understanding of my illness and the sheets have supported me to think deeper about things (Woman 4)'. They realised that they

were not alone, and their challenges were common to other women with endometriosis too. This introduced an experience of being normal which contrasted a previous feeling of being abnormal. 'I have always felt very abnormal but at the conversations it [her situation and behavior] was normalized and I gained tools and methods to explain the disease at home (Woman 1)'.

The focus group interview including four women six to eight months after the GSD conversations revealed that the new approaches to the disease and the acceptance of their situation were still maintained. 'My whole quality of life has improved. And I still have cysts on my intestines and daily pain, so it [the disease] is not ... so to say... much better. But something has happened to me and my handling of the disease has changed my life radically (Woman 1)'. Another woman describes 'I am at peace with myself and I am at peace with my illness (Woman 5)'.

Structure and organisation of GSD conversations

Because we aimed to assess if the GSD was feasible for implementation in our clinical practice, the women were asked about the overall organisation of the conversations. They found five conversations suitable but suggested two to four weeks between them would have provided time for reflection. One hour was the optimal length to get into the depths of the problems, and an undisturbed setting was valued. It was important for trust and openness that the same nurse facilitated all conversations. Most women did not care whether the nurse was dressed in uniform or not. It was suggested that the number of conversations could be individualised in the future based on needs. The four women who participated in the focus group interview would appreciate a long-term follow-up conversation one year after the GSD standard course (five conversations).

Quantitative results – questionnaires

EHP 30. Results of the EHP 30 questionnaires are presented in Table 4 and Fig. 2. In general, all dimensions appeared to improve from baseline to 2 weeks after the last GSD conversation, and in an overall perspective, this appeared to be maintained after 12 months except for the dimension 'Self-image'.

PAM. The results from the PAM questionnaire are presented in Table 4. The median delta change was one level in a positive direction after two weeks suggesting an increased ability in the women's knowledge, skills and confidence in managing own health. However, four out of the ten women had the same scores at level one before and after the GSD-endo conversations. After 12 months (data not shown), two out of the four women

continued to score level one before and after the conversations. After 12 months, the delta change was only 0.5.

Discussion

This combined qualitative and quantitative study provides important results from a newly developed empowerment-based intervention, GSD-endo, for women suffering from complex endometriosis. Research in caring for this patient group is sparse, and the women are known to have unmet needs (33). The thematic analysis provided detailed information about changes in the women's reaction to the condition enabled by GSD-endo: becoming less lonely with the condition, establishing a meaningful relationship with HCPs, gaining personal and disease-specific knowledge that facilitated new behaviours and initiated a process of acceptance. A quantitative inventory suggested that EHP-30 identified changes among the women which did not seem to be just as convincing for PAM.

The fact that the women felt isolated and alone with endometriosis was also found in a narrative review on the social and psychological impact of living with endometriosis (5), where some women reported to be reluctant to talk to others about their situation. Loneliness has been described due to lack of acceptance from partners (34). The women in our study had worries in relation to fertility, sexuality, partner and workability. Emotional distress was also a pervasive theme in the review by Cully et al. (5). Further, 'uncertainty' was found to impact on the women's lives both pre- and post-diagnosis due to uncertainty in relation to diagnostic delay, 'symptomatic uncertainty' due to the variability of symptoms and 'trajectory uncertainty' related to the future especially regarding fertility (5).

Not receiving support from the healthcare system was reported in a qualitative study where the women mostly highlighted negative experiences with HCPs who did not

Table 4 EHP 30 and PAM scores at baseline and 2 weeks after the last conversation (medians, interquartile ranges and median changes)

	Baseline (N = 10)	Two weeks after last conversations (N = 10)	Median change
EHP 30*			
Pain	55 (49–60)	41 (40–51)	–14
Control and powerlessness	73 (68–82)	54 (47–73)	–19
Emotional well-being	60 (45–69)	44 (39–52)	–17
Social support	78 (66–88)	56 (42–72)	–22
Self-image	67 (54–75)	42 (35–50)	–25
PAM	1 (1–1.75)	2 (1–2.75)	+1

*All EHP 30 values are rounded up to nearest whole number.

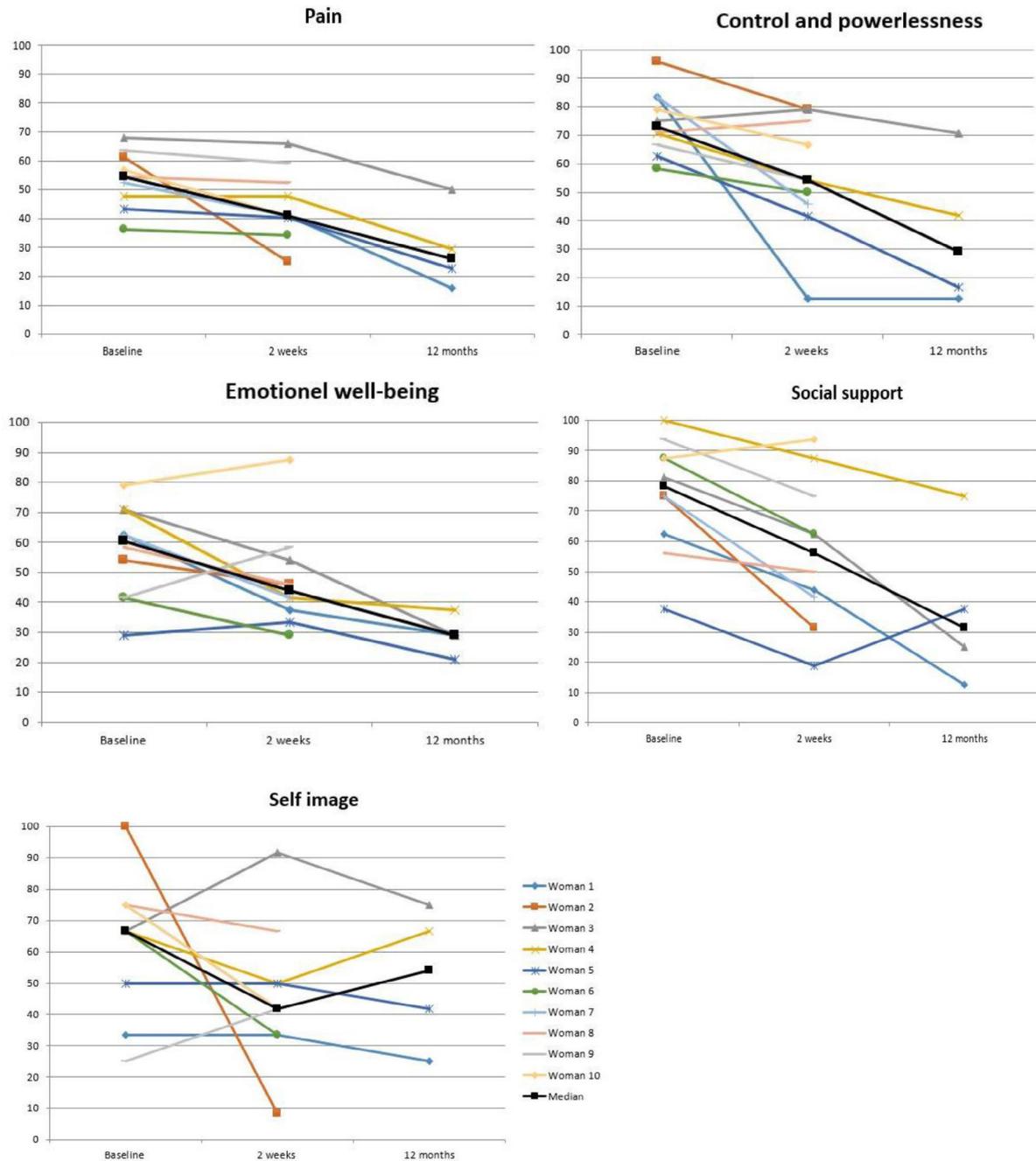


Figure 2 EHP dimensions at baseline, 2 weeks and 12 months for each participant.

prioritise their concerns or took them seriously (35). A recent Swedish study found women’s encounters with HCP’s of mixed character comprising experiences of confidence and understanding but also mistrust and humiliation (36). A qualitative study of clinicians’ perceptions of women’s experiences with endometriosis and of psychosocial care for this group found that most clinicians assessed themselves not adequately trained to understand and provide psychosocial care for this group and many found it not necessary to do so (37).

A key to action seemed to be the new personal knowledge provided by the women’s insight into previous behaviour regarding the disease gained through the preparatory GSD-endo sheets and the following conversations. Person-centred interventions with a holistic approach have been requested to support this group in handling the negative social and psychological impact of endometriosis and its treatment (5). Patient-centred endometriosis care and especially areas such as ‘continuity’, ‘respect’ and ‘information’ has been associated with

better HRQOL (38). Previously, it has been stated that in particular nurses are well-suited to deliver appropriate care to this group (39). Even though this statement was presented more than 10 years ago, it is still relevant today. We believe that supporting women's abilities to cope with endometriosis and enabling integration of life and disease, based on personal values and preferences, remain key tasks for nurses. Positive coping strategies focusing on the problem or on emotions in relation to endometriosis were in a recent review found to be associated with better mental health (40).

A recent study stated information, communication and education to be important areas in patient-centred endometriosis care (41). Our findings support disease and person-specific education to be an important empowering factor and necessary for the women to self-manage their condition. In our study, the women gained personal and disease-specific knowledge which in turn enabled them to articulate their challenges to HCPs, family members and colleagues, which was found to be an important empowering process. The women described gaining control during the GSD conversations which is in line with the overall purpose of GSD. The method was developed to support an empowerment process in which patients develop life skills enabling them to self-manage their disease in daily life (16). The women describe many examples of newly developed skills such as, being able to prioritise between problems, gaining the ability to communicate difficult feelings, increasing acceptance and developing their problem-solving skills. The latter was also an important outcome of GSD targeted women with gynaecological cancer (26).

Research in Self-Determination Theory has found that humans have three innate psychological needs: competence, autonomy and being able to create relationships with others. Thus, satisfaction of these needs leads to enhanced mental health and self-motivation (42). The women in our study described GSD-endo to enhance their sense of autonomy by addressing their individual needs. They developed life skills enabling them to relate to their significant others, and due to insight and education, they increased their own competence in handling the disease. Taken together, GSD-endo supported all three innate needs and increased the women's mental health and self-motivated problem-solving strategies.

Our findings indicate that GSD is a feasible method in providing person-centred support for out-patients with endometriosis but needs further testing in a randomised trial. In this pilot study, GSD empowered the women by facilitating the development of life skills. To our best knowledge, many methods exist that address elements of personal goal setting, shared decision-making and targeted support of frail individuals. But none of these combines theories and practice like GSD. GSD is unique because of the person-centred approach and, at the same

time, impact on HCP's mindset and understanding of the patient's individual needs.

Multidisciplinary approaches have been described as mandatory to reduce the impact of the endometriosis on QOL and sexual function (43). Our study indicates that nurses play a more active role in the team when they apply GSD to support women with complex endometriosis to cope with symptoms such as pain which is associated with reduced QOL, anxiety and depression (7).

This is in line with the before-and-after assessment especially on HRQOL (EHP 30) suggesting benefits of GSD-endo; however, this should be confirmed by a randomised trial. The EHP-30 scores in our study are in general higher (worse) than in an American cross-sectional study (44) probably because the women in our study were screened to have complex endometriosis.

Strengths of the study

Based on the expected needs of the patients, we chose GSD, which has shown benefit in other settings. We applied a qualitative analysis to show the potential effects of GSD in endometriosis. And we applied quantitative data to underpin these. Several researchers were involved in the analysis and interpretation of data contributing to different perspectives on the findings.

Limitations of the study

The nurses delivering this intervention had more than 20 years of experience. Their clinical experience may have affected the women's experience of GSD-endo, and therefore, the results may not be generalisable to a different setting with less experienced nurses. On the other hand, very experienced nurses have been found to be reluctant to apply evidence-based methods (45) but this was not the case in our study. One woman was referred to a psychologist and not interviewed. She was satisfied with the conversations, and they revealed her need for referral. If she had been interviewed, it might have contributed with other perspectives. We present few quantitative data collected before and after without blinding or a control group. We do not know if or how the women would have improved their scores over time without GSD-endo.

Perspectives

GSD-endo has the potential to benefit women with complex endometriosis, but this needs testing in a randomised trial where causality can be established. Since this study was completed, GSD-endo has been developed in a digital version where reflection sheets are hosted on the Public Danish eHealth Portal, Sundhed.dk. The conversations can now be delivered face-to-face, on the telephone or supported by video. A blended learning

certification programme in GSD has been developed. All these new features likely increase the feasibility of nationwide tests and implementations of GSD in several settings including complex endometriosis (www.guidedselfdetermination.eu).

Conclusions

Guided Self-Determination supported the women in developing self-management skills in relation to endometriosis and its symptoms. This was due to insight into their own needs and behaviours and their gained knowledge about the disease itself. The before-and-after assessment on EHP 30 suggested benefits, but this needs confirmation in a randomised trial.

Acknowledgements

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Ethical approval

The project was notified and approved by the Danish Data Protection Agency (JNR.2013-41-2427). According to Danish law, it was exempted from approval by The Danish Ethics Committee. The study was conducted in accordance with the Helsinki Declaration. Continuously, we had increased awareness of women in need of support from a psychologist. One woman was referred to

psychological therapy after two conversations because of a complex life situation with other challenges than endometriosis.

Conflict of interests

All authors declare no conflict of interests.

Author contributions

SMS, CS, DH and VZ designed the study. CS conducted interviews, the focus group interview was conducted by a communication consultant. SMS, CS and MLO analyzed data. All authors have contributed to writing the article and approved the final version.

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References

- Kennedy S, Bergqvist A, Chapron C, D'Hooghe T, Dunselman G, Greb R, Hummelshoj L, Prentice A, Saridogan E. ESHRE guideline for the diagnosis and treatment of endometriosis. *Hum Reprod* 2005; 20: 2698–704.
- Meuleman C, Vandenabeele B, Fieuws S, Spiessens C, Timmerman D, D'Hooghe T. High prevalence of endometriosis in infertile women with normal ovulation and normospermic partners. *Fertil Steril* 2009; 92: 68–74.
- Barbara G, Facchin F, Buggio L, Somigliana E, Berlanda N, Kustermann A, Vercellini P. What is known and unknown about the association between endometriosis and sexual functioning: a systematic review of the literature. *Reprod Sci* 2017; 24: 1566–76.
- Ramin-Wright A, Kohl Schwartz AS, Geraedts K, Rauchfuss M, Wolfler MM, Haeblerlin F, von Orelli S, Eberhard M, Imthurn B, Imesch P, Fink D, Leeners B. Fatigue – a symptom in endometriosis. *Hum Reprod* 2018; 33: 1459–65. [Epub ahead of print].
- Culley L, Law C, Hudson N, Denny E, Mitchell H, Baumgarten M, Raine-Fenning N. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update* 2013; 19: 625–39.
- Gambadauro P, Carli V, Hadlaczky G. Depressive symptoms among women with endometriosis: a systematic review and meta-analysis. *Am J Obstet Gynecol* 2019; 220: 230–41.
- Lagana AS, La Rosa VL, Rapisarda AMC, Valenti G, Sapia F, Chiofalo B, Rossetti D, Ban Frangež H, Vrtačnik Bokal E, Vitale SG. Anxiety and depression in patients with endometriosis: impact and management challenges. *Int J Womens Health* 2017; 9: 323–30.
- Lagana AS, Condemi I, Retto G, Muscatello MR, Bruno A, Zoccali RA, Triolo O, Cedro C. Analysis of psychopathological comorbidity behind the common symptoms and signs of endometriosis. *Eur J Obstet Gynecol Reprod Biol* 2015; 194: 30–3.
- Nnoaham KE, Hummelshoj L, Webster P, d'Hooghe T, de Cicco NF, de Cicco NC, Jenkinson C, Kennedy SH,

- Zondervan KT. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril* 2011; 96: 366–73.
- 10 Marinho MCP, Magalhaes TF, Fernandes LFC, Augusto KL, Brillhante AVM, Bezerra L. Quality of life in women with endometriosis: an integrative review. *J Womens Health* 2018; 27: 399–408.
- 11 Simoens S, Dunselman G, Dirksen C, Hummelshoj L, Bokor A, Brandes I, Brodzky V, Canis M, Colombo G I, DeLeire T, Falcone T, Graham B, Halis G, Home A, Kanj O, Kjer J j, Kristensen J, Lebovic D, Mueller M, Vignano P, Wullschlegler M, D’Hooghe T. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012; 27: 1292–9.
- 12 Verket NJ, Uhlig T, Sandvik L, Andersen MH, Tanbo TG, Qvigstad E. Health-related quality of life in women with endometriosis, compared with the general population and women with rheumatoid arthritis. *Acta Obstet Gynecol Scand* 2018; 97: 1339–48.
- 13 Zoffmann V, Kirkevold M. Relationships and their potential for change developed in difficult type 1 diabetes. *Qual Health Res* 2007; 17: 625–38.
- 14 Zoffmann V, Kirkevold M. Life versus disease in difficult diabetes care: conflicting perspectives disempower patients and professionals in problem solving. *Qual Health Res* 2005; 15: 750–65.
- 15 Zoffmann V, Harder I, Kirkevold M. A person-centered communication and reflection model: sharing decision-making in chronic care. *Qual Health Res* 2008; 18: 670–85.
- 16 Zoffmann V, Kirkevold M. Realizing empowerment in difficult diabetes care: a guided self-determination intervention. *Qual Health Res* 2012; 22: 103–18.
- 17 Weis J, Zoffmann V, Egerod I. Enhancing person-centred communication in NICU: a comparative thematic analysis. *Nurs Crit Care* 2015; 20: 287–98.
- 18 Finderup J, Bjerre T, Soendergaard A, Nielsen ME, Zoffmann V. Developing life skills in haemodialysis using the guided self-determination method: a qualitative study. *J Ren Care* 2016; 42: 83–92.
- 19 Jorgensen R, Hansson L, Zoffmann V. Changes in persistent delusions in schizophrenia using guided self-determination: a single case study. *Issues Ment Health Nurs* 2012; 33: 293–300.
- 20 Jorgensen R, Licht RW, Lysaker PH, Munk-Jorgensen P, Buck KD, Jensen SO, Hansson L, Zoffmann V. Effects on cognitive and clinical insight with the use of Guided Self-Determination in outpatients with schizophrenia: A randomized open trial. *Eur Psychiatry* 2015; 30: 655–63.
- 21 Linnet Olesen M, Hansson H, Ottesen B, Thranov IR, Thisted LB, Zoffmann V. The psychosocial needs of gynaecological cancer survivors: A framework for the development of a complex intervention. *Eur J Oncol Nurs* 2015; 19: 349–58.
- 22 Olesen ML, Duun-Henriksen AK, Hansson H, Ottesen B, Andersen KK, Zoffmann V. A person-centered intervention targeting the psychosocial needs of gynecological cancer survivors: a randomized clinical trial. *J Cancer Surviv* 2016; 10: 832–41.
- 23 Zoffmann V, Lauritzen T. Guided self-determination improves life skills with type 1 diabetes and A1C in randomized controlled trial. *Patient Educ Couns* 2006; 64: 78–86.
- 24 Zoffmann V, Vistisen D, Due-Christensen M. Flexible guided self-determination intervention for younger adults with poorly controlled Type 1 diabetes, decreased HbA1c and psychosocial distress in women but not in men: a real-life RCT. *Diabet Med* 2015; 32: 1239–46.
- 25 Husted GR, Esbensen BA, Hommel E, Thorsteinsson B, Zoffmann V. Adolescents developing life skills for managing type 1 diabetes: a qualitative, realistic evaluation of a guided self-determination-youth intervention. *J Adv Nurs* 2014; 70: 2634–50.
- 26 Thisted LB, Zoffmann V, Olesen ML. Labeled as lucky: contradictions between what women and health-care professionals experience regarding the need for help after the early stages of gynecological cancer. *Support Care Cancer* 2019. <https://doi.org/10.1007/s00520-019-04882-2> [Epub ahead of print].
- 27 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
- 28 Jones G, Kennedy S, Barnard A, Wong J, Jenkinson C. Development of an endometriosis quality-of-life instrument: The Endometriosis Health Profile-30. *Obstet Gynecol* 2001; 98: 258–64.
- 29 Jones G, Jenkinson C, Kennedy S. Evaluating the responsiveness of the Endometriosis Health Profile Questionnaire: the EHP-30. *Qual Life Res* 2004; 13: 705–13.
- 30 Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 2004; 39(4 Pt 1): 1005–26.
- 31 Stull DE, Wasiak R, Kreif N, Raluy M, Colligs A, Seitz C, Gerlinger C. Validation of the SF-36 in patients with endometriosis. *Qual Life Res* 2014; 23: 103–17.
- 32 Nutbeam D. Health promotion glossary. *Health Promot* 1986; 1: 113–27.
- 33 As-Sanie S, Black R, Giudice LC, Gray Valbrun T, Gupta J, Jones B, Laufer MR, Milspaw AT, Missmer SA, Norman A, Taylor RN, Wallace K, Williams Z, Yong PJ, Nebel RA. Assessing research gaps and unmet needs in endometriosis. *Am J Obstet Gynecol* 2019; 221: 86–94.
- 34 Strzempko Butt F, Chesla C. Relational patterns of couples living with chronic pelvic pain from endometriosis. *Qual Health Res* 2007; 17: 571–85.
- 35 Moradi M, Parker M, Sneddon A, Lopez V, Ellwood D. Impact of endometriosis on women’s lives: a qualitative study. *BMC Womens Health* 2014; 14: 123.
- 36 Hallstam A, Stalnacke BM, Svensen C, Lofgren M. Living with painful endometriosis - A struggle for coherence. A qualitative study. *Sex Reprod Health* 2018; 17: 97–102.
- 37 Young K, Fisher J, Kirkman M. Clinicians’ perceptions of women’s experiences of endometriosis and of psychosocial care for endometriosis. *Aust N Z J Obstet Gynaecol* 2017; 57: 87–92.
- 38 Apers S, Dancet EAF, Aarts JWM, Kluijvers KB, D’Hooghe TM, Nelen

- W. The association between experiences with patient-centred care and health-related quality of life in women with endometriosis. *Reprod Biomed Online* 2018; 36: 197–205.
- 39 Denny E. Women's experience of endometriosis. *J Adv Nurs* 2004; 46: 641–8.
- 40 Zarbo C, Brugnera A, Frigerio L, Malandrino C, Rabboni M, Bondi E, Compare A. Behavioral, cognitive, and emotional coping strategies of women with endometriosis: a critical narrative review. *Arch Womens Ment Health* 2018; 21: 1–13.
- 41 Geukens EI, Apers S, Meuleman C, D'Hooghe TM, Dancet EAF. Patient-centeredness and endometriosis: Definition, measurement, and current status. *Best Pract Clin Obstet Gynaecol* 2018; 50: 11–7.
- 42 Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *Am Psychol* 2000; 55: 68–78.
- 43 Vitale SVL, Vitagliano A, Noventa M, Laganà FM, Ardizzone A, Rapisarda AMC, Terzic MM, Terzic S, Laganà AS. Sexual function and quality of life in patients affected by deep infiltrating endometriosis: current evidence and future perspectives. *J Endometr Pelvic Pain Disord* 2017; 9: 270–4.
- 44 Soliman AM, Coyne KS, Zaiser E, Castelli-Haley J, Fuldeore MJ. The burden of endometriosis symptoms on health-related quality of life in women in the United States: a cross-sectional study. *J Psychosom Obstet Gynaecol* 2017; 38: 238–48.
- 45 Jorgensen R, Christiansen J, Nissen HB, Kristoffersen K, Zoffmann V. The deadlock of saying "That is what we already do!" A thematic analysis of mental healthcare professionals' reactions to using an evidence-based intervention. *J Psychiatr Ment Health Nurs* 2019; 26: 39–48.