

Between hope and fear: patient's expectations prior to pelvic organ prolapse surgery

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Abstract

Introduction and hypothesis The aim of our study was to analyse the patient's expectations (fears and goals (hopes)) in women who are scheduled for pelvic organ prolapse (POP) surgery.

Methods All consecutive women awaiting surgery for POP in a tertiary urogynaecological centre were included. A short questionnaire with two open questions on goals and fears with regard to the operation was used.

Results Ninety-six out of 111 distributed questionnaires (86%) were analysed. Goals and fears were categorized into five groups. De novo symptoms (63%), POP recurrence (34%) and surgical complications (29%) were the most important fears. Symptom release (96%), improved lifestyle (physical capabilities; 30%) and improved sexual life (18%) were important goals.

Conclusions A wide variety of expectations both positive and negative can be found in women before POP surgery and should be an integral part of preoperative counselling. Achieving the individual goals as based on expectations, positive (goals) and negative (fears), should be part of the POP surgery evaluation.

Keywords Pelvic organ prolapse · POP surgery · Hopes · Fears · Expectations

Abbreviations

POP Pelvic organ prolapse
UI Urinary incontinence

Introduction

Pelvic organ prolapse (POP) and urinary incontinence (UI) are common disorders in women and have a great impact on quality of life (QoL) [1–4]. There is an 11% lifetime risk of undergoing at least one operation for POP or UI, and there is a high prevalence of reoperations [5]. POP surgery is an important treatment for POP. There is no consensus regarding the best method of outcome assessment of POP surgery, but the achievement of patient-oriented goals gains importance [6, 7]. Traditional physician-determined measures of treatment success appeared to be insufficient to determine the quality of surgical outcomes and patient satisfaction [7–9]; this may be explained by the fact that surgeons and patients had different goals and expectations on the outcomes of surgery [10]. This has led to the introduction of disease-specific QoL questionnaires in order to determine the quality of surgical outcomes in a more patient-oriented manner [11]. But disease-specific QoL questionnaires may also lack the sensitivity to assess individual symptoms [12], and they disregard the goals of the individual patient [13–16]. Realistic and achievable goals may prevent dissatisfaction with surgical outcomes [17].

Goal achievement is now regarded as an important predictor for success after surgery. In the present study, we were specifically interested in the fears or negative expectations of our patients. Fears, justified or unjustified, may make

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patients refrain from effective treatment. In the literature, this subject has been given hardly any attention, neither in gynaecological surgery nor in the other specialties.

In this study, we summarize the patient's goals and fears before surgery in a group of women scheduled for POP surgery.

Materials and methods

Women were recruited from a tertiary urogynaecological centre in the Netherlands, the Radboud University Nijmegen Medical Centre. All consecutive women who were waiting for POP surgery during the study period from December 2008 till October 2009 were requested to complete a short questionnaire and return with a reply envelope. Outpatient counselling was performed by the outpatient gynaecologist who is in generally also the operating gynaecologist. In our study, the women were counselled by four gynaecologists who work with the same protocols and in the same group; most of the women in our study 68 (71%) were counselled by one gynaecologist (MV). The preoperative counselling before the operation was not altered for this study. Counselling generally started by the referring general practitioner, but we have no information on this. Outpatient counselling consisted of counselling about the various possible therapies, a brief oral explanation of the operation supported by the handout of a standardized folder as advised by the Dutch Society for Obstetrics and Gynecology (www.NVOG.nl). Patients were standardly offered the possibility for an additional counselling consult, but this is seldom used.

The one-page questionnaire contained an introduction and two short open questions. The introduction of the questionnaire was as follows: "You are scheduled to undergo POP surgery. We are studying the reasons for undergoing such surgery. Therefore we would like to ask you to answer as accurate as possible the following two

questions." The first question was "What are the most important goals you want to accomplish with the surgery? In other words what do you hope to achieve by the operation? You can, but need not necessarily, give a maximum of 5 targets, let your imagination run free!" The second question was "What are the most important things or situations that you would *not* want to reach by the surgery? In other words what do you fear a situation you are concerned about that could occur after the operation? You can, but need not necessarily, give a maximum of 5 things or situations. Let your imagination run free!"

The answers were collected, transferred into a database and categorized. Categorization was based on the answers and not on pre-existent categories. Simple statistical frequencies were used to describe the answers. Spearman's correlation coefficient test was used to test for potential correlations between the number of answers in the 10 categories (five hope categories and five fear categories). *P* values <0.05 were considered statistically significant. Statistical analyses were performed using SPSS version 16.0 (SPSS, Inc., Chicago, IL, USA). This study was not submitted for ethics approval since the procedures and questionnaires used are part of daily clinical practice.

Results

One hundred eleven women ($n=111$) were asked to answer our questionnaire, of whom 99 patients (89%) replied; one of those had cancelled the operation. Two questionnaires contained no useful information, and thus, 96 questionnaires (86%) were available for analysis.

The mean number of answers to the hope question was 2.9 (range 1–6), and the mean number of answers to the fear question was 1.8 (range 0–5). The demographics and surgical procedures for the participating women are shown in Table 1, and all women included are native Dutch women. The answers to the two questions are listed in

Table 1 Demographics and surgical procedures of the study population

	POP patients ($n=111$)
Age (years)	60 (23; 88)
BMI (kg/m^2)	27 (17; 63)
Parity	2 (0; 5)
Postmenopausal (yes)	65 (68%)
First POP surgery (yes)	80 (83%)
Planned surgical procedures	
Anterior and/or posterior repair	32 (33%)
Modified Manchester with anterior and/or posterior repair	41 (43%)
Vaginal hysterectomy with anterior and/or posterior repair	11 (11%)
Abdominal sacrocolpopexy	3 (3%)
Prolift operations (with or without anterior and/or posterior repair)	9 (9%)

Data presented as number (percentage) or median (range) as appropriate

n number of cases, *BMI* body mass index, *POP* pelvic organ prolapse

Tables 2 and 3, respectively. Most women (63 women, 66%) had more goals than fears; a minority had more fears than goals (10 women, 10%). The number of answers on goals correlated positively with the number of fears ($r=0.303$ ($P<0.01$)). Further, the hope of getting a better lifestyle category correlates positively with emotional health category ($r=0.254$ ($P<0.05$)); the hope of getting a better sexual life category correlates positively with the fear from deterioration of sexuality category ($r=0.232$ ($P<0.05$)).

Discussion

To our best knowledge, our study is the first on fears, besides goals, in relation to POP surgery. Fears and goals can influence decision making. Goals, certainly erroneous ones, may allow patients to go forward, with surgery when it would not be reasonable to expect those goals, but fears can also *greatly* influence decision making in patients and,

although often heard during consultations, has been given little attention in the available literature. Our results show that besides hopes (goals), there are also a significant number of fears in the patients when specifically asked for. It was, however, notable that the number of answers regarding fears was less as compared with the answers regarding goals. The number of goals and fears were, however, positively correlated. This may be simply a result of the ability of some women to verbalize their expectations better than others

One previous study in 1993 has studied fear for cataract operations in aged persons [18]. This study has found that 33% of the patients had fear and 32% felt tension about the operation; women feared the operation significantly more than men. Fears were associated with hypochondriasis, hysteria and hypomania.

The most striking finding in our study is that almost all women feared de novo symptoms, particularly UI. This finding matches well with our clinical experience. The fear

Table 2 Categorized answers on the first question “What are your most important goals, you want to accomplish with the surgery? In other words what you hope eventually to have achieved by the operation?”

Category	Characteristic answer	<i>n</i> (%)
1. Symptoms		92 (96)
Urinary symptoms		67 (70)
Disappearing of urine incontinence	“I do not get wet every time”	38 (40)
Disappearing of urgency/frequency	“That I can walk for two hours as before without having to pee 3 times”	26 (27)
Normalize micturation	“That I can pee normally as before”	18 (19)
No need for sanitary napkin	“That I can go out without Tena lady (sanitary napkin)”	10 (10)
Prolapse symptoms		50 (52)
Disappearing of prolapse sensation	“That no more flesh comes from my vagina”	50 (52)
No more need for vaginal pessary	“No need for using pessary”	5 (5)
Pain symptoms		29 (30)
Improvement of the pain (generally)	“Reduction in the abdominal pain”	20 (21)
Improve back pain	“No more back pain”	9 (9)
Bowel symptoms		20 (21)
Improvement of defecation	“That I can defecate normally as before”	17 (18)
Disappear of faecal incontinence	“No involuntary stool loss moments”	4 (4)
2. Lifestyle		29 (30)
Improve physical capabilities	“To do my work and sport optimally without all those problems”	29 (30)
3. Sexual life		17 (18)
Improvement sexuality	“That I can have sex normally as before without hinder”	14 (15)
Disappear of dyspareunia	“Sex without pain”	3 (3)
4. Emotional health		16 (17)
Improve body image	“That I become a young woman again”	9 (9)
Improve fatigue symptoms	“No more feeling tired”	8 (8)
5. Other		6 (6)
Disappear of menstruation	“No more bleeding, no more periods”	4 (4)
Decrease the chance to get cancer	“Prevent the risk of womb cancer, I use Tamoxifen for 4 years”	2 (2)

Data are presented as *n* (percentage)

n number of times reported

Table 3 Answers on the second question “What are your most important things or situations that you just would not want to reach by the surgery? In other words what you want to avoid, a situation where you are concerned that could occur through the operation?”

Category	Characteristic answer	<i>n</i> (%)
1. Getting new symptoms		60 (63)
Urine incontinence	“To become incontinent”	50 (52)
Pain	“New pain complaints”	12 (13)
Urine retention/incomplete urination	“That I use catheter to pee”	9 (9)
Faecal incontinence	“Damage to the anal sphincter”	5 (5)
2. Recurrence		33 (34)
Failure of the surgery	“That it has not helped”	22 (23)
Recurrence (soon in the future)	“That I soon get recurrence”	14 (15)
3. Surgical complications		28 (29)
Surgical complications	“That there are complications during or after the operation”	20 (21)
Complications of the general/spinal anaesthesia	“I get no adverse effects after anaesthesia”	8 (8)
Rejection of the mesh	“I hope that no rejection of the mesh occurs”	3 (3)
4. Deterioration of sexual life		16 (17)
Getting dyspareunia	“That my vagina become narrow that sex become impossible”	9 (9)
Sexually deterioration	“That sexual sense become less”	7 (7)
5. Lifestyle deterioration		8 (8)
Physical deterioration	“That hinders me in the daily activities”	8 (8)

Data are presented as *n* (percentage)

n number of times mentioned

of becoming incontinent after POP surgery may be a reason for refraining from POP surgery. The occurrence of stress UI (SUI) after POP surgery may be associated with the presence of occult stress incontinence before surgery [19, 20] which is estimated to be 36–80% in advanced POP [20]. The occurrence of postoperative SUI is, however, difficult to predict, and all studies on the subject show that the percentage of occult incontinence preoperatively is far higher as compared with the actual percentage of SUI after surgery [21]. The expectations of the women with regard to UI are thus somewhat discrepant with the reality. Furthermore, postoperative SUI can be managed rather effectively with tension-free mid-urethral sling operations [22]. This makes UI a crucial item for proper counselling before the operation.

In a recent study, the use of photos and videos to explain what patients could expect during and after the operation has reduced significantly preoperative anxiety [23]. Recurrence and failure after POP surgery were important issues women fear; this is more justified because the failure rate of POP surgery is high [5]. The patient's fear of surgical complications on the other hand seems rather high because the complication rates during POP surgery are in general low [21, 24].

The effect of POP surgery on sexuality, both fear for deterioration as well as hope for improvement, was an important subject in the women included in this study. We do not know how many women in our group were sexually active before or after the operation. A recent study reported

a significant improvement in the sexual function 2 years after POP and stress UI surgery [25]. In another recent study is concluded that the POP surgery with additional incontinence surgery resulted in decreased vaginal wall sensibility; there was no influence of the decreased vaginal wall sensibility on sexual well-being [26].

In our study, we did not use a predefined system to categorize the expectations, and previous studies had used different categories [15–17, 27]. There is no widely accepted system to categorize the goals for treatment. Lowenstein et al. [27] have categorized the goals into five categories: (1) goals related to symptom resolution, (2) goals related to lifestyle and/or quality of life improvement, (3) goals related to emotional outcome, (4) goals related to information seeking (aimed to gain more information about symptoms, treatment, or prognosis) and (5) other. Differences in goals between populations may be explained by differences in social and cultural environment. Factors such as age, culture, place and religion will affect the goals and fears of the patients who are going to be operated for pelvic floor dysfunctions.

Although it is known that POP is not a cause of pelvic or low back pain [28], 30% of the women in our population wished resolution pain as result surgery wish may be an unrealistic aim of the surgery.

It could be expected to find that the hope to get a better sex life positively correlates with the fear from deterioration and that the hope of getting a better lifestyle correlates positively with emotional health.

In conclusion, negative patient's expectations (fears) were present besides positive expectations (goals or hopes). Both and especially, sometimes erroneous, fears are important and should be an integral part of preoperative counselling. Further, the fears should be part of a comprehensive informed consent. Achievement of the expectations, both positive (hopes) and negative (fears), should be part of the evaluation of the outcome after surgery.

Conflicts of interest MW and MV have a consultancy agreement with and are on the Speaker's Bureau of Ethicon Women's Health & Urology. MV is a member of the European OAB faculty of Astellas. This study, however, was entirely instigated by the responsible researchers and funded by university-administered research funds. No commercial partner was involved in the study setup, study design, data collection, or whatsoever. The other authors have no conflicts of interest to declare.

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