


Patient-Reported Experiences After Hysterectomy: A Cross-Sectional Study of the Views of Over 2300 Women

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Abstract

Objective: To evaluate women's experiences after hysterectomy and predictors of their contentment and regret with the surgical approaches. **Methods:** Cross-sectional, Patient-Reported Experience Measures survey in 2319 Australian women aged 21 to 90 years (median age of 52 years) who had received hysterectomy in the preceding 2 years. **Results:** Overall, the vast majority of women (>96%) did not regret having had the hysterectomy. Women who received an open abdominal hysterectomy reported slower recovery with about 7% of women still not fully recovered after 12 months compared to those whose surgery was through a less invasive approach. Women who reported no adverse events, having been given a choice of type of hysterectomy, women who received an alternative to open abdominal hysterectomy, and women who felt prepared for discharge from hospital were significantly more likely to be content with their hysterectomy and report positive patient experiences. **Conclusions:** Compared with those who received a less invasive approach to hysterectomy, women who received open surgery were more likely to express negative experiences relating to their hospital stay and recovery from surgery. The results inform future improvements of care for women planning a hysterectomy.

Keywords

women, hysterectomy, patient-reported experiences, patient-reported outcomes

Introduction

Hysterectomy is the most frequently conducted major gynecological surgical procedure (1). Each year approximately 30 000 women in Australia, 434 000 women in the United States, and about women 800 000 in Europe undergo hysterectomy to treat benign conditions such as fibroids or abnormal uterine bleeding, or to prevent or treat cancer (1,2).

Several approaches to hysterectomy are available to surgeons. It may be performed by an abdominal incision (total abdominal hysterectomy [TAH]) or by less invasive approaches, including vaginal hysterectomy (VH), total laparoscopic hysterectomy (TLH), laparoscopic-assisted vaginal hysterectomy (LAVH), or robotic hysterectomy (RH). Cochrane reviews, meta-analyses, and cost-analyses compared these approaches and concluded that whenever clinically indicated, approaches other than TAH should be used (1,3-6). Yet in Australia, TAH rates remain high (~40%), whereas in other countries, TAH rates have

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declined faster (7,8). To better understand reasons for this, we explored the views of both surgeons and patients. Among 285 Australian obstetrics and gynecology specialists, the dominating barrier to practicing less invasive surgery was a lack of surgical training and mentoring (9). Among women who had a hysterectomy in the previous 2 years, the majority (62%) followed their doctor's advice on the surgical approach, and very few (<15%) sought a second opinion (10).

The current analysis forms part of our larger program of research to understand reasons for continuing high rates of TAH in Australia and specifically to describe the patients' experience of their surgery and recovery. While evidence on Patient-Reported Experience Measures (PREMs) in hysterectomy is sparse, studying PREMs can inform quality and safety improvement initiatives; allow comparisons between surgical techniques and assessment of their suitability for patient subgroups (11,12).

The aims of this study were (a) to compare women's experience in hospital after receiving a hysterectomy using 1 of 5 possible surgical approaches; (b) their postsurgical recovery; and (c) to determine whether contentment with surgery differed depending on the surgical approach, sociodemographic, or clinical characteristics.

Methods

The study was approved by the University of Queensland Human Research Ethics Committee (# 2014001451). Women who had received a hysterectomy in Queensland, Australia, in the preceding 2 years were invited to participate. Those who agreed completed the cross-sectional survey anonymously either online or by e-mail between July 2015 and January 2016.

Patient-Reported Experience Measures Questionnaire Development, Patient Identification, and Recruitment

Details of questionnaire development and recruitment have been described previously (10). In brief, the questionnaire was developed and piloted using an iterative process. First previous literature and reports of patient experiences were collected. These were then collated into a draft survey instrument that was provided for feedback to health professional and consumers, resulting in iterative improvements to ascertain clarity, face validity, and optimal order of questions. A copy of the final questionnaire is included in Supplementary file 1.

The Australian Department of Human Services facilitated recruitment. Department of Human Services staff, independently from the researchers, selected at random a sample of 6000 women using government reimbursement data and sent letters on behalf of the research team to these randomly selected women, explaining the study purpose and asking them to complete the survey if they were interested to participate. No reminders were sent, no information about

undelivered or returned invitations was available to the researchers. A comparison of characteristics of responders and nonresponders was therefore not possible. However, given the large number of completed surveys ($n = 2319$; 38.7%), the precision of estimates in proportions would be high ($\pm 2\%$).

Survey Questions and Analysis

The online version of the questionnaire was hosted using REDCap (Research Electronic Data Capture, Vanderbilt University). Participant characteristics comprising age, marital status, education, income, body mass index, type received and reason for hysterectomy, and comorbidities were collected and tabulated (Table 1).

Experience in Hospital

Five yes/no response items related to participants' hospital experience: (a) whether any problems were experienced as an inpatient (if yes, women were asked to specify the type of problem); (b) whether women felt well prepared for discharge from hospital; (c) whether a return to the operating theatre was required while an inpatient; (d) whether a return to hospital after discharge occurred; and (e) if a return to hospital after discharge occurred, whether a return to operating theatre was necessary. For each item, proportions of yes/no responses were compared by type of surgery (TAH, VH, TLH, LAVH, and RH) and analyzed using χ^2 tests.

Experience During Recovery at Home

Participants' return to normal function after surgery on 10 self-reported well-being outcomes were collected: (a) bending and stretching, (b) usual home activities, (c) return to work, (d) freedom from pain, (e) normal bowel function, (f) normal bladder function, (g) normal level of energy, (h) overcoming emotional effects, (i) acceptance of new body image, and (j) normal sexual function. For each of these dimensions, women were asked how long it took them to return to normal function (by 1 or 6 weeks, 3, 6, or 12 months). The proportion of women who had returned to normal by 6 weeks was compared using χ^2 tests. For each of the outcomes, we also report the time by which all women returned to normal function across all surgery types (equivalence time).

The Experience of Surgery

Participants were asked 6 reflective questions relating to their surgical experience, including whether they felt they were given a choice in the type of procedure they would receive. They were also asked if they (a) would make the same choice again, (b) felt their decision was wise, (c) felt the choice did them harm, (d) regretted the choice that was made, or (e) felt they made the right decision. Fisher's exact

Table 1. Participant Characteristics.^a

Participant Characteristics	n	%
Marital status		
Single	118	5.09
Married	1728	74.51
De facto/living with partner	175	7.55
Separated/divorced	186	8.02
Widowed	100	4.31
Unknown	12	0.52
Level of education completed		
Prefer not to answer	80	3.45
Primary school	27	1.16
High School	781	33.67
Trade/technical certificate	552	23.80
Degree	780	33.64
Other/unknown/no formal	99	4.27
Household income (AUD)		
<16 000	38	1.63
16 000-25 999	78	3.36
26 000-36 399	95	4.10
36 400-51 999	168	7.24
52 000-77 999	269	11.60
78 000-103 999	327	14.10
>104 000	756	32.60
Unknown/prefer not to answer	588	25.36
BMI (kg/m ²)		
Underweight (<18.5)	41	1.77
Normal (18.5-24.9)	876	37.77
Overweight (25-29.9)	723	31.18
Obese (>30)	633	27.30
Unknown	46	1.98
Type of hysterectomy received		
TAH	596	25.70
VH	474	20.44
TLH	467	20.14
LAVH	734	31.65
RH	29	1.25
Unknown	19	0.82
Morbidities at hysterectomy		
None	663	28.59
Heart disease	47	2.03
Hypertension	416	17.94
Lung disease	22	0.95
Diabetes mellitus	80	3.45
Ulcer/reflux/stomach	171	7.37
Kidney disease	20	0.86
Anemia/other blood	246	10.61
Cancer	292	12.59
Anxiety/depression	354	15.27
Osteoarthritis/degenerative arthritis	251	10.82
Back pain	338	14.58
Rheumatoid arthritis	43	1.85
Other medical	743	32.04
Reason for hysterectomy		
Fibroids	827	35.66
Endometriosis	364	15.70
Prolapse	558	24.06
PID	42	1.81
Hyperplasia	334	14.40
Heavy/irregular periods	853	36.78

(continued)

Table 1. (continued)

Participant Characteristics	n	%
Post menopause bleeding	144	6.21
Severe period pain	488	21.04
Family history of ec/oc	190	8.19
Abnormal smear	128	5.52
Cancer	321	13.84
Personal choice	225	9.70
Birth control	29	1.25
Don't know/recall	1	0.04
Other	413	17.81

Abbreviations: AUD, Australian dollars; BMI, body mass index; ec, endometrial cancer; LAVH, laparoscopic-assisted vaginal hysterectomy; oc, ovarian cancer; PID, pelvic inflammatory disease; RH, robotic hysterectomy; TAH, total abdominal hysterectomy; TLH, total laparoscopic hysterectomy; VH, vaginal hysterectomy.

^a n = 2319.

tests were used to compare responses by category (strongly agree, agree, neutral, disagree, and strongly disagree) by surgery type and results were plotted.

Multivariable logistic regression modeling was used to explore predictors of women's experience. A model was built with each of (b)-(e) reflections as dependent variables, with strongly disagree/disagree and neutral responses coded as 0; agree/strongly agree responses coded as 1. Independent variables were age, level of income (ordinal scale 1-10), whether partnered (0/1 not partnered/partnered), level of education (ordinal scale 1-6), whether women experienced problems as an inpatient (0/1 no problems/problems), whether women felt prepared for discharge (0/1 did not/did feel well prepared for discharge and recovery at home), whether they felt they had a choice in the type of hysterectomy (0/1; no/yes), how well-informed they felt about hysterectomy (ordinal scale 0-3), and type of procedure received (0/1; TAH/less invasive approach), prefer not to answer responses were excluded from the relevant models. All analyses were conducted in R version 3.4.1 (13). Alpha of .05 was used for all analyses.

Results

The survey was completed by 2319/6000 participants (response rate 38.7%). Participating women were between 21 and 90 years of age, with a median age of 52 years. Participant characteristics are shown in Table 1. Most women were married or living with a partner, had at least high school education, household incomes of \$54 000 or above, and were overweight or obese. Laparoscopic-assisted VH was the most commonly received procedure by 734 patients (31.7%) followed by TAH (596; 25.7%), VH (474; 20.4%), TLH (467; 20.1%), and RH (29; 1.3%; Table 1).

Table 2. Number and Cumulative Proportion of Women Who Had Recovered Important Functions at 6 Weeks Following Surgery by Type of Surgery Received and Time Point by Which Equivalence in Recovery Was Achieved.

Recovery Measure	Proportion of Women Who Returned to Full Function by 6 Weeks										P	Equivalence Time Point ^a
	TAH		VH		TLH		LAVH		RH			
	N	%	n	%	n	%	n	%	n	%		
(a) Bending and stretching	455	79.41	413	90.77	405	91.84	647	91.13	24	85.71	<.001	3-month
(b) Usual home activities	313	53.97	343	74.24	344	75.44	495	68.85	19	70.37	<.001	6-month
(c) Return to work	293	65.26	227	78.82	263	82.70	445	80.32	19	90.48	<.001	6-month
(d) Freedom from pain	304	54.29	330	81.08	334	78.22	519	74.46	21	77.78	<.001	-
(e) Normal bowel function	513	89.06	428	93.04	399	88.67	650	90.15	25	86.21	NS	6-week
(f) Normal bladder function	541	92.16	438	93.59	427	92.83	667	92.64	29	100.00	NS	6-week
(g) Normal level of energy	263	45.82	296	64.91	287	63.64	424	59.80	19	65.52	<.001	12-month
(h) Overcome emotional effects	290	61.44	257	78.35	257	71.39	381	67.43	15	71.43	<.001	6-month
(i) Acceptance of new body image	355	70.02	277	85.23	298	82.09	432	79.27	17	77.27	<.001	-
(j) Normal sexual function	170	35.94	153	45.40	154	43.75	266	43.39	9	36.00	.02	3-month

Abbreviations: LAVH, laparoscopic-assisted vaginal hysterectomy; NS, not significant; RH, robotic hysterectomy; TAH, total abdominal hysterectomy; TLH, total laparoscopic hysterectomy; VH, vaginal hysterectomy.

^a Time point by which no statistically significant difference in cumulative proportions by surgical type remained.

Patient Experience in Hospital

Common problems reported by women as an inpatient straight after surgery included nausea and vomiting, regaining bladder or bowel functioning, problems with blood pressure, infection, problems with pain relief, and feeling weak due to blood loss during surgery. The proportion of women experiencing problems during their inpatient stay varied significantly by type of surgery ($P < .001$) with the highest proportion reporting one or more problems among TAH recipients (144/596; 24.2%) and the lowest among TLH recipients (64/467; 13.7%). For the other procedure types, proportions of women experiencing problems were similar (VH 93/474 [19.6%], LAVH 137/734 [18.7%], and RH 6/29 [20.7%]). None of the 8 RH patients who returned to hospital after discharge were required to return to the operating theatre. The proportion needing to return to operating theater was higher in VH patients (17/53; 32.1%; $P < .05$) compared to those who had a TAH, LAVH, or TLH (17% [15/88], 19.8% [22/111], 21.6% [16/74], respectively). While the proportion of patients who reported feeling well prepared for discharge from hospital was significantly different by surgical type, it was universally high (>88%) across all surgical approach types (TAH 529/596 [88.8%], VH 443/474 [93.5%], TLH 427/467 [91.4%], LAVH 655/734 [89.2%], RH 26/29 [89.7%]; $P < .05$).

Patient Experience During Recovery at Home

Table 2 presents the data on return to full function in each of the recovery domains. By 6 weeks following surgery, normal bowel function had returned for 2015/2319 (86.9%) of women, and normal bladder function for 2102/2319 (90.6%) of women, and this did not differ significantly by type of surgery received. For the remaining 8 recovery

measures (bending and stretching, usual home activities, return to work, freedom from pain, level of energy, overcoming emotional effects, acceptance of new body image, and sexual function), the cumulative proportion of women reporting full recovery by 6 weeks differed significantly by the type of hysterectomy received (all $P < .001$, except $P = .02$ for sexual function). For all of these recovery components, women who had a TAH were less likely to have recovered by 6 weeks compared to other procedures Table 2.

The proportion of women who reported they had fully recovered 12 months postsurgery were comparable for all dimensions, except for freedom from pain and acceptance of body image. Overall, 35/596 (5.9%) TAH recipients still reported pain, compared with $\leq 2\%$ for the other procedure types ($P < .001$). Acceptance of new body image remained unresolved for 7.2% (43/596) TAH, 2.7% (13/474) VH, 4.1% (19/467) TLH, 3.4% (25/734) LAVH, and 0% (0/29) for RH recipients, 12 months after surgery ($P < .05$).

The Surgical Experience

Compared with women who received other types of surgery, a larger proportions of women who received TAH (240/596; 40.3%) reflected that they may not have been given a choice of procedure type compared to a smaller proportion (<27%) for the other surgical procedures (VH 107/474 [22.6%], TLH 124/467 [26.6%], LAVH 181/734 [24.7%], RH 2/29 [6.9%]; $P < .001$; Figure 1).

Overall, the vast majority of women (>82%) agreed/strongly agreed that they made the right decision to have a hysterectomy. The proportion varied ($P = .02$) with more women agreeing/strongly agreeing for VH 447/474 (94.3%), TLH 421/467 (90.1%), and LAVH 669/734 (91.1%), compared to TAH 522/596 (87.6%) or RH 24/29 (82.8%).

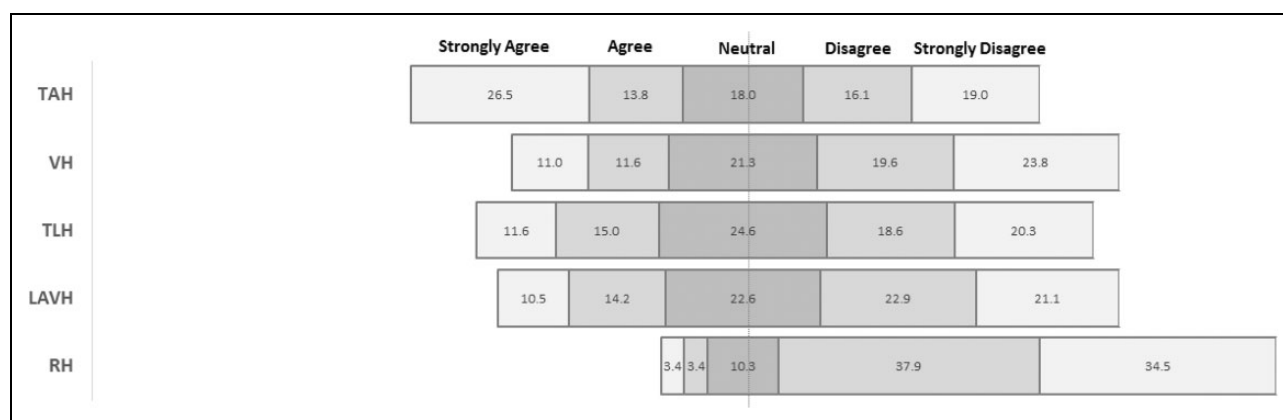


Figure 1. Agreement with the statement: “I was not given a choice of type of hysterectomy” by type of hysterectomy received. TAH (n = 596); VH (n = 474); TLH (n = 467); LAVH (n = 734); RH (n = 29). LAVH, laparoscopic-assisted vaginal hysterectomy; RH, robotic hysterectomy; TAH, total abdominal hysterectomy; TLH, total laparoscopic hysterectomy; VH, vaginal hysterectomy.

Very few women regretted having had the hysterectomy, ranging from 9/467 (1.9%) among TLH recipients to 21/596 (3.5%) among TAH recipients. When asked about whether they would make the same decision again, the proportion agreeing/strongly agreeing was significantly lower between RH (22/29; 75.9%) and TAH recipients (464/596; 77.9%), compared to VH, TLH, and LAVH recipients 391/474 (82.5%), 383/467 (82%), and 618/734 (84.2%), respectively ($P < .001$). The proportion of women who perceived that the procedure did them harm was highest among those who had received RH 3/29 (10.3%), TAH 28/596 (4.7%) versus VH 11/474 (2.3%), TLH 10/467 (2.1%), LAVH 17/734 (2.3%); $P < .01$. In contrast, no significant difference by procedure type was found in whether women felt the decision on type of procedure was wide ranging from 22/29 (75.9%) for RH to 414/474 (87.3%) for VH ($P > .05$).

Table 3 presents the findings of the multivariable logistic regression analyses. Factors independently associated with all 5 experience dimensions were whether women had any adverse events after surgery, whether they felt well prepared for discharge, whether they felt they had a choice about the type of procedure, felt well-informed and had a less invasive procedure. Age was only independently significantly associated with choosing the same procedure again, and the wisest choice. Level of income, whether women lived with a partner, and level of education were not associated with these 5 outcome dimensions (Table 3).

Discussion

This large cross-sectional survey reports for the first time women’s reflections on having a hysterectomy by 1 of 5 different surgical approaches. The findings are important because they show that the type of hysterectomy significantly influenced the women’s experiences and recovery. Further, the study identified that women who reported a surgical experience without adverse events, having choice in the type of hysterectomy, women who received an

alternative to TAH, and women who felt prepared for discharge from hospital were more likely to report positive reflections. These are potentially modifiable factors that can be used to design future health-care improvement interventions.

Previous studies examined the relationships between surgical approach to hysterectomy and women’s quality of life, for both benign and oncologic conditions (14-19). Most studies compared laparoscopic and open abdominal surgery (9-13), while 1 study compared TLH, VH, and TAH (8), and 4 TLH versus RH, reviewed in Albright et al (20). These studies all concluded that minimally invasive surgical approaches were associated with better postoperative quality of life.

In contrast, little data are available on PREMs specifically; only 2 studies have explored women’s satisfaction. In 2010, Kuppermann and colleagues examined the satisfaction following hysterectomy for 207 women with benign conditions (21). While most (63.9%) women reported that they were satisfied, the type of hysterectomy received was not reported, and the study was conducted in a period (1998-2008) when less invasive approaches to hysterectomy were yet to become widely available (21). In 2014, Schoenfelder and colleagues also examined patient satisfaction following gynecological surgery, finding that individualized care, clinical outcome, organization of discharge from hospital were predictors of overall satisfaction (22). The latter finding is consistent with our result that women who felt well prepared for discharge reported a better experience.

Only 1 previous study has compared PREMs across a range of available surgical techniques (23). The study, conducted in the United States in 2013, by Pitter and colleagues recruited 6262 women through the online support group “HysterSisters.” In contrast to our study, which included women who received treatment for cancer prevention or cancer, all participants in Pitter’s study received a hysterectomy for benign conditions. Consistent with our findings, these authors reported differences by surgical approach in

Table 3. Factors Associated With Agreeing or/Strongly Agree With 5 Statements of Contentment or Regret About Hysterectomy.

Factors	OR	95% CI	P Value
(a) If I had to choose again or had been able to choose, the decision would remain the same			
Age	0.98	0.97-0.99	<.001
Problems	0.5	0.38-0.68	<.001
Prepared	2.67	1.85-3.81	<.001
Choice	3.68	2.68-5.13	<.001
Informed	3.01	2.46-3.7	<.001
Less invasive approach	1.83	1.38-2.42	<.001
(b) It was the wisest choice			
Age	0.99	0.97-0.99	<.05
Problems	0.45	0.34-0.62	<.001
Prepared	3.1	2.13-4.42	<.001
Choice	3.69	2.64-5.26	<.001
Informed	3.81	3.08-4.73	<.001
Less invasive approach	1.39	1.03-1.87	<.05
(c) The choice did me a lot of harm			
Age			NS
Problems	2.85	1.73-4.63	<.001
Prepared	0.16	0.1-0.28	<.001
Choice	0.52	0.3-0.86	<.05
Informed	0.22	0.16-0.3	<.001
Less invasive approach	0.52	0.32-0.85	<.01
(d) I regret the choice			
Age			NS
Problems	3.12	1.8-5.32	<.001
Prepared	0.22	0.13-0.42	<.001
Choice	0.33	0.16-0.61	<.001
Informed	0.23	0.17-0.32	<.001
Less invasive approach			NS
(e) It was the right choice			
Age			NS
Problems	0.32	0.22-0.45	<.001
Prepared	5.15	3.43-7.64	<.001
Choice	3.35	2.23-5.18	<.001
Informed	4.22	3.32-5.4	<.001
Less invasive approach	1.7	1.18-2.43	<.01

Abbreviations: CI, confidence interval; NS, not significant; OR, odds ratio.

women's satisfaction, time to return to usual activities, and agreement that they would make the same decision again. In particular, similar to these previous findings, we also found that women who receive less invasive surgery had a more positive experience and that TAH recipients were more dissatisfied with outcomes and less likely to agree that they would make the same choice again.

Recovery after hysterectomy for most women was quick, with the majority returning to good bowel and urinary function by 6 weeks. Consistent with this, only 2% to 4% of women regretted to have a hysterectomy overall, similar to findings from a Swedish study where more than 90% of women were satisfied or very satisfied with having had the procedure (24). Across most measures, we found consistent differences in experiences between TAH recipients, and the recipients of less invasive hysterectomy. The proportion of

women experiencing problems as an inpatient was highest among TAH recipients and lowest among TLH recipients. At 6 weeks after surgery, for 8 of the 10 recovery measures, the proportion of women reporting having fully recovered was lowest among TAH recipients. One year after surgery, recovery was similar across all procedure types, except for the measures of pain and acceptance of new body image, where residual unresolved problems were still highest for TAH recipients. Compared with recipients of alternative approaches, a higher proportion of TAH recipients felt that they were not given a choice in the type of surgery. Total abdominal hysterectomy and RH recipients had the lowest level of agreement that they had made the right choice and that they would make the same choice again; these recipients also had the highest agreement that their decision had caused them harm.

Similar to an analysis of patient satisfaction in a sample of over 8000 patients attending 39 hospitals in Germany (25), experiencing problems as an inpatient was associated with negative reflections on the surgery. In contrast to our findings, Pitter and colleagues reported that receiving an RH was the only independent predictor of both satisfaction, and whether women would make the same choice again (23). In part, these differences may be explained by the much lower availability of RH in the Australian health system, systematic differences in the cohorts (we included both benign and oncologic cases), or the differences in recruitment methods.

Strengths and Weaknesses

While the survey was completed by a large number of women, the response rate was 39%, likely because we were unable to send women a reminder. While the sampling via the population-base health insurance Medicare ascertained complete coverage of women who had a hysterectomy, privacy regulations meant that we could not receive information about letters returned to sender, or details of women who opted not to participate. Because all of our participants received their hysterectomy in one of Australia's private hospitals, our findings may not be automatically applicable to women who receive a hysterectomy in the public hospital system (annually, around one-third of hysterectomies in Queensland occur in the public system) (26,27). Therefore, the use of private hospital data may limit the generalizability of the study to the broader community. However, our study has important strengths: none of the previous studies have as comprehensively explored women's contentment or regret following hysterectomy, or identified predictors of these emotions, drawing on the experiences of a large group of women across the range of contemporary surgical techniques; secondly, it overcomes 2 limitations of the previous study by Pitter and colleagues (a) by incorporating information about women's reflections on their surgical procedure making in the multivariable model and (b) by including information from women who received a hysterectomy for both benign and oncologic conditions.

Conclusion

This study provides new insights into women's experiences after hysterectomy. It also shows that the main factors associated with a positive experience were receiving surgery via a less invasive surgical approach, not experiencing an adverse event, and being well-prepared for discharge home from hospital. This information will be useful in improving the future care of women receiving a hysterectomy.

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Declaration of Conflicting Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: AO is the founder and managing director of SurgicalPerformance Pty Ltd, an Australian, private company that provides surgeons with a platform for collection of surgical outcome data; AO was a consultant for Covidien (New South Wales, Australia).

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Supplemental Material

Supplemental material for this article is available online.

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