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Research Paper

Factors influencing women's decision making in hysterectomy

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ABSTRACT

Objective: To explore factors influencing how well-informed women felt about hysterectomy, influences on their decision making, and on them receiving a less-invasive alternative to open surgery.

Methods: Online questionnaire, conducted in 2015–2016, of women who had received a hysterectomy in Australia, in the preceding two years.

Results: Questionnaires were completed by 2319/6000 women (39% response). Most women (n = 2225; 96%) felt well-informed about hysterectomy. Women were more aware of the open abdominal approach (n = 1798; 77%), than of less-invasive vaginal (n = 1552; 67%), laparoscopic (n = 1540; 66%), laparoscopic-assisted (n = 1303; 56%), and robotic approaches (n = 289; 12%). Most women (n = 1435; 62%) reported their gynaecologist was the most influential information source. Women who received information about hysterectomy from a GP (OR = 1.47; 95% CI 1.15–1.90), or from a gynaecologist (OR = 1.3; 95% CI 1.06–1.58), were more likely to feel better informed (p < 0.01).

Conclusion: This study is important because it helps clinicians, researchers and health policy makers to understand why many women still receive an open abdominal approach despite many learned societies recommending to avoid it if possible.

Practice implications: Additional information, or education about avoiding open abdominal approach where possible may lead to a greater number of women receiving less-invasive types of hysterectomy in the future.

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1. Introduction

Hysterectomy (removal of the uterus) is the most commonly performed major gynaecological surgical procedure. Annually, approximately 30,000 women receive hysterectomies in Australia; 434,000 in the USA [1,2].

In Australia in 2013–2014, 11,822 (38%) of hysterectomies were performed by total abdominal hysterectomy (TAH) through an open, abdominal incision, while less invasive approaches including vaginal hysterectomy (VH), total laparoscopic hysterectomy (TLH)

and laparoscopic assisted vaginal hysterectomy (LAVH) accounted for 8928 (29%), 5117 (16%), and 5381 (17%) of hysterectomy procedures, respectively [1]. Hysterectomy may also be conducted robotically (RH), though this approach is not widely available in Australia.

Despite its popularity, TAH is associated with significantly worse postoperative quality of life, pain, longer hospital stay, and a longer recovery period than less invasive approaches [3–5]. Based on level I evidence from systematic and Cochrane reviews, the American College of Obstetricians and Gynecologists (ACOG), American Association of Gynecologic Laparoscopists (AAGL), Society of Gynecologic Oncology (SGO), European Society for Medical Oncology (ESMO), European Society for Radiotherapy & Oncology (ESTRO) and European Society of Gynaecological Oncology (ESGO), and the Society of Obstetricians and

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Gynecologists of Canada (SOGC) have all published position statements and clinical guidelines supporting the use of less invasive alternatives to TAH for women with benign and malignant gynaecological conditions [6–10].

The aim of this study was to explore factors influencing how well-informed women felt about hysterectomy, influences on their decision making, and on them receiving a less-invasive surgical alternative to TAH.

2. Methods

We conducted an anonymous online survey of women who received a hysterectomy in Queensland, Australia in the preceding two years.

2.1. Questionnaire development

In 2014, in preparation of the present study, we developed, pilot-tested and refined a questionnaire to elicit information from women who had received a hysterectomy. By a process of iterative refinement, involving a review of the literature, a workshop of experts, interviews with ten women who had received a hysterectomy in the past, and pilot-testing with those women, we established face validity, and acceptability of the questionnaire.

The resulting questionnaire (Appendix A) comprised general demographic questions, and indication for the hysterectomy, together with multiple-choice questions relating to: (i) women's awareness about hysterectomy (knowledge of the different surgical approaches, and their relative pros and cons), (ii) women's sources of information about hysterectomy, and how well informed they felt, (iii) women's preferences about the type of hysterectomy they wished to receive, and type actually received (iv) influences on women's decision making relating to hysterectomy, and (v) women's experiences of their hysterectomy.

The questionnaire also contained questions that allowed free-text responses to allow detailed qualitative analysis. The present study is concerned with the multiple-choice awareness, informedness, preferences, and influences parts of the questionnaire; other study results will be reported in a separate manuscript.

2.2. Patient identification and recruitment

The study focussed on women who received a hysterectomy in the private health care system; these women are readily identifiable using government reimbursement data, and could be contacted through the government agencies' database.

Each year in Queensland, the costs of around 4000 (of a total of 6000 conducted; 67% hysterectomies are reimbursed, at least in part, by the Australian government [11]. Our study had a two year window, creating a sample population of 8000 women who had received reimbursement (from a combined total of 12,000 hysterectomies conducted in Queensland in the public and private health systems). The study had funding to support the recruitment, data collection, and analysis for 6000 participants.

A random sample of 6000 was selected from the available 8000 by the Department of Human Services (DHS), independent from the researchers using a computer generated random number list. The women in the sample were contacted by the DHS by post and invited to participate in the research by contacting the research team directly. No reminders were sent, and no information was available to the researchers on the number of letters returned to sender.

2.3. Data collection and analysis

The online survey was hosted using REDCap (Research Electronic Data Capture, Vanderbilt University); no identifying

information was collected from participants. All results were tabulated; characteristics of the participants were summarised using simple descriptive statistics.

2.3.1. Sources of information, and women's degree of informedness

We tabulated frequencies of responses relating to women's awareness of the available approaches to hysterectomy, specifically: (i) whether women were aware that more than one surgical approach exists, and (ii) their awareness of each specific approach (TAH, VH, TLH, LAVH, and RH).

We used ordinal logistic regression to explore relationships between level of informedness (four point scale of *not informed at all* to *very well-informed*), and (i) age, (ii) Body Mass Index (BMI), (iii) marital status (dichotomised into living with partner, living without partner), (iv) level of education, (v) household income (where disclosed), (vi) whether they had children, (vii) menopausal status at time of hysterectomy, (viii) comorbidities at time of hysterectomy (heart disease, high blood pressure, lung disease, diabetes mellitus, ulcer/reflux/stomach, kidney disease, anaemia/other blood, cancer, anxiety/depression, osteoarthritis/degenerative arthritis, back pain, rheumatoid arthritis, and other medical), (ix) reason for hysterectomy (fibroids, endometriosis, prolapse, pelvic inflammatory disease (PID), hyperplasia, irregular/heavy periods, post-menopause bleeding, severe period-pain, family history of endometrial/ovarian cancer, abnormal smear, cancer, personal choice, contraception, don't know/can't recall, and other), (x) who first suggested hysterectomy, and (xi) who informed them about hysterectomy. Results were presented as proportional odds ratios (the odds of a one unit change in the predictor variables leading to a one category-level change in level of informedness, given that all other variables in the model remained constant).

2.3.2. Procedure preferences and procedure received

Women could choose to preference only one surgical approach, more than one surgical approach, or express no procedural preference. Here we present two analyses; one for the entire cohort, and a sub-group analysis of the women who had a single procedural preference.

For the entire group, we tabulated overall frequencies and proportions of preferred vs. received procedures. For the women with single preference responses, we cross-tabulated frequencies and proportions of procedure received by the single procedure preferred.

2.3.3. Influences on decision making and procedure received

We used multinomial logistic regression analyses to explore relationships between factors influencing women's preferred-approach decision-making, and their receipt of a less invasive alternative to TAH. The influences (of which respondents could nominate 0, 1 or >1) were: surgeon's preference, surgical procedure's recovery time, surgical risks, sexual functioning, body image, family support person preference, cost, or other. Respondents could rank the importance of each influence on a four-point ordinal scale of *not at all important*, *a little important*, *somewhat important*, and *very important*. Because of insufficient numbers, RH was excluded from this sub-analysis.

Relative Risk Ratios of receiving each alternative surgical approach, with TAH as the reference procedure, and *not at all* as the level-of-importance reference, were used to describe associations; *p* values <0.05 were considered to be statistically significant.

All analyses were conducted in R Version 3.3.3 [12]. Ordinal logistic regression analyses were conducted using the *polr* function of the MASS package, multinomial regression analyses were conducted using the *multinom* function of the *nnet* package [13].

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