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Running Head: Women's Hysterectomy Experiences

Women's Hysterectomy Experiences and Decision-Making

Ayse K. Uskul\*, PhD Candidate  
York University  
Department of Psychology  
4700 Keele Street, Toronto, ON  
M3J 1P3 Canada  
e-mail: [auskul@yorku.ca](mailto:auskul@yorku.ca)

Farah Ahmad, MBBS, MPH  
University Health Network,  
Women's Health Program

Nicholas A. Leyland, BAsC, MD,  
FRCSC  
Mt. Sinai Hospital, Department of  
Obstetrics and Gynaecology

Donna E. Stewart, MD, FRCPC  
University Health Network,  
University of Toronto

\* Correspondence concerning this article should be addressed to the first author.

### Abstract

The goal of the study was to examine women's experiences with gynaecologic symptoms and how they decided to undergo hysterectomy. For this purpose, twenty-nine women were interviewed in hospital within three days of undergoing hysterectomy. The interviews elicited information about the nature of the problem that caused the women to seek medical help, actions taken to solve their problem, their relationship with their gynaecologist, information seeking patterns and decision-making about hysterectomy. Although findings revealed that the symptoms women suffered had a negative impact on their lives, most women delayed seeking medical help and attributed their symptoms to factors other than a physical problem in their reproductive system. Most of the participants' information about the symptoms and possible treatments came from their consulting other women with similar problems. The women reported that their gynaecologist did not initiate a comprehensive discussion about other treatments and their advantages and disadvantages. Only women who had informed themselves about other treatments actively discussed alternatives to hysterectomy with their physicians. The women's decision-making process about undergoing hysterectomy was difficult and depended primarily on the women's illness experiences, age, wish for future children, information they gathered from their gynaecologist and from other women. The findings are discussed in relation to the importance of information provision by gynaecologists and its effects on women's decision-making about hysterectomy.

Keywords: hysterectomy, illness experience, decision-making, qualitative study

Hysterectomy is one of the most commonly performed surgical procedures in the United States and Canada (Gentleman, Vayda, Parsons & Walsh, 1996), yet little is known about how women experience the pre-hysterectomy period, including their experience with symptoms, actions and treatments taken to solve their problem, relationship with their physicians and decision-making about hysterectomy. This paper reports on a study that was conducted to understand women's experiences with their symptoms before surgery and how they eventually decided to undergo hysterectomy.

#### Background: The discretionary nature of hysterectomy

Hysterectomy rates vary across countries. For example, Canada has a higher rate of hysterectomy than England or Sweden and a lower rate than United States (Kjerullf, Langenberg & Guzinski, 1993; Ontario Expert Panel on Hysterectomy, 2002). Australia has a higher rate of hysterectomy than a number of European countries, but a lower rate than North America (Santow & Bracher, 1992). Hysterectomy rates also vary with urban-rural residence with more hysterectomies performed in smaller, rural areas (Blais, 1993; Hall & Cohen, 1994).

Patient-related factors may also contribute to variations in hysterectomy rates. Women with less education and lower income are more likely to undergo hysterectomy than women with higher education and income (Coulter, Peto & Doll, 1994; Kjerullf, Langenberg & Guzinski, 1993). Most hysterectomies are performed between the ages of 35-49 (Brett, Marsh & Madans, 1997; Wilkoks, Koonin, Pokras, Strauss, Xia & Peterson, 1994).

Reproductive organ cancer is usually an indication for hysterectomy, but fewer than 10% of hysterectomies are performed for malignant conditions. Most hysterectomies are performed because of conditions such as fibroids, abnormal uterine bleeding, chronic pelvic pain, prolapsed uterus and endometriosis (Travis, 1985; Vessey, Villard-Mackintosh, McPherson, Coulter &

Yeates, 1992), where it is considered an elective procedure (Kramer & Reiter, 1997). The optimal rates of hysterectomies in any population are unknown, making it difficult to judge whether observed rates are too high or too low. This elective nature and varied prevalence of hysterectomy have fuelled debate about its indications, risks and benefits.

Undergoing hysterectomy includes many risks, despite improved surgical and anaesthesia practices. Moreover, if the ovaries are removed (oophorectomy), women may enter surgical menopause that might lead to earlier onset of physical and psychological changes such as hot flashes, mood swings and bone density loss. Even women who retain their ovaries may enter early menopause from a reduced blood supply to the ovaries. After hysterectomy some women report a decrease in their general sense of well-being and sexual satisfaction. In addition, women who undergo hysterectomy lose time from work during the procedure and recovery. Finally, hysterectomy puts financial burden on the health sector if it is performed unnecessarily (e.g. Bachmann, 1990; Cohen & Young, 1998; Ross, 1996).

Despite the knowledge about possible negative consequences related to hysterectomy and the presence of alternative treatments such as hormonal therapy, drug therapy, myomectomy, endometrial ablation, and embolization, hysterectomy rates are still high, especially in North America. Why is this? Firstly, alternative treatments to hysterectomy are not always successful. Physician related factors also play a role such as preference for a permanent solution, hospital affiliation (teaching vs. non-teaching) (Hall & Cohen, 1994), sex and age of physician (Bickell, Earp, Garrett & Evans, 1994; Coulter, Peto & Doll, 1994). Other factors reported include medical training that previously focussed on hysterectomy as the main solution for several gynaecological conditions (Travis, 1985) and the presence of better operative techniques and surgical equipment to perform hysterectomies (Wijma, Kauer & Janssens, 1984). Patients' preferences and expectations about treatments also undoubtedly influence decisions about

hysterectomy. (Marchant-Haycox, Liu, Nicholas & Salmon, 1998; Salmon & Marchant-Haycox, 2000).

### How do women decide to undergo a hysterectomy?

In previous studies, some factors that have been identified as playing a role in women's decision-making to undergo hysterectomy were women's perception of and beliefs about symptoms and treatment, communication with other women who have gone through similar experiences (Entwistle, Skea & O'Donnell, 2001, Williams & Clark, 2000), and discussion of alternative treatment techniques (Dorin, 1998; Corney, Everett, Howells & Crowther, 1992; Schriener & Tucker, 1997). The present study was designed to obtain an in-depth understanding of the effects of women's symptom experiences and women's relationship with their physician on their decision-making about hysterectomy by contributing to the existing knowledge in the following ways. Firstly, the present study was not limited to women's decision-making and experiences of hysterectomy as examined by previous studies, but also attempted to understand how women experienced their symptoms and how this might have led them to a hysterectomy. Thus, we intended to provide an understanding of a longer time frame by examining how the physical problems began and evolved, how women sought help for their problems, and how they eventually decided to have a hysterectomy. Secondly, this study was conducted in a Canadian context within a universal health care system. While most published studies on women's hysterectomy experiences focus on white Western women, this study was conducted in Toronto that is a highly multicultural city and our sample reflects a cultural and economic diversity that we hoped would enrich and contribute to the generalizability of our findings. Thirdly, although there have been quantitative Canadian studies on hysterectomy, to our knowledge there has not been any qualitative study conducted to provide a deeper understanding of the salient issues.

## Method

### Procedure and Participants

Participants were recruited from a large teaching hospital in Toronto, Canada after the approval of the study by the research ethics board. The gynecologic headnurse was contacted weekly to obtain a list of patients booked for hysterectomy for benign conditions. These patients were contacted in hospital within three days after surgery and were given a short description of the study and asked if they were willing to participate. Patients who could not understand English well enough to give informed consent or to complete the interview were excluded. Eligible patients who agreed to participate then signed a consent form. One researcher conducted a semi-structured interview with all participants. Interviews were not tape-recorded because some women had difficulty speaking loudly enough after recent surgery; some were sharing the room with other patients and were concerned about privacy and others did not want the interviews tape-recorded. As a result, the interviewer asked patients to speak slowly while she took detailed field notes on the interviews, and noted any nonverbal behaviors and the general atmosphere of the interview.

Twenty-nine women aged 35-80 (mean age of 50.2) were interviewed. Twenty-one participants were married, four were single and four were divorced or widowed. All women, except one, had children. Their ethnic background based on self-identification was eleven Canadians, eight Europeans, five Asians and five from Africa and the Caribbean. All but two had at least completed high school. Fourteen women had a total hysterectomy (uterus and cervix was removed), thirteen had a subtotal hysterectomy (removal of the uterus only), and two women did not know what kind of hysterectomy they had undergone. One of these women did not know whether her ovaries had also been removed and the other woman had no knowledge of the

operation. All participants had had an abdominal hysterectomy, except one who had had a vaginal hysterectomy.

The semi-structured interview guide contained questions in the following domains: demographics, nature of the problem that caused them to seek medical help, actions taken to solve their problem, their perception of and relationship with their gynecologist, patterns of decision-making about hysterectomy. Participants were offered the opportunity to ask questions and add further information.

The coding of the interviews was performed using thematic content analysis (Miles & Huberman, 1994) with the help of QSR-NUD\*IST (nonnumerical unstructured data indexing, searching and theorizing) (1995). An initial analysis was performed to find the major themes. A coding scheme reflecting these major themes was developed. Relationships among the categories were explored and categories were compared and contrasted to examine if women of different ages and cultural backgrounds differed in their accounts. The coding was a collaborative effort by the first and second authors who finalized results after discussion of any conflicting decisions.

## Results

Analyses performed to examine possible cultural differences between women from different ethnic origins did not reveal any systematic differences in ethnicity or age.

### Nature of the problem

Participants described in different ways the problem that had made them visit the doctor. Women who had had no symptoms had been informed about a problem at a check-up, at childbirth or when they visited their physician for another complaint. Such women described their problem by referring to the terminology used by their physicians, for example “fibroids” or “prolapsed uterus.” Other women had experienced symptoms such as irregular bleeding, menstrual cramps, painful and heavy bleeding, abnormal pain or pressure, bladder or pelvic pain,

painful intercourse, frequent urination and feeling constant weakness and tiredness. These symptomatic women reported experiencing these problems for a considerable time ranging from 6 months to 42 years, with a mean length of 4.6 years (42 years was excluded as an outlier).

Effects of symptoms on women's lives. Women with abnormal bleeding reported negative consequences of symptoms on physical, psychological and social aspects of their lives. Sometimes symptoms affected women's lives greatly; for example, heavy bleeding interfered with home and social activities and work. They reported that their lives were shaped around this heavy menstrual bleeding. One woman explained: "My heavy bleeding kept me home all the time. If I had to leave home, I had to make sure that I was close to a bathroom because I had to change my tampon every single hour". Chronic bleeding often resulted in anemia that caused tiredness and weakness. Women who had irregular bleeding complained about the unpredictability and lack of control they had over their bodies. One participant reported: "You don't have a life basically. You never know when it is going to come. It is very unpredictable. I used to have it one day, then two days nothing, and then again and so on". Some symptoms restricted women's activities and relationships with their children, husbands, friends, and work. Impaired function also caused lower self-esteem, impaired sense of well-being, nervousness, irritability, feelings of helplessness and depression. One woman summed up how she felt about herself and her life: "I was getting suicidal. I couldn't live like that anymore. I had too many unpleasant days. I was in constant trouble and constant discomfort". Other women reported mild symptoms which were inconvenient, but tolerable such as abdominal bloating, not being able to sleep on their abdomen, back-pain and increased urination.

Causal attributions. Most women did not attribute their symptoms to any particular cause. Eight women remembered having attributed their problems to aging, stress or hormones. One woman was suspicious that diet injections had caused her heavy bleeding, while the rest thought

that it was normal and all part of being female since so many women suffered from it: “I thought women have to live with it”. There was only one woman who attributed the ‘malfunctioning’ of her body to a physical problem in her reproductive system and thought that her heavy bleeding might be caused by a cyst.

#### Actions taken to deal with the problem

Delay in help seeking. The majority of the women waited a long time before seeking medical help and three major themes emerged from this. The first was the adoption of a ‘wait and see’ approach in which women chose to self-monitor symptoms hoping that they did not represent anything serious or that they would spontaneously go away with time. One woman who knew about her fibroids decided: “I waited for about 6 months [and hoped it would] go away. I was close to menopause anyway, so I thought that it would change.” The second theme related to the fear that some women had in relation to the consequences of potential treatments. One woman who was told that she had a fibroid said: “I waited, I put it off. I was undecided. It might have meant that I couldn’t have any kids and I had a couple of miscarriages, so it was hard to decide.” The third theme related to social responsibilities and daily hassles such as caring for other sick people in their family or helping their adult children with newborns, that made women delay seeking help. One woman explained: “It started last summer, but my husband got a heart attack, and I had to take care of him. So, I postponed it. He told me to go, but I wanted to be with him.”

Information seeking and formation of ideas about treatment. Although seeking medical treatment early was not typical for these women, seeking information was very common. The preferred method was talking with other women with similar problems. Seven women mentioned that they read medical books or journals or searched the Internet to learn more about their symptoms and treatment. During the information seeking process, women tended to form their

own ideas about possible solutions to their problem: “I was thinking of hysterectomy. That was one choice, and then there was medication that would make fibroids shrink, but they would grow again”, “I read about three treatments: hysterectomy; let it go and when you enter into menopause it will shrink; and inserting coils to block the fibroid’s nourishment”. Some women acted upon the information they obtained: “[...] Then I heard about embolization. I learned where it was performed and saw the doctor who specialized in it, but he decided that it wasn’t for me”.. Women who were determined that hysterectomy would be the best solution were usually influenced by friends or family members who had had hysterectomies and strongly recommended them. Three women reported that they had no idea about treatments before they consulted their gynecologist.

Use of complementary treatments. Only three women reported using complementary treatments. Although Chinese medicine, herbal teas, natural oils and exercise were mentioned, they were seldom tried. One woman, however, reported that she avoided Western medicine as much as possible, but finally saw a medical doctor because her symptoms did not go away after many complementary treatments.

#### Patients’ perceptions of their interaction with gynecologists

After living with symptoms for some time, women decided to seek medical help through their family physicians. Depending on the severity of symptoms and test results, family physicians then referred women immediately to a gynecologist or decided to first try other solutions such as watchful waiting, waiting until menopause so fibroids would shrink or bleeding would stop or trying Kegel exercises for urinary incontinence. Eventually, all of these women were referred to a gynecologist because none of these methods proved satisfactory for them.

Perceived information provision. Women were asked if they thought they received enough information from their gynecologists about their problem, alternative solutions and the

advantages and disadvantages of each. Initially, women said that they were satisfied and reported: “The doctor explained me everything“, “He was very detailed”, “I got all the information I needed.” However, the information was exclusively or predominantly about hysterectomy. When the interviewer asked again whether they discussed any alternative treatment methods, they were not able to be specific. Two women were critical in their accounts: “I got to know much of the information from the Internet. I didn’t learn a lot from him. He showed me what he was going to do during the operation, but he didn’t tell me much about other treatments or the post-operative phase”. “I thought it was my responsibility to figure it out. He did not tell me everything. When he did not tell me anything, then my friends and family would say ‘ask him this or that’”. Another woman reported problems with her previous gynecologist: “That was one of the problems I had with that doctor. He asked no questions and answered none of mine. Then I was referred to my current doctor by my family physician.”

Treatment offered and its acceptance. Women were asked to describe what kind of treatment their gynecologists advised. In only four cases was hysterectomy mentioned as the first and only choice (due to the size and location of fibroids). Other women with fibroids were advised to wait and see if their fibroids would shrink after menopause or to try medication first. For all women with a prolapsed uterus, pessaries or Kegel exercises were suggested first to help with urinary incontinence.

Women were asked about their acceptance of the treatment suggested by their gynecologist. When hysterectomy was offered as the initial solution, reactions depended on women’s age, wish for future children, symptom severity and trust in the doctor. Six women who were young or who were not comfortable with their physicians’ communication skills did not accept hysterectomy right away. Ten women who thought they had suffered long enough or who did not want more children were more ready to accept hysterectomy. Five women sought a

second opinion, and when given the same treatment recommendation, they decided to undergo hysterectomy. Women who were offered an initial treatment that did not include hysterectomy accepted and adhered to it whether it was watchful waiting, medication or Kegel exercises.

Discussion of alternative treatments. When participants were asked if they had discussed other treatments with their gynecologist, women who had collected information before the consultation reported that they had asked about alternative treatments. One woman said: “I asked him about laser surgery. He scanned me and said that the uterus was very deep and if he used laser, he wouldn’t be able get everything”. Women who passively accepted their physicians’ treatment offer perceived asking about different treatments to be unnecessary or inappropriate: “I didn’t ask him. I thought that it was something for an expert”; “No, I took it for granted, I mean what the doctor said. I had trust in the doctor”; “No, whatever the doctor tells me, I’ll do it”.

### Making the decision

Factors affecting decision-making. All women in the study had undergone hysterectomy, but some women took longer to decide to undergo the surgery after their physician had advised it. Women who were concerned about fertility, surgery, premature menopause or not being able to fulfill their responsibilities at home or at work took longer to decide. Such women reported that they were advised by their gynecologists to think about it until they were comfortable with the decision and none mentioned any pressure from their doctor. It seemed that women accepted hysterectomy faster if their lives were adversely affected by symptoms; they did not wish to have children or were strongly influenced by other women recommending hysterectomy.

Some women continued the decision-making process after agreeing to undergo hysterectomy. Two women who were comfortable with their uterus being removed were concerned about removal of their ovaries causing early menopause and negotiated with their physicians to keep them. One woman explained: “ I accepted the hysterectomy part, but not the

ovaries. I did more research on that. He said if the ovaries were damaged, then he would take them out, but if not, he'd keep them intact. I still have the ovaries and the cervix. I want to go into menopause when I am due.”

Although women were, in general, confident about having undergone the surgery, a few of them referred to the decisional conflict they had experienced before the surgery. “Of course, it is surgery. I wasn't sure if it was the right solution. I had my ups and downs”, “It wasn't totally OK. I made a decision, but always kept questioning that decision. Am I going to open Pandora's box, will the surgery cause other problems? You never know. I called the doctor to cancel it, and then I thought and left a message at 1.00 am to say that I wanted to have it”. Emotions such as anxiety and fear were also frequently mentioned in relation to the risks of undergoing a surgery, receiving anesthetics and the detection of additional problems during the surgery.

Most important factors for the final decision. Patients were asked what the most important factors were that led them to decide to undergo hysterectomy. Women who suffered from heavy abnormal bleeding particularly referred to the decreased quality of their lives caused by the symptoms. One woman stated, “I wanted to feel healthy, be able to do things that I used to. I wasn't a normal woman anymore. It was impossible to live with that pain and bleeding”. Some women mentioned the size and growth of their fibroids as the main reason for their decision. “It was the danger that it could cause some damage to the internal organs. The fact that it was growing so rapidly made me scared”. Other women referred to their doctor's decision as the most important determining factor, “It wasn't me who decided. I was not suffering too much. He had the reports and he had already made up his mind. I went there and he told me that I had to be operated”. In general, women saw hysterectomy as a relief from their symptoms.

It was not only the patient and/or the doctor who was involved in the decision-making. After the gynecologist offered advice, women talked to their families, friends, other women who

had undergone hysterectomies, and their husbands before making their final decision. Although it wasn't the general pattern, some women again searched for further information. One woman explained, "I talked to other women. But the stories I heard from them did not affect my decision. There were so many stories. It was mainly the literature search that helped me. I wanted to know about its success rates and risks".

### After the Surgery

The women were asked how they felt about having undergone hysterectomy and what changes they expected in their bodies. All women emphasized the relief of having the surgery over. They mainly expected positive changes and were looking forward to life without their previous symptoms: "I won't go through pain and bleeding again. With that, I will also get emotional stability". Nevertheless, ambiguous expectations and discomfort about possible negative consequences of menopause were frequently mentioned, particularly in relation to the effects of hysterectomy on sexual drive and functioning, and the effects of hormones after surgery.

### Discussion

In this study, we examined twenty-nine women's symptom experiences and interactions with gynecologists and how those affected their decision to undergo hysterectomy. Three important findings were identified with regard to women's decision to undergo hysterectomy. First, how women perceive, interpret and deal with their symptoms had significant impact on women's decision-making. Second, the influence of friends, family, and other women's experiences and opinions appeared to be a critical factor for some women. Third, information received from gynecologists appeared as a major factor in perceiving hysterectomy as a good solution to the gynecological problems women had been experiencing.

The findings regarding symptom perception, interpretation and management, including casual attributions, delay in seeking medical care and relying on social ways of information seeking suggest that women can benefit from having access to both general and specific information about women's health. Despite increasing information on women's health, there seems to be a need for health education to help distinguish between what is normal and abnormal bodily functioning. For example, educating women to distinguish between normal and abnormal vaginal bleeding or identifying other common gynecologic problems may contribute to making timely decisions in terms of health care and information seeking.

The influence of other sources of information appeared to be strong. The majority of the women reported that they had already formed their opinion about the best treatment before visiting a gynecologist. For example, some women were so convinced by other women (family, friends or others) on the superior effectiveness of one particular strategy –in most cases hysterectomy- that they made it clear to the gynecologist that this was what they wanted. However, the inherent danger of inappropriate comparison with, and inaccurate information from, other women might well be problematic. Unless other compelling information is offered by gynecologists, the (possibly incorrect) preformed ideas will persist and have a strong influence on women's decision-making.

The information the women received from their gynecologists also played a vital role in women's decision-making. Most women in this study reported that information they received from gynecologists focused on hysterectomy, but failed to mention alternatives to this treatment in keeping with previous studies (e.g. Corney, Everett, Howells, & Crowther, 1992; Entwistle, Zoe, & O'Donnell, 2001; Scriven & Tucker, 1997). Women who reported having discussed alternative treatment methods with their gynecologists were mainly women who had discovered information themselves before they consulted their physicians. These women were also more

actively involved in the determination of the type of surgical procedure (e.g. vaginal vs. abdominal approaches and oophorectomy vs. retention of ovaries) and exploring the advantages and disadvantages of different procedures. In general, unless a woman asked specific questions about the procedure or alternative methods, this was not typically raised by the gynecologist, suggesting that women who did not have access to information or did not feel the need to search further were disadvantaged in terms of being informed about other treatment options. This finding also suggests that information about the advantages, disadvantages, and outcomes of treatments for benign uterine conditions could facilitate women in becoming informed about their options and in formulating salient questions to pose at the gynecologic consultation.

One goal of this study was to contribute to the generalizability of the results by having the study conducted in a hospital that hosts patients from different cultural backgrounds. Our findings did not reveal any systematic difference in hysterectomy experiences between women with different cultural backgrounds, unlike a few other studies that have reported cultural differences (e.g. Lalinec-Michaud & Engelsmann, 1989). This may be due sample characteristics as the interviews were conducted only with fairly well educated women who could speak and understand English. This was mainly due to the lack of a multilingual research team to conduct interviews with women who were not fluent in English. This limited the cultural diversity and different levels of acculturation represented in the sample. The lack of cultural differences may not be replicated in a sample that includes new immigrants who are less acculturated. Moreover, findings in this study also have to be evaluated considering the high level of education of the sample. In addition, one has to remember that this study was conducted in a universal health care system and the results may not be generalizable to settings where economics determine access to health care.

The fact that interviews were conducted shortly after hysterectomy and in a hospital setting may have influenced the results as previous studies suggest that patients' retrospective perceptions of decision-making shift over time (e.g. Larsson, Svardsudd, Wedel, & Saljo, 1989). Further research should include women of more diverse backgrounds and serial interviews conducted longitudinally from onset of symptoms to the year following surgery to obtain a more complete picture of women's decision-making about hysterectomy.

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