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Identifying What Matters to Hysterectomy Patients: Postsurgery Perceptions, Beliefs, and Experiences

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Purpose	Hysterectomy is the most common nonobstetrical surgery for women in the United States. Few investigations comparing hysterectomy surgical approaches include patient-centered outcomes.
Methods	The study was performed at Henry Ford Health System (Detroit, MI) between February 2015 and May 2015. A total of 1,038 eligible women — those 18 to 65 years of age and who had an electronic medical record-documented Current Procedural Terminology (CPT®) code or an International Statistical Classification of Diseases, Ninth Edition (ICD-9) code of hysterectomy between December 2012 and December 2014 — were selected and recruited. A question guide was developed to investigate women's experiences and feelings about the experience prior and subsequent to their hysterectomy. Analysis utilized the Framework Method. Study data were collected through structured focus groups with 24 posthysterectomy women in order to identify patient-centered outcomes to employ in a subsequent cohort study of hysterectomy surgical approaches. One pilot focus group and 5 additional focus groups were held. Qualitative data analysis, using data from coded transcripts of focus groups, was used to identify themes.
Results	Focus groups with women who previously had a hysterectomy revealed their pre- and posthysterectomy perceptions. Responses were grouped into topics of pre- and postsurgical experiences, and information all women should know. Themes derived from responses: 1) decision-making; 2) the procedure (surgical experience); 3) recovery; 4) advice to past self; and 5) recommendations to other women.
Conclusions	These analyzed data suggest a need for increased education and empowerment in the hysterectomy decision-making process, along with expanding information given for postoperative expectations and somatic changes that occur posthysterectomy. Findings about perceptions, beliefs, and attitudes of women having undergone hysterectomy could support health care providers deliver more patient-centered care. (<i>J Patient Cent Res Rev.</i> 2018;5:167-175.)
Keywords	hysterectomy; patient expectations; focus groups; qualitative data analysis; surgery; gynecology

Hysterectomy is the most common nonobstetrical surgical procedure for women in the United States.¹ While there is a growing number of uterine-sparing approaches for addressing many of the various indications for this surgery, hysterectomies are likely to remain a common

procedure for the foreseeable future. Surprisingly, despite the high rate of hysterectomy, no evidence-based clinical care guidelines based on patient-centered outcomes exist. Previous guidelines are based on clinical factors such as blood loss, length of hospital stay, and complications; however, patient concerns have not been central to these decisions.

Prior research studies on hysterectomy have used standardized quality-of-life measures, yet this approach may not necessarily have facilitated guideline development influenced by patient-desired

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outcomes.²⁻⁴ It is possible that women may have different goals for their surgery than information that is reflected in standardized quality-of-life assessment. For example, some women might prefer an “open” hysterectomy in which the incision is made very low beneath the waistline versus having the appearance of multiple small-port incision scars on the abdomen from a laparoscopic procedure — even if the laparoscopic procedure might be associated with a quicker return to work or reduced blood loss.

A growing number of studies have investigated the relationship between hysterectomy surgical approach (eg, vaginal vs abdominal vs laparoscopic, supracervical vs total) and patient-reported outcomes in various populations; however, few studies have focused on outcomes specifically identified by hysterectomy patients as being of greatest importance to them.^{2,4-8} The personal health goals and preferences of each patient are considered patient-centered outcomes, outcomes that, if understood, could influence clinical care.

This paper reports on the first step in our overall goal to identify and compare patient-centered outcomes across surgical approaches among black and white hysterectomy patients at Henry Ford Health System (HFHS) in Detroit, Michigan. While previous work did identify women’s beliefs about hysterectomy, this earlier work did not include women who had already had a hysterectomy.⁹ To identify the patient-centered outcomes of interest in our longitudinal study of hysterectomy patients, we conducted focus groups with hysterectomy patients who had their surgeries at HFHS hospitals. This work, we believe, is among the first reports of hysterectomy patients’ priorities for their clinical care, decision-making, and recovery related to hysterectomy.

METHODS

Following approval from the institutional review board, initial conversations were held with 4 hysterectomy patients who volunteered to discuss their experience, individually, with one of the authors (G.W.). The women had different surgeons and surgical approaches. The women were asked to describe their health prior to the surgery and recount their experiences regarding the process of deciding to have the surgery, type of surgery, and their recovery. They were asked to share

comments about what they would want other women to know about hysterectomy. The following themes were discussed: reason for surgery, satisfaction with the surgery, and possible fears due to the surgery.

Summaries of the discussion with these 4 women provided the information that was used to create the questions for the focus group discussion guide. In total, 6 focus groups were initially scheduled with patients from HFHS, with additional focus groups planned in the event that saturation of themes was not reached after the initial wave. To account for participant responses being affected by the time since surgery, 3 different groups of women, defined by the time since hysterectomy, were recruited for participation. Postsurgery time periods were defined a priori: 0–6 months; 6–24 months; and 24–60 months. Black and white women are the most common race groups among HFHS patients, and focus groups were stratified by these two races (based on feedback from the pilot focus group). Race was defined by the classification recorded in the electronic medical record (EMR) of each woman.

Women were selected from an electronic data pull through HFHS’s virtual data warehouse, and an EMR review was used to confirm eligibility. Patients having an EMR-documented CPT[®] code of hysterectomy or a related ICD-9 code (68.3–68.7, 68.9) from December 2012 to December 2014 (N=2,455) were selected for participation. Patients less than 18 or greater than 65 years old (n=203) and patients who were deceased or status unknown (n=424) were excluded. Patients with a record in the HFHS tumor registry for a cancer diagnosis were excluded (n=447), as cancer patients have a different treatment course than women undergoing hysterectomy for noncancer reasons. Women without a phone number or address or who had an unknown race also were excluded (n=15, n=1, and n=218, respectively). Non-English speakers were excluded (n=109). Participants also were recruited through electronic advertisements in the employee newsletter at HFHS. There were 1,038 eligible women identified.

A portion of the eligible women were postal mailed an introduction letter to the study. The letter described the purpose of the focus groups and indicated that someone from our staff might call to invite their participation in a focus group. A phone number was included for

questions or interest in participation. We sent batches of letters to small subsets of the eligible women until the focus groups were filled. In total, 280 (27.0% of eligible patients) letters were mailed to women encompassing the 3 time periods of 0–6 months (n=105), 6–24 months (n=105), and 24–60 months (n=70) posthysterectomy. Five letters were returned to sender. From 773 recruitment phone calls, 39 women agreed to participate and 24 women attended a focus group.

Participants were given their choice of two dates to attend a focus group per postsurgery time point. Focus groups were scheduled throughout the day and region to better accommodate women. All focus groups were audio-recorded and transcribed for qualitative data analysis. Each focus group was facilitated by one moderator, one assistant, and a notetaker. Focus groups lasted approximately 90 minutes. Participants were compensated \$40 and provided refreshments. At the focus group, participants were asked to complete a brief survey that collected additional demographic data. Written informed consent was obtained prior to each focus group.

Transcribed responses to the focus group questions were entered into a spreadsheet to facilitate matrix-style Framework Method analysis.¹⁰ Content analysis was completed iteratively, with study goals and focus group questions providing the initial organizational framework. Experienced reviewers (G.L.A., H.O.), who participated in running the focus groups and who have previously worked on focus group research published in peer-reviewed publications,¹¹⁻¹³ read through each transcript at least 2 times and entered relevant topics and direct quotes. Separately, the study principal investigator (G.W.) listened to all focus group recordings. Preliminary codes to identify topics, themes, and subthemes were identified, discussed, revised, and applied to the data.¹⁴ The reviewers met periodically for consensus checks to identify any additional subthemes and to check consistency of the coding.

A list of topics was identified by the analysis team. During the course of analysis, coders reviewed the same randomly selected transcripts, and identified and compared themes until no new themes were identified. Direct quotes to represent themes were identified by speaker number and date of the focus group session.

The mean intercoder calibration of topics and themes across the calibration categories was 90%.

RESULTS

In total, 24 women attended a focus group between February and May 2015. At the focus groups, participants self-identified their race as black (n=12) or white (n=11); 1 participant did not report her race (ie, unknown). All participants were within 5 years of their hysterectomy. Focus group participants were categorized by time since surgery and race: up to 6 months (n=7: black [4], white [3]); 6 to 24 months (n=6: black [4], white [2]); and greater than 24 months to 60 months (n=10: black [4], white [6]). As responses were consistent across all race and “timing” groups, we did not conduct additional focus groups (saturation was reached). Three participants did not complete the entire voluntary postgroup survey.

Demographic information extracted from the EMR is presented in Table 1. Overall, average participant age was 49.6 years (SD: 12.3 years) and average time since surgery was 1.7 years (SD: 1.4 years).

Ensuing results are presented by topic, theme, and subtheme. Responses generally grouped into topics of pre- and postsurgical experiences, and information all women should know. Response themes included 1) decision-making, 2) the procedure (surgical experience), 3) recovery, 4) advice to past self, and 5) recommendations to other women. Selected quotes are presented below and all quotes are verbatim (B = black woman; W = white woman).

The Presurgical Experience

Decision-Making (Personal Perceptions): Many women shared worries about age, preexisting conditions, previous women’s health experiences, and stories from other women as affecting their decision of having a hysterectomy. Many expressed that a hysterectomy eliminated their ability to carry a child, and several talked about the stigma of not having all their reproductive organs, leaving them “incomplete” as a woman. Others stated that their life was at risk if they did not have a hysterectomy.

W: “I don’t know that I was prepared at all, only because again, it was an immediate type thing ... his [the doctor’s] advice was, ‘You’re not going to get

Table 1. Demographics by Race and Time Posthysterectomy for Focus Group Participants

Characteristic	Total study population	Black race (n=12)			White race (n=11)		
		0–6 months	6–24 months	24–60 months	0–6 months	6–24 months	24–60 months
Participated in focus group, n	24*	4	4	4	3	2	6
Completed postgroup survey, n	22†	2	3	5	3	2	6
Age, mean ± SD	49.63 ± 12.25	49.92 ± 10.40			49.18 ± 15.52		
Years since surgery date, mean ± SD	1.69 ± 1.42	1.41 ± 1.19			2.10 ± 1.68		
Marital status, n							
Married	10	1	1	3	1	--	4
Divorced	6	1	--	1	1	1	2
Widowed	--	--	--	--	--	--	--
Separated	--	--	--	--	--	--	--
Never married	4	--	2	--	1	1	--
Partnered	1	--	--	1	--	--	--
Unknown	3	--	--	--	--	--	--
Income, n							
<\$25,000	4	--	1	--	1	1	1
\$25,001–\$50,000	2	--	--	1	--	--	1
\$50,001–\$75,000	5	--	--	3	1	1	--
<\$75,000	4	--	--	1	1	--	2
Unknown	9	2	2	--	--	--	2
Education level, n							
< High school	2	--	--	--	--	2	--
High school diploma/GED	4	--	1	--	2	--	1
Associate or technical degree	1	--	--	--	--	--	1
Bachelor's degree	4	--	--	4	--	--	--
> Bachelor's degree	3	--	--	1	1	--	1
Unknown	10	2	2	--	--	--	3
Structures removed, n							
Ovary(ies)	11‡	1	3	2		1	3
Fallopian tube(s)	17‡	4	4	1	1	2	4
Cervix	13‡	2	2	1	3	1	3
Uterus	24‡	4	4	4	3	2	6
1 structure	4			2			2
2 structures	4	1		1	2		
3 structures	11	3	3		1	2	2
4 structures	5‡		1	1			2

*Includes 1 participant of unknown race from the “0–6 months since surgery” group.

†Includes 1 participant of unknown race; excludes two participants who did not complete the questionnaire.

‡Includes 1 participant of unknown race.

GED, general equivalency diploma; SD, standard deviation.

any better. It's not going to get any different. This is just the route you have to go. Um, and this is what you can expect.' And the whole time he's holding my hand ... so I didn't need any more preparation to — to go through with this. I just needed to know that I was confident in his decision."

Decision-Making (Social Support): Women who had time to consider their options prior to surgery reported talking with their doctors, family, partners, and other women who had hysterectomy experience. Most women spoke with other people when making their decision, except for a few participants who required an emergency hysterectomy for urogynecologic complications. Younger women reported not having a peer close in age to consult, making their decision difficult. A few women researched on the internet or prayed on their decision, and some women expressed reluctance to discuss their hysterectomy with others due to its life-altering effect on their ability to reproduce. Further, some women mentioned the stigma of being “less of a woman” due to a hysterectomy as a reason to not seek social support. Regardless of preference to seek advice from others or investigate independently, most women indicated they believed they had enough information to make a decision about having the surgery, with many reporting reliance on physician recommendations. Some women felt they did not have a choice about having the surgery or surgical type.

B: *“I had serious conversations with my husband. He wanted to let me know that he was supportive and whatever I decided, he was with me. But, you know, in having a conversation with him, I was kind of convinced that I really needed to have it done because of the growth.”* [continued] *“There was also a stigma attached ... wasn't something that I wanted to discuss with everybody either. And especially when you're young and you have a hysterectomy, you're looked upon as less than a woman. That stigma, it's there and it's real ... lost your reproductive organs, and so you're kind of less than a full woman.”*

Decision-Making (Personal Goals for Surgery): When asked about what surgical outcomes were important and what would improve their quality of life, many women reported a long history of symptoms due to fibroids, especially pain and discomfort, years of abdominal distension and heavy menstrual bleeding,

painful intercourse, and reduced cancer risk.

B: *“I just want to have a better quality of life. I don't want to have to keep having this issue. I don't want to have to keep having this pain during sex. I don't want to keep having this discussion with my husband like, 'No, I don't want to do it tonight because it hurts sometimes.' I don't want to keep having these nuances that are just driving me nuts if I can do something about it.”*

The Procedure (Surgical Experience): Women reported feeling informed of the surgical plan pre-hysterectomy; some said they had been given options, and nearly all knew the plan could change during surgery. Women described some of the surgical approaches as “getting cut” and “cut me,” referring to an abdominal hysterectomy. The idea of a midline or transverse incision may have delayed their hysterectomy decision. Most participants knew the type of surgery that was performed based on their scars.

W: *“We talked about it ... I said, 'Well, how are you going to do it?' I remember that. And he said, 'We'll probably do it laparoscopically because ... it's easier,' or whatever. I think I probably asked him more than he asked me. But he already had his way of doing it ... I didn't want to be cut all the way open.”*

Generally, women were aware of the physiological consequences of removing certain organs (eg, removal of the ovaries creating surgical menopause). Frequently, women mentioned their own preference and their doctor's goal for keeping the cervix and ovaries. Some women were not sure about what organs were removed. Most women were comfortable with the discussions they had with their doctors, but a few women were not comfortable with the decision-making process, and some expressed that their doctor had his or her own surgical preferences.

B: *“I had a total laparoscopic hysterectomy. And that 'total,' I'm like, 'Does that include my ovaries because you're saying total?' He said, 'No,' and he explained it to me, you know, the proper name for it and when they do take your ovaries, you know. So he was, um, real — pretty easy to talk to, and I don't think there's nothing I didn't ask at the time.”*

The Postsurgical Experience

Physical Recovery: The recovery period after surgery required substantial changes to women's daily activities,

including loss of independence, slower movement, and restrictions to their activities of daily living (eg, no heavy lifting). Some women experienced unexpected complications postsurgery. Many relied on others for home-related activities (eg, chores, shopping, driving). One woman discussed the long-term postsurgical pain she experienced due to positioning during her surgery. For participants who spoke about sexual intimacy during recovery, there was a clear absence of desire to be sexually intimate.

W: *“Because yeah, I— I didn’t want that because I knew the recovery would be harder. I knew that the emotional part for me would be difficulter [sic], had I had to have that. So again, I don’t think you can prepare yourself for even what they’re telling you is going to happen, let alone the outcome of it ... let alone the recovery part of it. And then again, mine was not having enough energy. I was just angry that I wasn’t there yet, to be able to get back in the [usual routine], you know ... and that eats at me not being able to do the ‘norm’ (some laughing).”*

Recovery Expectations (Physician-Provided Information): Women with hysterectomy-related complications identified that their recovery was not what they expected, whereas women with few or no complications said their recovery postsurgery was as anticipated. Some women recalled discussing the recovery process with their physicians but felt insufficiently informed. Regardless of complications, participants thought their recovery would be different than what their physician quoted.

B: *“Well, they were better than I thought they would be. I was — like, I really didn’t think I’d be able to do it that fast — but I was kind of hoping I wouldn’t be able to do it that fast so I could stay home longer (laughing), but I didn’t — but I did fine.”*

Recovery Expectations (Family/Friends): Some women did not have discussions with family or friends about the recovery because of the aforementioned stigma. Some noted that they knew everyone’s recovery would be different due to each person’s uniqueness. For the participants who did rely on social support for recovery advice, it was from women who previously had a hysterectomy.

B: *“And I didn’t ask anybody about, you know, afterwards. I just asked about before the surgery.*

And then, um, from the people that I asked before the surgery, they were like, ‘[I] should have had it done a long time ago. You know, I shouldn’t have waited and suffered with, um, what I had to go through.’ But yeah, I mean and I didn’t expect, you know, to feel like that after recovery. So I went into it — and then I still have to go back now so the doctors can look at me. I haven’t made that appointment to see if everything is okay.”

Information All Women Should Know

Advice to “Past Self”: When asked what they would tell themselves if they could go back, for the most part, women said they wished they would have had the surgery sooner and not delayed it. For women who experienced complications, they would talk with their doctor more before the surgery about potential complications. Several women mentioned that they would not have had previous surgeries (ie, myomectomy) but would opt for a hysterectomy. One woman said she would make her doctor pay closer attention to her symptoms postsurgery.

B: *“I would have told myself, ‘When you’re 41, have a hysterectomy’ ... have an interactive — interpersonal communication with your doctor so that you can discuss things that are related to your health in the GYN community. And don’t be embarrassed by it, you know. Find somebody who will talk to you that you can talk to and that you can dialogue with so that you can make better decisions. Because I would not have had that myomectomy; I would have had a hysterectomy.”*

Recommendations to Other Women: Participants suggested that women referred for hysterectomy should do their own research and not depend solely on physician recommendations. They encouraged seeking social support from others familiar with the experience and that women should ensure there is a support system at home or a caretaker during recovery. Suggestions included making a plan to take generous time off at work in anticipation that the recovery time is longer than expected, as they experienced. Participants suggested that other women consider a second opinion, make the decision for themselves, and to consider the surgical impact on quality of life. Some women suggested taking a holistic “take care of yourself” approach and that the whole process is not as scary as it sounds.

W: "Talk to your friends and other women, whether they're your friends or associates or whatever. But ask around and just find out so you know what questions to ask when you go in."

Parting Thoughts

Most women would not have done anything differently related to their hysterectomy experience, and nearly all said they were satisfied with the surgery and its results. For the few who reported complications, it seems that the quality of life postsurgery outweighs any complications they faced prior to surgery or during recovery.

B: "Every month when I ovulated, I would have a lot of, uh, pain and nausea and just be really, really ill. And they said the only way — I was told by one doctor the only way to rid that was to have a complete hysterectomy and have my ovaries removed, which I wasn't going to do ever. So ... but all of my issues that were related to my menstruating and everything have gone away. And I just feel like a different person now. I am so blessed."

DISCUSSION

The Institute of Medicine defines patient-centered care as "providing care that is respectful and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions."¹⁵ From analysis of our focus groups with hysterectomy patients removed from surgery at varying intervals, we identified themes and beliefs about their goals and experiences that may better support health care providers in delivering patient-centered care to women undergoing hysterectomy. These results have influenced the data being collected for a prospective cohort study of women undergoing hysterectomy at HFHS. This ongoing cohort study, which follows women for a year after surgery, includes general questions about satisfaction, pain, and current health state, but also includes validated questionnaires on decisional conflict and regret, sexual function, and depression, domains of interest gleaned from these focus groups. Focus group participants also were asked to review potential cohort study materials for language, appeal, applicability, sensitivity, and importance. Combined with clinical data and surgical details from the EMR, the objective of the ongoing cohort study is to provide a unique and complementary contribution to the overall field of the longitudinal experience of hysterectomy patients.^{3,4,16-20}

These focus group data suggest a need for increased procedure education, social support, and empowerment in the decision-making process, along with expanding information currently presented on postoperative expectations and bodily changes that occur posthysterectomy. As has been previously shown, participants reported the importance of support from family, friends, and other women in their surgical outcomes.²¹ When deciding to undergo a hysterectomy, women were primarily concerned with age at surgery, preexisting conditions, previous health experiences (eg, myomectomy), and potential stigma of being "less of a woman," unable to reproduce, and "incomplete." These themes have been reported previously in work with public health clinic patients and prehysterectomy and uterine artery embolization patients.^{9,22,23}

Presurgical education could affect surgical satisfaction,²⁴ but the focus group participants indicated they had enough information to make a decision prior to surgery. While participants often relied on physician recommendations, they would advise other prehysterectomy women to research for themselves and not solely rely on physician recommendations. Because women relied on physician recommendations and preferences, some felt they did not have a choice, even when options were given and they were informed of the surgical plan prehysterectomy. Interestingly, while participants felt well-informed presurgery, some participants were unable to report which organs were removed during the surgery.

Reported reasons to undergo a hysterectomy to improve quality of life were pain and discomfort, painful intercourse, and heavy menstrual bleeding, with some participants waiting a decade or more after presentation of symptoms. Participants stated that they would have had the surgery sooner and would not have undergone previous gynecologic surgeries. As a tacit expression of satisfaction, most women would not have done anything differently related to their hysterectomy experience, and nearly all said they were satisfied with the surgery and its results. Quality of life posthysterectomy appeared to outweigh any complication concerns pre- and postsurgery.

Limitations

There are two main limitations in our investigation. First, our sample is from one geographic area and may

not be generalizable; however, overlapping themes with prior work suggest that some themes may supersede region. Second, our sample size and participation is small, which could limit representativeness; however, focus group participants were representative of the typical patient population at HFHS, and thematic saturation was reached in the focus groups. Despite this, we recruited from a very diverse urban and suburban population, and we were able to identify repeated themes across our focus groups, regardless of time since surgery or race.

A strength of this study is the inclusion of women up to 60 months postsurgery, as the groups provided short- and long-term perceptions after having a hysterectomy. Findings about the perceptions and beliefs of these women may support health care providers in addressing concerns of women pre- and posthysterectomy.

CONCLUSIONS

When delivering patient-centered care, providers should consider each patient's goals and expectations pertaining to surgical knowledge, surgical choice, social support, decision-making, body image, gravidity, and operative workflow. Providers may focus on education, social support, and decisional empowerment.

Patient-Friendly Recap

- Hysterectomy, in which part or all of a woman's uterus is removed, is commonly recommended for those with symptoms like chronic pain or bleeding.
- The authors interviewed women who had undergone a hysterectomy to glean insights into their experiences, particularly in regards to selecting a surgical approach.
- Women generally expressed satisfaction in their surgery choice and results, though some felt uninformed about potential after-effects.
- Feedback from focus groups was used to steer design of a larger ongoing study on long-term hysterectomy outcomes.

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Author Contributions

Study design: Sangha, Wegienka. Data acquisition or analysis: all authors. Manuscript drafting: all authors. Critical revision: Bossick, Sangha, Wegienka.

Conflicts of Interest

None.

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