ORIGINAL ARTICLE

"Tender Care": Iranian Women's Needs to Cope with Hysterectomy and Oophorectomy- A Qualitative Content Analysis Study

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ABSTRACT

Background: Gynecological surgeries associated with loss of feminine organs evoke more personal, interpersonal and psychological distress that may diminish women's quality of life. Women need and seek support to cope with various distresses which may change over the course of diagnosis to treatment. This study aimed to explore Iranian women's needs to cope with hysterectomy and oophorectomy.

Methods: This qualitative study was conducted in Kerman and Tehran, Iran from 2015 to 2017. Thirty interviews were conducted with 28 eligible participants including 24 main participants including one gynecologist, one midwife and one nursing faculty member, one gynecologist and one midwife and 2 husbands. They were recruited through purposeful sampling. Data were collected through semi-structured and in-depth interviews and analyzed with Graneheim and Lundman's method of conventional content analysis. The trial version of the MAX QDA 10 Software was used to manage the coding process.

Results: "Tender care" emerged as the main theme. It was comprised of three categories: "to be well-informed, "to be treated with compassion in healthcare setting", and "to be welcomed in the society". **Conclusion:** Women after hysterectomy/oophorectomy were preoccupied with many physical and emotional concerns. They need a whole package of care which consists of proper information to know what to do, a well-prepared/trained healthcare setting to meet their needs, and visibility in the society as a whole person. A multidisciplinary approach must be activated to meet their coping requirements and it is necessary to address these needs in each level of healthcare services.

KEYWORDS: Hysterectomy, Adaptation, Qualitative research, Women, Iran

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INTRODUCTION

Hysterectomy is the most common women's surgical procedure worldwide.¹ More than half of them are done with Bilateral Salpingo-oophorectomy(BSO).² Patient management after major gynecological surgeries may be difficult due to great challenges such as loss feminine organs and fertility,³ sexual dysfunction,⁴ fear of losing attractiveness and rejection by husband,⁵ disturbed body image,⁶ diminished quality of life⁷ along with physical symptoms due to surgical menopause after the surgery.⁸

Premenopausal women who had undergone a planned gynecological surgery had a greater need for information about the surgery than postmenopausal women⁹ and they needed more professional help for their sexual problems.4 Women who had undergone abdominal hysterectomy reported that they had received their informational support from the Internet, followed by family/friends, books/magazines, and other resources.¹⁰ Iranian adolescent girls reported that they needed sexual and reproductive health (SRH) services due to inadequate knowledge about SRH; changes in the cultural and social norms about sexual issues; religion's emphasis on sex training of adolescents by parents; and the existence of a cultural taboo regarding SRH.11 The need for knowledge and informational support was also very important for Iranian gynecological patients' companion.⁵ For providing patientcentered care, healthcare providers should identify, prioritize, and fulfill the patients' biological, psychosocial and spiritual needs through delivery of humanizing care.12

In Iranian society, women rarely seek help for their gynecological problems; they may delay their treatment, and the routine appointment with a gynecologist is not a common behavior. They tend to use traditional remedies or ignore the symptoms.¹³ Kerman is the largest province in the southeastern Iran and the third province of the country in terms of religiosity and family values.¹⁴ Given that the perceived support among different cultures may be varied and it is intertwined

with race, culture and ethnicity,¹⁵ qualitative studies with context-based understanding of the phenomenon can produce priceless information about in-depth experiences of women. Therefore, this study aimed to explore Iranian women's need to cope with hysterectomy and oophorectomy.

MATERIALS AND METHODS

This is a qualitative study with content analysis approach which was performed in Kerman and Tehran, Iran, during 2015-2017. In this method, the researcher has interpreted the results by presenting data in words and themes which involves understanding, interpretation and conceptualization of the underlying meanings of qualitative data.¹⁶

A total of 30 individual interviews with 28 participants (24 main participants, 1 gynecologist, 1 midwife, and 2 husbands) were performed. Three women in the main group were health professionals (gynecologist, nursing faculty member and midwife); they were just mentioned in the main group and interviewed according to their dual roles (as healthcare provider and main participant). The first five women were recruited purposefully among family members, close friends and colleagues of the first author due to their ease of access and 13 were selected among the eligible patients in the gynecological wards of two educational hospitals in Kerman, Iran, and the remaining 6 participants were introduced by other women. Twenty-five participants lived in and were interviewed in Kerman and the remainder (3) was living in Tehran, Iran. We interviewed two women in decision making process for surgery and three months later. During the interviews with main participants, the need for including other people with the greatest impact on women's experience was raised and we continued the participants' recruitment by theoretical sampling. Therefore, we sought the perspectives of gynecologists, midwives and husbands in this regard and the patients' experiences were confirmed by these key

informants. The husbands were introduced by their wives, and gynecologists and midwives accepted the researcher's request for participation in the study. The inclusion criteria for recruiting the participants were: being Iranian, speaking Persian, being in the premenopausal state when undergoing total abdominal hysterectomy (TAH) with/without oophorectomy due to the benign conditions, passing at least 3 months from the surgery, and being willing to share their experiences. Women with gynecological cancer were excluded. We selected premenopausal women due to the differences between younger and older women's experiences in this process.^{9, 17} The cause of the surgery included fibroids, endometriosis, severe uterine bleeding, and suspicion of malignancy in the future. In order to increase the probability of discovering different opinions in this group, maximum variation was considered via selection of participants (women, husbands, gynecologists and staff) of various ages, educational level, employment, marital status. As we telephoned each participant before each interview was scheduled, we did not have any dropouts. During the recruitment of the participants, no eligible religious minorities had had the surgeries in the mentioned hospitals. Sampling continued until the emerged concepts and categories were saturated and no new data were obtained.

Data were collected through in-depth, semi-structured, and face-to-face interviews. The first interview was the pilot interview, revealing some deficiencies which directed the further interview process. Before the interview, each participant received a phone call from the first author who introduced herself and described the aim of the study in brief. Interviews lasted between 45 and 90 minutes. They were carried out by the first author in a comfortable and private place for participants, such as the researcher or participants' workplaces, hospitals or homes to assure their confidentiality and comfort while no one else were present. Only two participants in the decision-making process were interviewed twice (before the surgery and 3 months later); the rest were interviewed once. After each interview, field notes and memos were made to guide the subsequent interview and research questions. After explaining the study objectives, the researcher began to ask general questions using the interview guide. A sample of questions that elicited the participants' experiences about the support needs of women is presented in Table 1. The interviews were voice recorded and immediately transcribed verbatim.

Interviews were analyzed using Graneheim and Lundman's (2004) conventional content analysis guidelines. There are manifest messages vs. latent messages in each text that require interpretation depending on the depth and level of abstraction. ¹⁸ In this inductive process, the researcher read through transcribed texts over and over to get sense of the whole. Then, the meaning units (words, sentences or paragraphs) which answered the questions about the kind of support women got or needed from the decision making process

Table 1: The sample questions asked during the interviews

Participant	Questions
Woman	"How did you decide to do the surgery?", "What did you need in the decision making process?",
	"Were you satisfied with the information and support you received in each stages of your
	disease?"; "Were your expectations of health services addressed?"; "What kind of support did
	you have or might have to cope with complications?"
Husband	"What did you know about your wife's surgery?"; "Did you get enough support from healthcare
	providers?"; "What can healthcare professionals do for people like you?"; "How did you help
	your wife?"; "What were your special needs after the surgery to help your wife?"
Healthcare	"Did your patients ask questions about the surgery, its complications and available treatments?";
provider	"In your experience, what kind of support do women and their husband need to cope with
	surgical consequences?"; "Is the healthcare setting equipped to meet the women's need?"

to post-surgical recovery were selected, condensed and labeled with codes. Similar codes which represented similar concepts were classified into subcategories and then made into a category (manifest level). Each category emerged from a group of content that shared a commonality, so the categories were internally homogeneous and externally heterogeneous. The relationship between the underlying meanings in categories, which is an expression of the latent meaning, emerged as the main theme. The trial version of the MAX QDA 10 Software was used to manage the coding process. The concept of trustworthiness was used to ensure the validity and reliability of the qualitative research according to Guba and Lincoln's criteria,19 as indicate here. Credibility was achieved through prolonged engagement with data, adopting maximum variation in the selection of participants, time sampling, peer debriefing, member checking by three participants, reflexive journaling of the researcher's preconceptions during the research process and building rapport and trust. Initial codes were made by two researchers and the remaining members agreed on the coding process, labeling and interpretations, and a panel of experts agreed with the coding process. Data triangulation was sought by reviewing the nursing documentation on the patient's records, looking for educational resources in the gynecological wards, and non-participatory observation in the field. Transferability was achieved through thick description of the sampling strategies and context, and purposeful and theoretical sampling to get rich data. Confirmability was reached by audit trial, reflexive journaling and data/researchers triangulation. Dependability was confirmed by presenting audit trial to experts, coderecode process, and triangulation of data and researchers. Ethics committee approval was obtained by the Research Ethics Committee of Kerman University of Medical Sciences (IR.Kmu.REC.1394.517). The interviews were conducted by the first author. Written

informed consent was signed by all the participants before each interview commenced. It included the purpose of the study, name, telephone number and work address of the researcher, and availability of professional help if they were suffering from negative feelings. The participants were informed about the right to withdraw from the study even after the interview, the process of voice recording the interviews, and how their anonymity and their confidentiality would be preserved.

RESULTS

Twenty eight people participated in this study, including 24 main participants (one nursing PhD, one gynecologist and one midwife were also healthcare providers), one female gynecologist, one midwife, and two husbands. All the main participants were married and only one was widowed and one single. The mean age of the main participants at the time of surgery was 40.87±4.52 years old (the youngest was 30 and the oldest was 48). The participants' demographic data are presented in Table 2.

Overall, 3536 codes were extracted and condensed into 11 subcategories and 3 categories. Then, the properties and dimensions of the patients' needs were revealed and "Tender care" emerged as the main theme. This theme consisted of three categories: "to be well-informed with 4 subcategories", "to be treated with compassion in healthcare setting with 4 subcategories", and "to be welcomed in the society" with 3 subcategories (Table 3). 'Tender care' emphasized that our participants needed some kind of care beyond the routine care they received. They requested empathy from healthcare setting and society by considering their informational, emotional and social needs to make an informed decision and to lighten the burden of the surgical consequences. In the following section, the direct quotations from the participants are presented to define each category.

1. To be Well-Informed

"To be well-informed" was the first step in

Table 2: Demographic characteristics of the study participants

Participant's No.	Age (year)	Education	Employment status	Type of surgery
1	47	Elementary	Housekeeper	TAH+BSO ^b
2	52	Academic	Housekeeper	TAH+BSO
3	44	Nursing Diploma	Nursing aid	TAH+BSO
4	44	Secondary	Housekeeper	TAH+BSO
5	47	PhD	Faculty member ^a	TAH+BSO
6	50	Academic	Retired	TAH+BSO
7	47	High school	Home job	TAH
8	50	High school	Housekeeper	TAH+BSO
9	49	Secondary	Housekeeper	TAH+BSO
10	47	Secondary	Housekeeper	TAH+BSO
11	32	Academic	Actor	TAH+BSO
12	46	Elementary	Housekeeper	TAH+BSO
13	49	Secondary	Housekeeper	TAH+BSO
14	50	Academic	Housekeeper	RRBSOc
15	58	Academic	Retired Teacher	RRBSO
16	60	Gynecologist	Gynecologist ^a	TAH+USO ^d
17	49	Diploma	Midwifery aid	TAH+BSO
18	43	Elementary	Housekeeper	TAH
19	51	Elementary	Home job	TAH+BSO
20	48	Diploma	Housekeeper	TAH
21	40	Secondary	Seller	TAH
22	39	Academic	Midwife ^a	TAH
23	47	Diploma	Clerk	Decision- making
24	40	Diploma	Housekeeper	Decision- making
Healthcare provider				
25	50	Gynecologist	Gynecologist	N/A ^e
26	50	Academic	Midwife	N/A
Husband No.				
27	43	Associate degree	Engineer	N/A
28	50	PhD	Faculty Member	N/A

a: shared in both of main participants and healthcare providers' group; b: Total Abdominal Hysterectomy + Bilateral Salpingo-oophoerctomy; c:Risk- Reduction Bilateral Salpingo-oophoerctomy; d: Unilateral Salpingo Oophorectomy; e: Not Applicable

Table 3: Main theme, categories and subcategories that emerged through data analysis process

Theme	Category	Subcategory
Tender	To be well-informed	Reproductive health knowledge
Care		Alternative treatments other than surgery
		Surgical consequences
		Spousal informational needs
	To be treated with compassion in	Receiving individualized care
	healthcare setting	Considering patients' psychological reactions to surgery
		Establishing sexual consultation centers
		Delivering culture-based health services
	To be welcomed in the society	Emotional and financial support from the spouse and close family
		Establishing support group to share women's experiences
		Changing community views about hyseterctomized women

comprehending and accepting the condition and is the first part of the need for "Tender Care". It had four subcategories in terms of: reproductive health knowledge, alternative treatments other than surgery, surgical consequences; and spousal informational needs. This information empowered them and enhanced the patients' outcomes.

1.a. Reproductive Health Knowledge

Lack of "reproductive health knowledge" accounted for delaying treatment and impacted the women's coping strategies. Younger and educated women might search for information in the Internet, but the older and low educated ones did not have this choice. Only three women were well-informed about the situation they may face and this led to informed decision making and better adjustment. A nursing faculty member said she had the chance to receive all she needed and decided consciously (her sister was a gynecologist). She said:

"Nothing was ambiguous for me and the decision was undoubtedly right. I was preparing for the consequences particularly because I live alone and am not married". (p.5)

Being knowledgeable about the surgery was the main need of women, especially in the decision-making process.

"...We should know what will happen next, especially to our sexual life, but no one has an exact answer. Doctors just insist on doing the surgery". (p.24,27)

1.b. Alternative Treatments other Than Surgery

Some of the participants stated they've never been offered "alternative treatments other than surgery", so they believed the last option was proposed at first. Those who were younger expected more information regarding other options such as hormone replacement therapy or minimally invasive treatment, to take an informed decision.

"The doctor visited me and just said 'tomorrow morning go to the hospital for an operation. You have to have a hysterectomy and oophorectomy as soon as possible.' You know, it was too soon to throw away everything (feminine organs)!. I was so scared, but she did not offer any choices, so I trusted her". (p.12)

1.c. Surgical Consequences

Some women reported they did not have enough information about the "surgical consequences" such as sexual dysfunctions, vasomotor symptoms of menopause and psychological problems and these were never discussed with the gynecologists, so they thought everything would be all right afterwards.

"If I knew the sexual complications before, I would have never done this surgery. It ruined the intimacy I shared with my husband. The doctor just said 'you must pretend to be satisfied in sex; all women do this. Thus, I tried hard to get information from a woman I knew who had experienced it....but you know, women do not like to speak of this part of life. Then, I started searching in the web and finally I found it!!". (p.11)

1.d. Spousal Informational Needs

Husbands also requested to be informed about the female anatomy, surgical complications and whether the surgery would impact their wife's sexual life or not.

"In the doctor's office, you see a board with these words on it: 'No men allowed coming in.' I'm asking you; who should tell me what is going on? Enough information would help me understand her better". (p.27)

2. To be Treated with Compassion in Healthcare Settings

"To be treated with compassion in healthcare setting" was the second part of 'Tender care' need of women that may help them better deal with the surgery. This category consisted of receiving individualized care, considering the patients' psychological reactions to surgery, establishing sexual consultation centers, and delivering culturalbased health services. All participants stated that the healthcare system should provide some sort of help for women and their spouses to overcome their problems in the field of sexual, psychological and emotional needs. Since women have not been formally educated about SRH, the role of healthcare providers to inform them about these issues in the case of surgery is so vital and important.

2.a. Receiving Individualized Care

Our participants needed "receiving

individualized care". Their surgery was not the same as the other surgeries. It involved their femininity, fertility, identity and their relationships which must be considered very cautiously, but they were not. In this situation, they needed their stressful conditions to be considered by physicians and nurses and received individualized and tailored care.

"I was 30(yr) when I had the surgery. I had the worst experience in the operating room (tears in her eyes), waiting 7 hours for operation; there was no difference between me and other women who were about 50 years old or more!!! I had an infant in the house whom I had not seen for a week!!,.... I had to remove my feminine organs in the midst of my youth, but no one cared and no one saw my husband's reactions either!". (p.11)

2.b. Considering the Patients' Psychological Reactions to the Surgery

Removing the uterus and ovaries was very stressful for women in this study, especially in the context of vague future of surgery. They encountered the sense of loss and psychological problems that must be pre-diagnosed and treated promptly. One participant expressed her feelings during the surgery and up to one year later. She said while crying:

"The night before the operation I was speaking to my womb; I touched my abdomen saying 'where will you be tomorrow? Will you be in the hospital trash?'...It was like losing a baby for me!! But no one understood me... I was mourning for a year. I think they should have realized this before the surgery and suggest that I should see a psychologist". (p.22)

2.c. Establishing Sexual Consultation Centers

Women reiterated that there was nowhere to address their physical, sexual and psychological concerns after the surgery. They thought it was necessary for them and their spouse to cope with the sexual dysfunctions, particularly for those who were younger, and experienced menopause after the surgery. In this regard, one gynecologist said:

"Unfortunately, women rarely revisit us for their sexual concerns after the surgery, but I think the most suitable person to help them is a sex therapist. She can advise couples on how to rebuild their sexual life". (p.25)

2.d. Delivering Culture-Based Health Services

"Delivering culture-based health services" was an important finding in this study. All women were Muslim and for them it was very challenging to get help for gynecological issues from others, even from their close family. Women indicated that despite many problems they faced after the surgery, they did not opt to get help because of shyness, fear of being stigmatized or unavailability of centers with female staff to alleviate the women's sex problems.

"I have had intercourse hardship since the time of surgery, but I never sought help for this, due to embarrassment. No Iranian woman does this. I would have to go to the pharmacy where a man is behind the counter; I would never talk to him about my sex problems!". (p.2)

3. To be Welcomed in the Society

Here, society was used to address everything around women that has an effect on their experiences about making sense of the surgery. This society ranged from close family members, such as the husband, to the broad community cultures about how they see a woman without feminine organs. This category completed the last part of the need for 'Tender care' and consisted of Emotional and financial support from the spouse and close family members; Establishing a support group to share the women's experiences; and changing community views about hysterectomized women.

3.a. Emotional and Financial Support from the Spouse and Close Family Members

For those women who more easily tolerated the operation afterwards, receiving efficient "emotional and financial support from the spouse and close family members" was significant and for those who were deprived of this support, the experience was awful. All women, except one, expressed that without their support they could have never managed the surgery.

"My husband did not even pay the cost of the surgery for me. I did not benefit from his empathy. It was so hard for me to tolerate this burden alone. You know, I have lost everything and there was nobody to console me, neither my husband nor my family was there to comfort me."(p.6)

3.b. Establishing Support Group to Share Women's Experiences

"Establishing support group to share women's experiences" with other women in a safe manner without judgment was another need of women after the surgery. Because of the unspoken nature of the sexual issues, most women did not talk to anyone, even their mother or sisters about their feelings after the surgery. It led to feeling alone and isolated. They needed a place where they could reveal their worries with those who had the same experiences.

"I do not like to speak with women who are not like me. I feel distressed when someone asks me about my surgery, but when I meet someone who is the same as me; we talk about our experiences and exchange information with each other. Finding these people is difficult, but if there was somewhere for women like me, I would never feel isolated and alone." (p.1)

3.c. Changing Community Views about Hysterectomized Women

"Changing community views about hysterectomized women" was the last issue that emerged from the data in this category. One of the most important issues that compelled women not to discuss their feelings, conceal their surgery from others and feel isolated was how hysterectomized women were viewed by others in the community. Most of the women, even those who were educated, did not find it easy to

say they had removed their feminine organs.

"I told everyone that I had a mastectomy, but I did not let everyone know I had a hysterectomy too; you know our society; I am a well-known person; people should not know my condition. They have no good opinion about women who have done this surgery!". (p.16)

DISCUSSION

The main goal of this study was to obtain a deep understanding of the kind of support that Iranian women need to cope with surgical consequences of hysterectomy and oophorectomy. This study revealed the need for "Tender care" as the main need of these women that is beyond the cares they have received and required empathy and sensitivity of social organizations. Their perceived needs depended on their cognitive and education level and the information they have got; the healthcare setting's available resources; and the way the community responds to their needs. Our findings are in the same line with other studies, ^{20, 21} but with some differences in dimensions

Our participants' experiences revealed to be well-informed would enhance their ability to encounter surgical consequences. Being well-informed will facilitate cognitive and behavioral coping and lead to resistance against stress, redirect inappropriate coping activities, facilitate the problem-solving process, and result in the ability to tolerate increased levels of stress.²² Most of our participants' level of knowledge about reproductive health was low even those who had academic degrees. It may be due to the lack of official sexual teaching systems in schools and universities, and the lack of sex education tailored to the needs of the community have worsened this issue.²³ Our participants' concerns about lack of knowledge about surgical anatomy, procedures, and consequences and husbands' insufficient knowledge about the surgery was mentioned in other studies.^{5, 9} Our results were contrary to the findings of other patients that felt well-informed about

these issues.²⁴ It may be due to the fact that in developed countries sexual health educations is provided as a supplement to their school-based sex education policies,²⁵ and there is societal openness, comfort and pragmatic governmental policies.²⁶ Thus, it is not surprising that our women were not aware of their problems, treatments and the available resources.

The second category of this study was: "to be treated with compassion in healthcare setting". All women emphasized their need for being supported by the physician and nurses in the setting because of not fulfilling their family developmental cycle which is mentioned in previous studies.^{27, 28} The need for individualized care in critical care units and psychological consultation centers was mentioned in other studies^{12, 20,} ^{21, 29} and delivering culture-based services was pointed out elsewhere.³⁰ In contrast, women in developed countries mentioned that their healthcare providers were caring and sensitive to their individual needs,31 and they benefited from expertise of the specialist nurses.32 Unfortunately, in Iran there are no gynecological specialist nurses and it is mostly the midwives who work in gynecological wards and may not have enough time or are not well-educated enough to provide individualized patient education.

"To be welcomed in the society" is referred to all those around the women's environment that help them cope with the day-to-day realities of their conditions. For our women, the first and most important external support that may help them cope with problems was their spousal support both economically and emotionally. Spousal support was an essential component of women's successful adherence to preventing care.33 In general, those who had better support adapted more quickly with their new condition. Our participants liked sharing their concerns and experiences with someone like themselves and mostly refused to speak to others over the years due to shame and embarrassment. "feeling ashamed" was expressed as the negative cultural viewpoint of the society that compels women not to speak with others.²⁰ Most of the women pointed out that there was a need to establish a center for women with similar experiences in order to share experiences, learn from each other and more importantly realize that "you are not alone with this condition". Peer support helps the patients by providing hope and a way to cope, replaces other social roles that are weakened by disease, and offers understanding through shared experiences.³⁴ Our participants expressed the need for "changing community views on hysterectomized women". They experienced being stigmatized among other women. It was obvious that women believed that men had negative feelings about women who had undergone hysterectomy mostly because of some beliefs that these women were not sexually attractive and could not have children anymore.35 Hysterectomized women may feel disarmed from every female attributes,⁴ so it is expected that they may see themselves as disabled persons that may be rejected by their husband or community. The need for running programs through the media and TV for gynecological diseases to promote public health culture was previously emphasized;5 also, it was mentioned as "the need for de-stigmatization of reproductive loss after hysterectomy".36

We faced some limitations in this study which may restrict its implications. These results may be applied in a setting similar to our context. Most of our participants lived in Kerman, Iran, which is highly influenced by tradition and religion as mentioned before. Thus, it is recommended to research about women's experiences in other metropolises in Iran and with other religious orientations. It would have been more effective to include more husbands in this study, but due to religious and cultural barriers men tend not to discuss their intimate relations with women.

CONCLUSION

Findings of this study extended our perception of the kinds of support Iranian women needed

to cope with hysterectomy and oophorectomy that has not been reported before. It is recommended that healthcare providers should be trained regarding patient education in sexual disorders, support groups be established for hysterectomized women, public culture be promoted for gynecological surgeries, and virtual support groups be used to help people overcome their cultural barriers to seek sexual help which maintain their privacy, anonymity, and there is no need for physical presence or taking their time.

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