

## Why do young women accept hysterectomy? Findings from a study in Maharashtra, India

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**ABSTRACT:** Hysterectomy among young women is being raised as a matter of concern by women's health advocates in India. This paper is based on a qualitative study conducted in the state of Maharashtra, which attempts to understand the ways in which women overcome the barriers in accessing health services for reproductive morbidities, the reasons for accepting hysterectomy as 'the' treatment as well as the implications of hysterectomy on women's health. Total 44 in depth interviews were conducted with women, who had undergone hysterectomy and were below 45 years at the time of interview. Fear of cancer, failure of medical treatment, practical difficulties in living with reproductive health problems, fear mongering by the doctors and belief in the hysterectomy as the best treatment, these were some of the reasons for which women accepted hysterectomy. Most of these hysterectomies were conducted in private hospitals. The study indicates the need for further research for explicating the role of private health sector in medicalising different reproductive events occurring in the life of women.

**KEYWORDS:** Reproductive Health, Access, Hysterectomy, India, Fear of Cancer.

### 1 INTRODUCTION

Hysterectomy among young women is being raised as a matter of concern by women's health advocates in India. [1] Various news reports have highlighted the spate of hysterectomies in states like Andhra Pradesh, [2] Rajasthan, [3] Bihar [4] and Chhattisgarh. [5] Health insurance scheme was found to be one of the facilitators of this spate of hysterectomies in these states.

This issue of hysterectomy is as an illustration of women's access to reproductive health services. The studies looking at women's access to healthcare have highlighted several barriers faced by women in accessing health services such as cultural barriers, [6] financial barriers, [7] non-availability of health services and denial of permission from the family. [8] These barriers are evident from the fact that several women are still not able to access basic health services such as antenatal care or services for safe delivery. [9] Within this milieu of lack of access, one can see that interventions such as Caesarean sections, hysterectomies and Assisted Reproductive Technologies (ARTs) are also rising among certain sections of society. These interventions warrant further exploration to find out the ways in which they impact women's lives.

In India, though there are no large scale surveys estimating prevalence of hysterectomy, studies in limited geographical areas have indicated prevalence rates of hysterectomy ranging from 4 % to 10 %. [10], [11], [12] The National Family Health Survey gives age disaggregated data regarding menopausal<sup>1</sup> women. According to this survey, 12.7% women in the age group

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<sup>1</sup> All women who are not pregnant and not postpartum amenorrhoeic whose last menstrual period occurred six or more months preceding the survey [9]

of 30 to 45 years were menopausal where hysterectomy was one important reason for attaining menopause. [9] Hysterectomies among young women have been highlighted by other studies as well. For e.g. a study conducted in the state of Andhra Pradesh revealed that average age at which surgeries were done was 28.5 years. [12] Considering the health consequences of hysterectomy such as increased risk of osteoporosis and heart diseases, it is important that hysterectomy is considered only after exploring the options of medical treatment adequately.

In this context, the present study conducted in the state of Maharashtra, attempts to examine hysterectomy as one of the situations of health care access. The focus of the study was to understand the ways in which women overcome the barriers in accessing reproductive health services, the reasons for accepting hysterectomy as the treatment as well as the implications of hysterectomy on women's health. This paper talks about the reasons for which women accepted hysterectomy for the various reproductive morbidities they were facing.

## **2 STUDY SETTING**

Maharashtra is the second largest state in India both in terms of population (112 million) and geographical area (308,000 sq. km.). Maharashtra contributes about 14.4 per cent of India's Gross Domestic Product. This state ranks 5<sup>th</sup> in the country with Human Development Index of 0.572. [13] Utilisation of health services is mostly from private health sector. [14] Proliferation of the private health care sector is evident from the fact that from the seventies to the nineties, the private beds have increased four and a half times. [15]

## **3 METHODOLOGY OF THE RESEARCH**

This paper is based on a qualitative study, where total 44 in depth interviews were conducted with women who had undergone hysterectomy and were less than 45 years in age at the time of interview. The study uses the definition of health care access given by Meera Chatterjee, which indicates that access requires negotiation of barriers beginning with the individual and progressively involving family, and ultimately the state/ market in health care. [16] Primary objective of the research was to study hysterectomy as an illustration of women's health care access to understand the ways in which women overcome the barriers in accessing health care. The study also looked into women's perceptions about reproductive morbidities and the influence of these perceptions on the acceptance of hysterectomy, the process of decision making within the household before undergoing hysterectomy. Another aspect of the study dealt with the ways in which the financial barriers were overcome for undergoing hysterectomy and importantly, the study documented the experiences of women regarding effects of hysterectomy on their physical health.

### **3.1 LIMITATIONS OF THE RESEARCH**

This study exclusively focuses on the perspectives and experiences of women who have undergone hysterectomy, whereas the perspectives of health care providers have not been taken in to account. Another limitation is that given the limited geographical coverage of the study, the findings of the study are not generalisable.

### **3.2 LOCALE OF THE STUDY**

The study covered 14 villages from two districts viz. Pune and Satara in the state of Maharashtra. From Pune district, Velhe and Purandhar sub-districts were included in the study, whereas, from Satara district, Wai and Khatav sub-districts were included.

In a previous survey conducted in the state of Maharashtra to study the inequities in access to health care across gender, caste and class, reporting of hysterectomies was higher from Satara and Pune districts. Hence, further qualitative study was conducted in the same blocks of these districts. In the previous quantitative survey, districts and blocks were selected using stratified random sampling method.

### **3.3 SAMPLING**

Purposive sampling method was used for selection of villages so as to cover villages near to the sub-district town as well as far from the sub-district town. Respondents were selected using snowball sampling method. Sampling size was not decided a priori. Saturation sampling was used and interviews were continued till no new information was being generated. Total 44 interviews were conducted in 14 villages.

### 3.4 TOOLS FOR DATA COLLECTION

For conducting in depth interviews, an open-ended guide was used where broad areas of enquiry included knowledge of role of reproductive organs and attitudes about menstruation, information about previous reproductive events such as deliveries, use of contraceptives and history of sterilisation, questions related to the gynaecological problems for which hysterectomy was done, regarding acknowledgement of woman's problems by other family members, regarding permission from the family for seeking care, about interactions with the health care providers consulted, experience of the surgery and health problems faced after surgery and the financial implications of the surgery. All the interviews were recorded and subsequently transcribed and translated into English. Data was analysed thematically.

The study was conducted conforming to ethical principles. Written informed consent was sought from all the participants prior to starting the interview. The study was reviewed by the Institutional Ethics Committee.

## 4 FINDINGS

### 4.1 SOCIO-DEMOGRAPHIC PROFILE OF THE RESPONDENTS

Out of the 44 respondents, maximum number of respondents (21) belonged to the age group 36 to 40 years at the time of interview. Lowest age of the respondent was 30 years and highest age at the time of interview was 45 years. In the study, lowest age at which surgery was performed was 22 years whereas majority of the respondents (34) got operated between 31 to 40 years of age. Almost one fourth of the respondents reported that they got operated before the age of 30 years. 41 respondents were married at the time of interview, two were widow and one was separated from husband. Regarding educational status, it was seen that one fourth had never been to school, seven had studied up to 4<sup>th</sup> standard. More than half of the respondents (26) had studied beyond 5<sup>th</sup> standard. More than two third (30) of the respondents were engaged in agricultural work. Six respondents were home makers, whereas remaining were either working as village level health functionaries or were self-employed. Majority of the respondents (29) were Hindu Maratha which is a dominant caste in this region. Eight respondents belonged to Other Backward Class category and five of them were from scheduled castes. Religion wise classification of the respondents revealed that 38 were Hindu, three were Neo-buddhist and one was Muslim.

### 4.2 REPRODUCTIVE MORBIDITIES REPORTED BY THE RESPONDENTS

44 respondents reported total 98 symptoms. Eight respondents reported that they suffered from only one symptom before surgery. Out of these eight respondents, three had pain in abdomen, three had menstrual problems and one respondent each was suffering from prolapsed uterus and white discharge. Out of 44 respondents, 27 respondents reported various menstrual problems such as continuous menstrual bleeding, frequent menstruation, heavy bleeding during menses. Almost half of the respondents (21) complained about pain in abdomen associated with other symptoms. Twelve respondents suffered from prolapsed uterus. Four respondents faced difficulties in passing urine due to prolapsed uterus. Almost one-third respondents spoke about white discharge as one of the problems for which surgery was undertaken.

Majority (39) of the hysterectomies reported in the study were conducted by private doctors. Out of remaining five hysterectomies, two were conducted in public hospitals and three in charitable trust hospitals.

### 4.3 REASONS FOR ACCEPTING HYSTERECTOMY

From the study, following reasons emerged for which the respondents accepted hysterectomy-

- **Fear of cancer-**

More than half of the respondents (25) mentioned fear of cancer as one of the major reasons for taking decision about surgery. Out of these 25 respondents, 15 respondents reported that the doctor spoke about possibility of cancer whereas other respondents thought of cancer even though the doctor had not said anything about it.

It was seen that the doctors hinted towards cancer as a fatal disease requiring significant money for treatment. One of the respondents reported that her doctor said, *"Today the surgery will cost 8000, later (when there is cancer) we cannot guarantee even if you give 32000"*.

Most of the respondents who had fibroids or white discharge said that the doctor told that this can go on cancer. One of the respondents reported that her doctor said, *"If you don't operate, the problem will increase, if the wound (cervical erosion) increases, it may go on cancer, and then anything can happen."*

Out of total 11 respondents who got operated within one year of onset of reproductive health problems, seven decided in favour of surgery because the doctor had mentioned the possibility of cancer. Out of these seven respondents, two underwent surgery within 15 days of onset of health problems.

- **Failure of medical treatment-**

Three fourth of the respondents (33) reported span of more than one year between onset of health problems and actual surgery. In case of 23 respondents, this gap was more than one year and less than five years, whereas 10 respondents had tried medical treatment for more than five years before undergoing surgery. Almost one fourth of the respondents said that they considered the option of surgery over medical treatment as they got only temporary relief when they were taking medicines. As soon as the medicines were stopped, the problems of bleeding resurfaced. Respondents were also wary about taking medicines for long duration due to the notion of allopathic medicines causing side effects. In terms of cost of medicines and cost of surgery, some of the respondents said that rather than paying every month thousand rupees for medicines, they felt that it's better to get operated as it would be one-time expense. Recurrent visits to the doctor to take medicines and follow up were also troublesome for the respondents.

*"Every month, I suffered from bleeding for at least 15 days and then within 8 days next periods started. I used to take injections, but it stopped only temporarily. Since we are poor, I went to nearby doctor and not any big hospital. My husband used to fight with me as I was always unwell, I am having recurrent problem and I don't have so much money to visit again and again. I have to go to field for earning wage, so I decided to go for surgery".* (43 years old respondent, operated at the age of 36 years for problem of excessive bleeding)

- **Lack of faith in alternative treatments to hysterectomy-**

In some of the cases of prolapsed uterus, the doctor had suggested use of ring pessary/ repair surgery; however, respondents felt that with the kind of heavy work they have to do, it's better to go for removal of uterus rather than undergoing repair surgery.

*"After the birth of my elder son, the bag started coming down. The baby was in breech position, so lot of pulling was done at the time of delivery. However, in next two deliveries there was no such problem. So after the delivery of third child, I went to the public hospital for treatment. The doctor said that they will do the surgery to fix the bag and insert ring, but I thought that I have to carry heavy loads so again the bag may come down so I opted for hysterectomy".* (35 years old respondent operated at the age of 32 years for prolapsed uterus)

Sometimes it was seen that the respondents wanted to avoid surgery and asked for alternatives to it. However, the health care providers declined such requests. For e.g., one of the respondents said that she had asked the doctor if only fibroid can be removed keeping uterus. However, doctor declined saying that the surgery will not be possible in his hospital. The lack of faith in other alternatives to hysterectomy among the respondents was partially because the health care providers were often found to belittle these alternatives and suggest that hysterectomy would be permanent resolution.

- **Fear of complications and subsequent death-**

In some cases, the respondents were worried thinking that these reproductive health problems could be fatal. The families also readily consented for surgery out of fear of fatal complications.

*"One night I had severe pain in abdomen just like delivery pains, my husband took me to doctor where he gave injection and saline. Next day, the doctor did the sonography and told us that there are fibroids in your uterus and you will need surgery, otherwise these fibroids will grow. My husband went to meet other doctors to get second opinion; all of them said that the surgery was necessary."* (36 years old respondent operated at the age of 28 years for pain in abdomen)

- **Practical difficulties in living with reproductive health problems**

Gynaecological morbidities were seen to interfere with daily routine, thus hampering women's capacity to work. As seen previously, most of the respondents were engaged in agricultural work. Many of the respondents who suffered from bleeding problems faced difficulties in managing the bleeding while they were working in the fields. These respondents were using rags during menses. The respondents said that by repeated washing, this cloth often becomes hard and at the time of menses, it becomes even harder once it soaks blood. During their work in the fields, there is no place for changing the rags. Prolonged use of cloth irritates the skin of thighs and leads to wounds. Also if the bleeding is more, women can't go to field for work.

Due to these reproductive morbidities, many times women's ability to contribute to the agricultural work reduced. This caused dual financial burden to the families as, in addition to the expenses for the treatment, they also had to pay for hiring

agricultural labour. Hence, hysterectomy was preferred rather than medical treatment. Lack of information among women about the role of uterus beyond reproduction caused them to think uterus to be dispensable organ once it has fulfilled its function of producing children. Similar thinking was propagated by the doctors.

- **Fear of complications instilled by the doctors**

Some of the respondents, who were initially unwilling to undergo hysterectomy, asked the health care providers about the possible implications if surgery is not done. The responses of health care providers were such that it created fear among the respondents. Besides hinting towards cancer as one of the implications, some of the respondents shared that her doctor told her if surgery is not done then your uterus will get rotten; there could be holes in it.

- **Community acceptance for the hysterectomy as best treatment**

From the study, it was seen that in these areas, hysterectomy has received acceptance from the community at large. Sometimes the expertise of the healthcare provider was doubted if he/she does not suggest hysterectomy.

*"I was trying to avoid surgery, however there was no relief from bleeding problem despite taking medicines for three years. The doctor was saying that I don't need hysterectomy but the relatives and neighbours started criticising my husband for not taking me to a 'good' (expert) doctor". (45 years old respondent operated at the age of 44 years for problem of frequent menstruation)*

## 5 DISCUSSION

The socio-demographic profile of the respondents highlights the low educational and income levels among respondents. Studies conducted in other parts of the world also show similar trend. [17,18] One of the reasons given is that highly educated women are also offered alternative treatments than hysterectomy, as, it is difficult to pressurise the educated women for surgery. [19]

Acknowledgement of illness is described as the first hurdle in health care access for women. [6], [7] The present study revealed that women acknowledged and revealed the reproductive morbidities due to the practical hindrance caused by them. Studies conducted previously had brought out the fact that women are socially trained to be secretive about the matters related to reproductive organs. [20] Given the increase in reporting about hysterectomies from different parts of the country, one can say that women are now feeling less inhibited to talk about reproductive health problems.

Regarding overcoming the barrier of seeking permission from family, it was seen that due to the perceptions of risks associated with reproductive illnesses such as cancer and subsequent death, the families had consented for hysterectomy sometimes without exploring adequate medical options for the underlying illnesses. However, the consent for hysterectomy was more out of practical purposes as, families required the contribution of women either in the form of agricultural labour or for raising children. Hence, there is not much change in the primacy given to women's health status. There are studies which substantiate that women's health becomes priority of the family so as to ensure that they are able to fulfil their domestic roles. [21]

Normalisation of gynaecological illnesses such as white discharge, prolapsed uterus etc has been highlighted through studies which showed that given the wide prevalence of these health problems, women considered them to be part of life and did not think about getting treated. [22] Similarly, the present study shows that now the surgical procedures for reproductive problems of women are also getting normalised in the community.

As mentioned in the previous section, fear of cancer was one of the important drivers behind the decision regarding hysterectomy. A study conducted in Taiwan which looked in to the decision making regarding hysterectomy had also found that women who could overcome the fear of benign fibroids turning into malignant ones, decided against surgery. Whereas, women who faced irrational psychological obstacles opted for surgery. In this study, fear of fibroids turning malignant was the best predictor of the decision. Also, those women who believed that uterus is merely an organ for producing children, thought it was useless after having children, hence decided in favour of surgery. [23] The present study also confirms these findings.

## 6 RECOMMENDATIONS

First and foremost need is to conduct national level study to estimate prevalence of hysterectomy in India. Health activists and civil society groups have demanded inclusion of hysterectomies as a component in the fourth round of National Family Health Survey. [9] Most of these surgeries are conducted in private hospitals, however, the current mechanisms for

regulating private hospitals are quite rudimentary and the implementation of laws is not so stringent. Hence, it is also essential that mechanisms for regular audits should be institutionalised so as to avert unnecessary surgical interventions. As mentioned previously, hysterectomy is one of the illustrations of how women's bodies are being subjected to unnecessary interventions. Caesareans and Assisted Reproductive Technologies are the other examples. Hence, there is a need for further research for explicating the role of private health sector in medicalising reproductive events and its impact on different spheres in case of women.

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