CHAPTER 9

ACCEPTANCE OF HYSTERECTOMY

One of the main objectives of the present study is to understand the underlying reasons for acceptance of hysterectomy as a treatment for the reproductive illnesses. Before this chapter delves into the details of the reasons for acceptance of hysterectomy, I would like to narrate the case story of Nandini who is the respondent with lowest age at hysterectomy.

Case- story of Nandini, who underwent surgery at the age of 22 years

Nandini is a 31 years old woman from Khatav block of Satara district. She has studied up to 9th standard. Her husband, who has studied up to 10th standard, works as a driver. The household owns five acres of land and Nandini does agricultural work along with the household chores. Nandini attained menarche at the age of 15 years and was soon married off even before she could complete her 10th standard. At the age of 16, Nandini had her first delivery and delivered a baby boy. In her next pregnancy, she suffered from jaundice. The second born child was a baby girl who died after six months. Subsequently at the age of 21 years, Nandini had her third delivery and gave birth to another baby girl. Her first two deliveries were at home and third one took place in the hospital.

After her third delivery, Nandini did not get menses for 2 to 3 months. After that she started facing problems like heavy menstruation and prolonged menstruation. She reported that once she got periods which continued for 15 days and the bleeding was so severe that she had to change the rags almost every hour. She passed clots at the time of menses. After a gap of 8 to 10 days, her bleeding used to commence. Along with bleeding problem, she also felt that the uterus had moved down.

She started taking medicines from a local doctor. However there was hardly any relief. Then she consulted one of the well known gynaecologists in the nearest town. Medicines given by this doctor provided temporary relief. Once the medicines were stopped, the problem of bleeding resurfaced. As part of the treatment, once the doctor also did curettage to stop bleeding. The doctor said that she was very young to undergo hysterectomy. The medical treatment was costing about 1000 rupees every month. Nandini then consulted another doctor. The second doctor gave medicines for one or two months and then suggested hysterectomy. Sonography had revealed a fibroid in the uterus. The doctor said that as it is one day you will have to get
operated. The doctor had also said that if she does not get operated then this problem can turn into cancer. Her mother in law had also had hysterectomy; hence the family knew about the surgery and agreed immediately for the surgery. Finally, Nandini underwent vaginal hysterectomy at the age of 22 years.

Nandini’s case story shows that the decision making process was relatively uncomplicated. The factors which led to the decision of hysterectomy in case of Nandini were ineffective medical treatment, high cost of medicines, and fear of cancer introduced by the doctor. Mother in law having undergone hysterectomy further facilitated this decision. Her case story in a way typifies the wide acceptance of the hysterectomy in this area as at no level second thought was given to the decision. The story also reveals that the lack of knowledge about the consequences of the surgery has led to uncritical acceptance of hysterectomy.

The chapter would now delineate the individual level, household level, community level and health system level factors that led to the acceptance of hysterectomy in case of the respondents of this study.

Figure 9.1 Factors That Lead to the Acceptance of Hysterectomy

Source: Field data
9.1 Reasons for Accepting Hysterectomy

Following reasons emerged from the narratives of the forty four respondents who were interviewed in the present study-

9.1.1 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. Sunita reported that her doctor said, “Today the surgery will cost 8000, later (when there is cancer) we cannot guarantee even if you give 32000”. (40 years old respondent from Wai block operated at the age of 33 years)

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.

‘...because if you have white and red discharge, it may go on to cancer. Therefore even if there is little problem, women go and tell the doctor to remove bag, see what we think is that it is better to spend 20 to 25000 rupees now but tomorrow if we get cancer, do we have lakhs of rupees for treatment? Despite so much of expense, the person will die...... there are women in this village who have died of cancer, even if cancer is in any part of body, it descends down, so we think it is ok to do surgery now, even if we spend some money now, we can earn that by working for next 4 years’ (Neelam, 36 years old respondent from Wai block operated six months prior to interview)
Case story of Ashwini who had operated out of fear of cancer

Ashwini is a 38 years old respondent from Khatav block of Satara district. She was operated at the age of 34 years for the problem of polymenorrhoea. Ashwini has studied up to 5th standard and works as agricultural labourer. She belongs to OBC category. Ashwini narrates her story....

“I was married off at the age of 11 years. After one year of marriage, I got menses. I had four children by the time I was 18. Then after many years, I started getting period every fifteen days... I had pain in tummy....it bled just like water...I became very weak.... I felt I will die anytime...I could not work...my children were in school....I was so tensed at that time....even today I feel stressed....I have to marry my daughters.....I was facing financial problems at that time...my husband does not have proper job....there is no support from my mother in law......then one day I went to see Dr. A in Waduj....he said that there is wound on your bag...he gave me medicines....but there was no relief....then when I went to see him second time, he said that you need surgery...he said that you may get cancer....I was scared...then I discussed with husband and daughter.....my daughter is educated.....she said that if the doctor has advised surgery then you should do it, otherwise there could be complications.....my husband was not willing....but we took the decision of surgery......and went for surgery after a month or so....”

Ashwini’s narrative brings out the immense fear women have about cancer due to reproductive health problems and subsequent death.

In the present study, very few respondents informed that the specimen was sent for further testing to confirm the pathology. In fact Gayatri (41 years old respondent from Khatav) had requested her doctor to send the specimen for histopathology as she wanted to alleviate the fear of cancer, but the doctor had not conceded to her request. Given the fact that the specimens were not sent for histopathological examination indicates that the doctor did not have doubt of cancer.

9.1.2 Perceived 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. Hormonal treatments are given to treat some of the clinical conditions where menorrhagia or poly-menorrhoea is the symptom. However, hormonal treatments mostly provide relief till they are being taken and also it is essential that they have to be taken regularly without even a gap of single day. Given the workload, women in the rural areas may be finding it difficult to the adherence to hormonal treatment and thus getting the impression that the treatment is not effective.

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 is 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 fields for earning wages, so I decided to go for surgery”. (Nilima, 43 years old respondent, operated at the age of 36 years for problem of excessive bleeding)

9.1.3 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”. (Medha, 35 years old respondent from Velhe block operated at the age of 32 years for prolapsed uterus)
9.1.4 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.” (Maya, 36 years old respondent operated at the age of 28 years for pain in abdomen)

9.1.5 Greater Acceptance of Hysterectomy in the Community

In the study, it was seen that the respondents were annoyed when they were suffering from frequent or heavy menstrual bleeding. When one health care provider denied surgery, they changed the providers till they found a health care provider who advised surgery.

Manju narrates her experience of enduring the illness,

“I again started getting periods every 15 days, at the time of periods, I had severe breast pain, it was so painful that I could not even touch the breast, at the time of bath, I felt like I am dying, I was fed up of recurrent bleeding, so I went to ‘A’ hospital, there Dr. ‘D’ did USG, then I went to ‘B’ hospital, there they said I am young and denied surgery, but I thought if I have so many problems at this age, what will happen if the problem increases with age, then Dr. ‘C’ examined me in ‘A’ hospital, he said that you should have removed the bag last year only. Earlier treatment was given for cervicitis (jakhma kadhyla hotya) but again the problem of white discharge and frequent menses started. My colour had become purple like Jamun.(jambhul) people were saying that I must have caught some disease, last year ‘D’ doctor had said why are you getting operated so early, you are not even 40. But next year I got operated in his hospital. (41 years old respondent from Velhe block operated at the age of 40 years)

In Chapter 3, the conceptualisation of the research chapter, the barriers that women need to overcome to access health care services have been enunciated. Unlike the earlier studies of 1980s and 90s when the term ‘culture of silence’ was coined to describe women enduring reproductive infections and gynaecological morbidities, this study has observed that women who have gone through hysterectomies were open
about their reproductive health morbidities they faced. It was also interesting to observe that women discussed these with their spouses as well as with other women in the family and neighbourhood. There seems to be greater receptivity in the families regarding women’s illnesses. Overall improved levels of education and awareness were identified by the respondents as positive factors which helped them articulate their problems.

9.1.6 Practical Difficulties in Dealing 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 cannot go to do wage work in agriculture. 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 a dispensable organ once it has fulfilled its function of producing children. Similar thinking was propagated by the doctors.

Another important factor behind ready acceptance of hysterectomies was negative attitude towards menstruation. In colloquial terms, menses is regarded as ‘adchan’ which means ‘inconvenience’. In the study, it was seen that managing menstruation especially if there is abnormal bleeding was very inconvenient for the respondents. Several menses related taboos such as hindrance from participation in religious functions or doing household chores created a negative experience towards menses. However, in the study none of the hysterectomies were done only to get rid of menses
as it is seen in the study conducted in Gujarat. (Ranson and John, 2002; Kothari T., 2014)

Most of the respondents were apprehensive that in case they die due to the complications of existing illness, then it will affect their children. Hence, they sought care promptly. This indicates that rather than concern for their own health, the concern was more about being able to fulfil their role as mothers. None of the respondents articulated seeking care as their entitlement to be healthy.

Dilemma regarding surgery was evident in the minds of some of the respondents. On one hand, they had heard about health problems occurring due to hysterectomy in early age and on the other hand, they constantly feared about cancer. In this situation, many of them considered surgery as better option as it meant getting rid of fear of cancer permanently. Respondents were also afraid of surgery; however, fear of surgery was overridden by fear of cancer.

9.2 Differential Operation of Familial Permission in Case of Hysterectomy

It is well established fact that familial permission is a critical step in the process of women’s access to health care. The internal hierarchies within the family based on age, gender and kinship status dictate the decision making power, control over resources and levels of autonomy among individuals. Women in the reproductive ages, particularly young married daughters-in-law enjoy less power in making decisions pertaining to contraception, family size, seeking health care and so on. Household’s response to health problems is also linked to the kind of health problem and the implications it has to women’s chances of marriage or having children.

In this study, the exploration of the question of permission to women who seek hysterectomies, there have been interesting observations. In certain cases, the concern of the husband for women’s health was observed. It was also 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 reasons 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. Other studies also substantiate that women’s health becomes priority of the family so as to ensure that they are able to fulfil their domestic roles (Aseno-Okyere & Dzator 1997; Iyer 2005).

Thus the access to health care for women is largely influenced by the patriarchal social context. In this system, responsibility of raising children, managing household chores, taking care of elderly and contributing to household economics are entrusted to women. Any problem that provides constraints to the delivery of these responsibilities is addressed without any delay.

### 9.2.1 Household Level Factors That Led To the Acceptance of Hysterectomy

A close analysis of all the cases provided insights into the various factors that led to the acceptance of hysterectomy by families.

a. Educational status of husband – in most of the cases, the husband was educated. It was seen that very rarely the husband or the family denied permission to seek care in such families.

b. Elderly women in the family acknowledged that there is change in the attitude of husband towards wife. In their generation, husbands never bothered about wife’s wellbeing but these days husbands are more caring. Some of them also thought this may be due to the impact of media.

c. The belief regarding gynaecological ailments turning fatal was very strong and hence surgery was accepted as treatment.

d. Treatment of cancer would be costlier and futile hence hysterectomy was seen as preventive measure for cancer.

e. From the narratives, it was apparent that the families did cost-benefit analysis of getting hysterectomy done as against continuing with the medical treatment. First, as compared to multiple visits which are essential while taking medical treatments, it was felt that hysterectomy would be one time cost and hence was preferred. Second comparison of cost was done with the treatment of cancer. It was articulated that if the avoidance of hysterectomy leads to cancer then the treatment of cancer would be several times higher in cost than hysterectomy.
Also, there is no assurance of positive outcome of cancer treatment, thus it was felt that it is better to get the hysterectomy done as it will prevent cancer.

9.3 Community Beliefs That Influenced the Acceptance of Hysterectomy

The presence of women who have undergone hysterectomy has created an ecology of acceptance of surgeries. Since several women in the community have already accepted hysterectomy, it has become a routine procedure which does not warrant much justification. Women speak to other women in the community who have undergone hysterectomy before making their decision. In all the cases, other women who had experienced hysterectomy reinforced the need for hysterectomy saying that the delay could have serious implications.

“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”. (Madhu, 45 years old respondent operated at the age of 44 years for problem of frequent menstruation)

Manju, (41 years old respondent from Velhe block) who was suffering from continuous bleeding told that she got operated because her husband was irritated due to her recurrent illness. Her bleeding problem had become cause of tension between the couple, hence one day she went to the doctor and got operated.

The Health Belief Model (Rosenstock, Strecher, & Becker 1994) is useful in understanding the potential influences on an individual's decision to access health services. According to this model, individual perceptions, modifying factors and the possibility of action contribute to an individual's decision to seek health care. In case of hysterectomy, it was seen that fear of cancer and subsequent death were major individual as well as community perceptions which had defined the use of health services. Modifying factors such as age of women where younger women sought prompt treatment to be able to fulfil their domestic role and household income influenced the actual utilisation of health services. In some cases, modifying factors such as advice from friends and relatives and information received during health programmes also influenced the decision to seek care. In the health belief model, the likelihood of action is the product of the perceived benefits of seeking care minus the
perceived barriers to doing so. In the case of hysterectomy, the perceptions about benefits of hysterectomy were much higher as compared to the barriers in accessing this treatment, which led to uncritical acceptance of hysterectomies.

9.4 Health Level Factors That Led To the Acceptance of Hysterectomy

9.4.1 Availability of Health Care Services

The chapter on locale of the study has brought out the proliferation of private health facilities in these two districts as well as the abundance of options of transport have also been confirmed. Thus availability or physical accessibility was not the barrier for women in the selected area.

Absence of primary care treatment for gynaecological problems in public health facilities was one of the reasons why women had to seek health care for reproductive health problems in the private sector, which was costly and thus permanent solution was found more preferable. Giving incomplete information about the nature of illness or about post-surgery problems had also led to decision of hysterectomy. The fear of cancer has been mainly propagated by the health care providers.

It is a duty of the medical professionals that they educate their patients regarding various body functions and give proper scientific medical information about the disease and the treatment options. However, the gender biased attitude of doctors becomes evident as they propagate the biased view that role of uterus is confined to reproduction. Patriarchal values of medical professionals and the role of the content and process of medical education in reinforcing these values has been brought forward by the analysis of the textbooks of gynaecology and obstetrics. (Iyengar, 2005)

After this discussion about the reasons behind acceptance of hysterectomy, the next chapter provides details of the impact of hysterectomy on different domains of women’s lives.