CHAPTER 7

CROSSING THE INDIVIDUAL LEVEL AND FAMILY LEVEL BARRIERS IN HEALTH CARE ACCESS

In the previous chapters, the thesis has highlighted the rationale for the study, the conduct of the study, details of the context in which hysterectomies were studied and information about the women whose experiences the study has attempted to capture.

In the following four chapters, findings of the study are being presented. This study depicts women’s experiences of reproductive lives. In this study, an attempt has been made to delve into women’s experiences from menarche to menopause, which was surgically induced in all these cases. The study elicited information about important event of the reproductive life such as menstruation and deliveries. The research also brings out women’s experiences of surgical menopause.

The key findings of this study have been organised as follows-

Chapter 7 i.e. the present chapter begins with the narration of women’s experiences and attitudes of menstruation. Subsequently it delves into the reproductive health problems for which hysterectomy was done. The section tells about women’s perceptions of the causes of their health problems and also talks about how and when women acknowledged that their health problem requires treatment. Next section in this chapter then elaborates all the household level processes that take place before undergoing hysterectomy. The subsequent chapter narrates the stories of interactions with the health care providers highlighting how these interactions led to the acceptance of hysterectomy. The last chapter in the findings section i.e. Chapter 9 delineates the individual level, household level, community level and health systems related factors which led to the acceptance of hysterectomy. Chapter 10 then recounts women’s experiences of how hysterectomy has impacted their health as well as work capacity.
In this chapter, following research questions are answered-

1. When do women acknowledge the need for treatment for the gynaecological morbidities?
2. How do women’s perceptions about menstruation and reproductive health influence the acknowledgement of need for treatment?
3. How does health care access get prioritized within the family in these cases of hysterectomies?

**Section I- Respondents’ Attitude towards Menses and Knowledge about Reproductive Health System Functioning**

As mentioned in the methodology section, one of the objectives of the study is to understand women’s attitude towards menstruation and knowledge about reproductive health system functioning. This information was sought for getting better understanding of health beliefs related to reproductive tract morbidities to understand how these beliefs then influenced the decision of acceptance of surgery.

**7.1 Menarche- Commencement of Reproductive Life**

The saga of reproductive life of a woman begins from the time of menarche. Menarche is defined as the onset of first menstruation. (Dawn, 2000) In Indian context, menarche has been ascribed huge importance in women’s life as it signifies the ability to reproduce. In the patriarchal system, women’s reproductive abilities are given immense importance as begetting male heir for the family is considered as their responsibility.

**7.1.1 Age at Menarche**

According to medical textbooks, the menarche can occur anytime between the ages of 10 years to 16 years. The median age of menarche was 13 years in the given sample. Lowest age at menarche reported by the respondents was 11 years and highest age was 17 years. In the study it was seen that the respondent who started her menstrual periods at the age of eleven years described that she got her menses very early (*laee lavkar aali pali*) and the respondent who started menstrual periods at the age of 16
years described that she got menses quite late (Ushirach aali). Medical textbooks suggest that social class, nutrition and environment are important factors influencing menarche (Dawn, 2000; Dewhurst, 2000) Women’s knowledge about the expected age of menarche is mostly empirical. Since majority of women in Indian communities attain menarche between 12 and 15 years of age, probably that is considered as appropriate age and girls who attain menarche before or after this age limit are seen as precocious menarche or delayed menarche.

7.1.2 Experience of Menarche

In case of majority of the respondents, menarche was an event for which they were not prepared at all. Barring two respondents, none of the other respondents had any clue about menses. Out of the two respondents who had some idea about the menstrual period before its onset, one was told by her friend about bleeding and in case of second respondent; mother had told that she will get menses when she comes off age. For all other respondents, menarche came as a shock; they were clueless about why suddenly they are bleeding. Many of them suspected that they might have injured themselves inadvertently. It was when they reported to their family members about bleeding, they came to know that this is natural and all women face this once they grow up. Some of the respondents narrated how the menarche was celebrated. One of them said that her aunt gifted her new saree and bangles on the fifth day of first period. Menses was seen as something given by God. One of the respondents shared that her mother said this is like rebirth. (punarjanm)

7.1.3 Taboos Associated with Menstruation

Some of the respondents shared that they followed the practice of segregation during menses where they were kept isolated during periods. Segregation was called as shivashiv (touching here and there) Though several of them reported that they followed the practice of segregation during periods, none of them faced any inconvenience due to this isolation. They were so convinced about the need for isolation that they felt it would be inappropriate not to follow the practice. Some of them also expressed displeasure about the younger generation not following this practice anymore. This was mainly felt because they considered themselves to be
impure during those days. Some of the emotions narrated by women were fear (bhiti), feeling of being polluted (ghan), aversion towards periods (nako vatayache).

Some of the respondents reported that they did not enter kitchen during menses. In nuclear families, following this practice was found to be cumbersome, as the husband had to cook in those days. In fact in one case, the respondent said that her husband was relieved after she underwent surgery as it freed him from monthly cooking. The origin of this practice is in the belief that women are impure during menses and the food gets vitiated if it is cooked by menstruating women.

In Indian culture, taboos regarding menses have been prevalent since ages. Bela Kothari (2010) in her paper talks about some of the taboos in Indian culture which are associated with menses. She notes that in the Indian society, beliefs about the impure or toxic status of the menstruating woman for example, handling pickled food by menstruating woman quickly spoils it or destroys its shelf life, have been accepted without any serious attempt at verification or scientific validation. (Kothari B., 2010)

Some of the lay theories which are given regarding physiology of menses also suggest that periods are meant to "cleanse out your insides" and serve to "purify". (Martin, 1987 quoted in Kothari B., 2010) One of the logics provided to justify segregation is often that women need rest during the menstruation period and hence they are exempt from household chores. However, in reality women do certain tasks such as sorting/cleaning grains which are equally arduous. Some believe that women are secluded during menses because they are considered vulnerable to "attaching spirits" during menses. Another view of menstruation is that women accumulate so much power in their blood that it has to be drained away regularly. (Kersenboom, 1969; de Tourreil, 1995 cited in Kothari B., 2010) There are two broad explanations for origin of menstrual taboos. First explanation is that the taboos are psychogenic in nature and they have originated out of fear of menstrual blood and second explanation is that these taboos are sociogenic in nature where patriarchal social systems perceive the menstruating woman as impure or dirty. (Kothari, B. 2010)

In the patriarchal system, menstruation is used as a pretext to justify the inferiority of women to men. Akin to the practice which prohibits dalits from entering the temples, women are also forbidden from entering temples or attaining religious functions
during menses. Few other studies have also documented the taboos associated with menstruation in India. The paper by Garg et.al (2001) noted that avoidance of sexual intercourse was found to be one of the commonest taboos in the urban slum of Delhi where the study was conducted.

### 7.1.4 Experiences of Menstruation

In colloquial language in the study area, menses was often referred as ‘adchan’ which literally means inconvenience. It was also called as ‘pali’ or ‘baherchi hone’ (condition where one needs to sit outside). From the experiences narrated by the respondents, it emerges that they faced practical difficulties in managing menstrual periods. In rural areas, women do not wear inner clothes so women feel anxious if they might stain their clothes and will have to face embarrassment.

While recounting the experiences related to menstruation, one of the respondents described that she found menstrual periods as problematic (paalicha tras vaatayacha). In some cases the problem was due to severe dysmenorrhea which incapacitated women during menses. Respondents also reported that they felt relieved (mokale) and agile (tadtdadit) every month after periods get over. Some of the respondents believed that if they had severe bleeding for few cycles then the blood gets drained and hence, they face amenorrhea or scanty menses later. Those who did not get periods every month considered it to be a problem (pali barobar nahi) and were treated for it.

Due to the dysmenorrhea as well as practical difficulties in managing menses, some of them loathed periods. (pali mhatle ki nako vatayache) Women expressed the discomfort caused by use of cloth during menses. Sanitary napkins were not widely available in those days. Women said that cloth becomes rough and hard after soaking blood and because of friction in the thighs, they suffer injuries. One of the respondents said that obviously menses are troublesome. (tras vatnarch) Women reported feverish (kankani yaychi) feeling during menses. Drying menstrual clothes was considered as problem. Embarrassment was associated with menses. One of the respondents mentioned about heavy menstrual bleeding since onset of menses. She was told by her mother that she was well nourished, that’s why she may be bleeding more. (khallyapillyali taakat aahe mhanun jaat asal)
From the narratives, it was seen that overall menstruation had a negative connotation in women’s life.

7.1.5 Information about Menstruation

The respondents told that in the last few years, the schools have started giving information to girl children about the basics of physiology of menstruation, which is good. However, when these respondents were in school, there was neither any such programme giving information nor there were other sources which women could avail to know about menstruation. The only piece of information given by mothers is that this happens to all women and there is no escape from this. In addition, they are told about how to use rags during periods to prevent staining other clothes.

Respondents considered that people in the villages are ignorant (gaavandhal) about these issues and hence they have no idea about why women get menses. They considered that now there are some progressive changes (sudharana), so girls are being educated about these issues. Women also said that in those days there was not so much fuss about these issues. Some of them were convinced that it is important to know about these things before one starts getting periods. Two of the respondents who were working as ASHA told that during ASHA training they were given information about menstrual cycle like when does it start, what care should be taken, how to maintain hygiene etc. In the training, they were told that unwanted blood is thrown out. The cultural understanding about menses is that it is the process of expulsion of dirty blood. (Garg, Sharma, Sahay 2001) The same belief was being affirmed in the trainings. The only respondent, who was told by her mother beforehand, spoke about what her mother had told her. Menses was communicated as a problem which every woman has to face every month. Since her mother was educated till seventh standard, she felt it was important to prime her daughter about this important issue. It was interesting to hear that her mother had given quite detailed information about menstrual periods such as what are the signs of onset of menarche; that it is natural to get menses. Her mother had clearly articulated that some get it early and some get it late depending on the hormones and the nutritional status and health status of girls like if they are fit or frail. Respondents also said that in some cases the mothers had warned them about not disclosing that they have attained
menarche. Women’s experiences show that given the secrecy and shame associated with reproductive processes, they seldom get a chance to get scientific information about these issues.

### 7.1.6 Knowledge about Size and Location of Uterus

Respondents were asked about how big they thought the uterus was and where was it located in our body. Out of 44 respondents, 15 reported that the doctor had shown the specimen of uterus after surgery, however, only five women had seen it and in rest of the cases, it was seen by the relatives, who then described its appearance to these women. One of the respondents who had seen the specimen of uterus after surgery said, ‘*He showed me the bag, it was small and in the middle of it there was fibroid, it was black and of a size of lemon.*’

Out of 44 respondents, eight told size of the uterus to be around 4 to 5 inches. Rest of the respondents gave varied descriptions about the size of the uterus. Some of the different descriptions about the size of uterus were like of a size of a pear, *don haat* (size of two palms), as broad as five fingers together, - of a size of a mango, of a size of an apple, of a size of a big lemon, like the seed of *karanji*, of a size of palm, of a size of a fist and like an egg (described how it looked when it was prolapsed).

One of the respondents told that she had thought that the uterus must be at least of a size of coconut as such a big baby comes out of it; however, after surgery the doctor showed her the uterus which was quite small.

In one of the villages, women said that some women may have two uteri, one is where the baby grows and the other is for menses. After some discussion around the issue, it was reported that in that village, there was a woman whose tubal ligation surgery failed twice and she became pregnant even after second surgery, hence they thought that some women may have two bags, one on each side and of a size half of the palm. Most of the respondents guessed about the location of the uterus in the body from the scar of the surgery.

It is important to note that all these respondents had several interactions with the physician who operated upon them. However, during none of these interactions, the
doctors took the opportunity to educate women about the physiology of menstruation or role of reproductive system.

Section II- Reproductive Health Needs Articulated by the Respondents

7.2 Defining Health Needs

The process of accessing health care services begins with the acknowledgement of health needs. Akin to the concept of access, the concept of health needs is also a multifaceted and has no universal definition. Bradshaw (1972 cited in Oliver, Mossialos 2003) has articulated four types of need; they are normative need, felt need, expressed need and comparative need. Normative need is the one which is defined by experts. Vaccination is an example of normative need. Felt needs are the perceived needs of the individual, such as feelings of pain. When the individual seeks help for felt needs, they are labelled as expressed needs, whereas comparative needs are the needs of a group of people who have characteristics similar to that group which has access to certain service.

The studies which have looked into women’s health care access reveal that not acknowledging the reproductive health needs of women is the initial barrier for accessing health care services. Perceptions of health needs and subsequent use of health services is influenced by the health beliefs i.e. the attitudes, values, and knowledge that people have about health and health services. (Anderson 1995) Anderson has categorically said that to understand the use health services, it is important to consider people’s view of their own general health and functional state, as well as how they experience symptoms of illness, pain, and worries about their health and whether or not they judge their problems to be of sufficient importance and magnitude to seek professional help.

Before discussing the various reproductive morbidities faced by the respondents, the following table gives brief information about medical terminology for various reproductive health problems commonly faced by women.
### Table 7.1 Information about the Common Reproductive Health Problems

<table>
<thead>
<tr>
<th>Reproductive Health Problem</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amenorrhoea</td>
<td>Absence of menstruation</td>
</tr>
<tr>
<td>Dysmenorrhoea</td>
<td>Painful menstruation incapacitating woman</td>
</tr>
<tr>
<td>Poly-menorrhoea</td>
<td>Too frequent menstruation at regular intervals of two weeks but less than three weeks</td>
</tr>
<tr>
<td>Menorrhagia</td>
<td>Excessive menstrual loss in amount or duration or both</td>
</tr>
<tr>
<td>Metrorrhagia</td>
<td>Inter-menstrual irregular uterine bleeding</td>
</tr>
<tr>
<td>Pelvic Inflammatory Disease</td>
<td>Lower abdominal pain, Vaginal discharge Fever, may be associated with menstrual irregularities</td>
</tr>
<tr>
<td>Cervical erosion</td>
<td>Persistent white discharge, Metrorrhagia, Backache, Chronic ill health, dysuria</td>
</tr>
<tr>
<td>Trichomonous Vaginitis</td>
<td>Copious vaginal discharge, itching at external genitalia, painful sexual intercourse, pain at the time of passing urine</td>
</tr>
<tr>
<td>Monilial Vaginitis</td>
<td>Thick curd-like white discharge, intense itching at external genitalia</td>
</tr>
<tr>
<td>Bacterial Vaginitis</td>
<td>Persistent foul, yellow-grey vaginal discharge, painful sexual intercourse,</td>
</tr>
<tr>
<td>Non-cancerous tumours of uterus- Fibromyoma/fibroid</td>
<td>Menorrhagia, feeling of lump in abdomen, symptoms of anaemia develop gradually</td>
</tr>
<tr>
<td>Prolapse of genital organs</td>
<td>Herniation of the pelvic organs through the vagina</td>
</tr>
</tbody>
</table>

Source: Dawn, 2000

#### 7.2.1 Reproductive Health Problems Described By the Respondents

Given the qualitative nature of the study, there is no attempt to give prevalence of reproductive health problems for the studied area. The information about health problems has been sought to understand the lived experience of women who undergo hysterectomy and to see how this experience impacts their decision for surgery. To understand the nature of the reproductive health problems, the symptoms were categorised in categories mentioned in the table no 5.1.

The respondents described host of symptoms which they faced before undergoing surgery. Thirty six respondents spoke about more than one problem whereas eight respondents had spoken about single health problem for which surgery was undertaken. Total 97 health problems were mentioned by forty four respondents.
Menstrual problems were reported by majority (24) of the respondents. Second most complaint was pain in abdomen which was reported by 22 respondents. White discharge was reported by 15 respondents. One fourth (12) of the respondents reported that they suffered from prolapsed uterus at the time of surgery. Due to the recurrent blood loss, menstrual problems were associated with weakness in case of seven respondents.

**Figure: 7.1 Reproductive Health Problems Reported By the Respondents**

Out of those eight respondents who had single health problem at the time of surgery, three respondents had pain in abdomen for which they underwent hysterectomy. Whereas, other five respondents reported menstrual problems, prolapsed uterus and white discharge as the health problems for which surgery was undertaken.

Out of 22 respondents who reported two health problems at the time of surgery, menstrual problems combined with pain in abdomen was the commonest symptom reported by five respondents. Pain in abdomen which was the second most common symptom was reported with backache, prolapsed uterus and white discharge. Prolapsed uterus with difficulty in passing urine was mentioned by three respondents. White discharge was reported along with backache and itching in vagina.

Source: Calculated from field date
Age wise reporting of the problems was seen to find out the symptoms for which young women i.e. women who were operated at or before the age of 35 years underwent hysterectomy. In the study, there were twenty five respondents who were 35 years or less at the time of surgery. Out of these twenty five respondents, eight had menstrual problems, equal number had pain in abdomen, six had prolapsed uterus and three had white discharge before hysterectomy.

In the study conducted by Singh and Arora (2008) in Haryana also out of 70 women who were interviewed, 74% had undergone hysterectomy for menstrual disorders. Whereas in the study conducted by Dr. Kameswari and Dr. Vinjamuri (2007) in Andhra Pradesh, out of 132 women 87 women (66%) had problem of white discharge and burning sensation while urinating. In the study by Desai et al. (2011) in Gujarat, the main symptom for which hysterectomy was performed was ‘spoiled uterus’ which was cited by 61% women in the sample of 178 hysterectomy cases.

Overall the nature of reproductive morbidities is such that it creates hindrance to women’s daily life. For e.g. menstrual problems need confining to one place as women have to change the cloth several times and every time the cloth needs to be washed and dried. Similarly, when the prolapse becomes severe and the uterus remains outside the vagina, it creates difficulty in walking or doing any task which requires lifting loads. At the time of urination, they have to manually push the uterus upwards. Similarly, in case of white discharge if the discharge is foul, then women feel ashamed to participate in the social functions. Hence overall these health problems hinder women’s participation in work and social life.

The present study has tried to understand the lived experience of women who suffer from gynaecological morbidities in rural context. The narratives of the respondents underscore the difficulties of the rural life where the work load is immense. The following quotes try to highlight the severity of the reproductive health problems as experienced by the respondents.

‘...the menses continued for almost three weeks.... then it stopped for four days and again started bleeding... I had to change pads almost five, six times in a day...I had to wash the (blood soaked) clothes five six times a day...there were clots...as big as kernel...I had lost hunger...I could not eat....I was so irritated...I took medicines but there was no relief...It used to bleed continuously like it bleeds when you cut the
goat...I was really frustrated and so I decided to get operated....’ (Nasreen, 33 years old respondent from Khatav block operated at the age of 30 years)

‘I had continuous menstrual bleeding (angavarun jayache), initially it was for 4,5 days,... then gradually it went on increasing....after an year, it became very severe, plenty of bleeding, every half hour I had to wash clothes, ......’ (Madhu, 45 years old respondent from Velhe block operated at the age of 44 years)

‘I had bleeding for 15 days every month (angavarun jath 15 divas jayache, pali yaychya 8 divas aadhi band vhyache, mag parat chalu vhayache) the bleeding used to stop eight days before next period.....then again it used to start.....this went on for 3,4 years.....I never got relief from menses in this period... (Nilima, 43 year old respondent from Velhe block operated at 36 years)

‘..... there was severe bleeding during menses... I could not sit, clots were passing, I had severe pain in abdomen, I had bleeding for 8 days every month...I could not even get up in those 8 days.’ (Shubhangi, 42 year old respondent from Velhe block operated at 40 years)

‘I had pain in abdomen, continuously, (compulsory pot dukhayache), after that I had severe burning sensation during urination, urine was very hot, ....lot of burning sensation, even the smell of urine became bad....’ (Manju, 41 year old respondent from Velhe block operated at 40 years)

Medha (35 year old respondent from Velhe block who was operated at the age of 32 years) recounts how negligence at the initial stages of illness led to worsening of morbidity. Medha says,

‘...the bag started coming out after the birth of my elder son, at that time the baby was in head up position, at the time of delivery, lot of mishandling had happened... but the next two deliveries were relatively hassle free...two, three months after the birth of younger daughter, I had gone to Sassoon general hospital, they told me that your bag needs to be pulled up, and then you will have to rest after the ring is inserted....but I did not take it seriously...later it became very cumbersome, I could neither stand nor sit properly....additionally I started getting white discharge...I was unwell all the time.....

The respondents had vivid memories of the onset of these health problems as well as their progression. Neelam, who was operated six months before the surgery reminisces about how her health problem progressed towards hysterectomy.
‘Last year, in the month of May, I lifted some heavy weights at the time of working in the field. After I came back from the work, I noticed that there was white discharge; I thought it is because of lifting heavy loads and it will go away. But later it started stinking, I also started getting backache. I suffered for almost one year, later on, there was itching, I felt fullness of abdomen, leg cramps..... (Neelam, 36 years old respondent from Wai block who got operated at the age of 36 years)

‘Fifteen days after my last delivery I had fallen from chair, at that time I had injured myself. I was wet nurse (oli balantin) at that time. (Initially) I had only back pain, but after a year, the bag started coming out. (Sunita, 40 year old respondent from Wai block, who was operated at the age of 33 years.)

Most of the respondents paid attention to the health problems only when they started to affect their work. Despite having realized the need for care by women, health access gets delayed due to familial situation.

Priti from Velhe block of Pune district narrated how after listening to the information about reproductive health problems in a village meeting, she decided to undergo hysterectomy immediately.

‘I used to get menses every fifteen days. (pandhara divasatch yaychi pali) I took pills for 4 years, sometimes I took tablets continuously for two months then I used to stop medicines and then on 5th day I again started the pills, I did like this for almost 4 years.... one day during village meeting, a slideshow was shown where information about women’s illnesses was given... five six madams had come to talk about women’s health problems...they said that if anybody has bleeding problems then they should immediately seek treatment.....after listening to that information, I was shocked...I said rather than this illness getting further aggravated...I should go and seek treatment (Priti, 39 years old respondent from Velhe block)

From the overall narratives regarding reproductive illnesses, it was seen that within the rural agricultural context, where women’s work involves several hours outdoors in the field, management of reproductive morbidities was difficult.

7.2.2 Age at Onset of Problems

Out of the 44 respondents, two of the respondents were facing the problem of dysmenorrhea since menarche. Majority of the respondents started facing reproductive health problems by the age of 30 years.
reproductive span of 20 years from menarche to menopause. Considering that the

Figure 7.2: Age at Onset of Reproductive Health Problems

Source: Calculated from field date

Case story of Bhagyashree who suffered from the gynaecological problems since menarche

Bhagyashree, who was operated at the age of thirty-two, was suffering from dysmenorrhea since menarche. Bhagyashree has studied up to 5th standard. She attained menarche at the age of 12 years. Since beginning, she had severe dysmenorrhea. The pain was so severe that she could hardly do any work during menses. She had consulted doctors even before marriage. The doctors gave some tablets which provided temporary relief. Doctors told her that this problem would go away after marriage, however, in case of Bhagyashree, the problem continued even after having two children. According to Bhagyashree, the pain during menses was akin to labour pains. After few years of her last delivery, Bhagyashree also started suffering from white discharge. The doctor told her that there is lesion on the mouth of uterus (cervical erosion). Bhagyashree had asked the doctor if this problem can be treated by medicines. However, doctor said that the medicine would cure temporarily, but the problem would recur. If the surgery is delayed then it can turn into cancer. The family thought that if the problem recurs, every time she will have to be taken to hospital. Instead, it is better to get operated and hence surgery was undertaken. (40 years old respondent from Purandar block of Pune district)

In the sample, it was seen that most of the women were married by 18 years, then within next five to six years, they achieved their desired number of children and by the age of 25 years most of them underwent sterilisation surgery. After that, within five years, i.e. by the age of 30 years, they started facing various reproductive health problems, for which medical treatment is tried for 3 to 4 years. After which around the age of 35 years, they underwent hysterectomy. So on an average these women have reproductive span of 20 years from menarche to menopause. Considering that the
average age of menopause in India is 44 years (Bharadwaj et al., 1983; Padmadas et al. 2004), these women are reaching menopause 10 years before the age they would have reached menopause which is considerable reduction in their reproductive spans.

### 7.2.3 Duration between Onset of Problem and Surgery

Respondents were asked about the time period between onset of the problems and actual time of surgery. Considerable variation was seen in the duration for which respondents were suffering from the problems. Shortest duration between onset of symptoms and surgery was less than seven days whereas longest duration was 28 years. Out of the 44 respondents, 14 respondents got operated within one year of onset of problems, 20 respondents took treatment for more than one and less than five years and then got operated. For 5 respondents, duration between onset of symptoms and surgery was more than five but less than 10 years and four of the respondents reported that they suffered for more than 10 years before resorting to surgery.

**Figure 7.3- Duration between Onset of Problems and Actual Surgery**

![Duration Between Onset of Problems And Actual Surgery](image)

Source: Calculated from field data

In the present study, there were five respondents who were operated within one month of onset of health problems. Analysis of the socio-demographic characteristics of the respondents who took the decision of surgery in a short span of time reveals that all of them were operated before 40 years of age. Except one respondent, all were less than
40 years of age at the time of interview. Two were from Wai block, two were from Purandar and one was from Velhe block. Two of them were not educated, two had studied up to fourth standard and one had studied up to 9th standard. Four were engaged in agricultural work whereas one was a home maker. Two were operated for pain in abdomen, one was operated for amenorrhoea and white discharge and two were suffering from menorrhagia. Out of five respondents, doctor had spoken about possibility of cancer in three cases which triggered the decision to undergo surgery. In other two cases, though the doctors had not mentioned about cancer, they had hinted that avoiding surgery could be dangerous.

In the study, respondents at both the ends like the one who got operated after one single episode of pain in abdomen was captured as well the experience of the respondent who endured her problem of dysmenorrhoea for 28 years was also captured. Given below are these two case stories.

Case story of Sandhya who suffered from dysmenorrhoea for 28 years

Sandhya attained menarche at the age of 12 years and had severe dysmenorrhoea since menarche. She had consulted several doctors before marriage as well as after marriage but most of the medicines were only temporarily effective. At the age of 16 years, Sandhya was married off and she had her first child at the age of 17. Sandhya’s husband was very cooperative and took good care of hers during menses. Since she was almost bedridden during menses, her daughters started sharing household chores from very early age. After her daughter was married off, Sandhya felt very embarrassed to talk about her menstrual problems in front of her son in law. Just before surgery, Sandhya had also started suffering from frequent bleeding (polymenorrhoea). She did sonography for this problem. The sonography revealed that there is a fibroid in the uterus. The doctor said that surgery is essential otherwise the fibroid may burst inside. The doctor estimated that the cost of surgery would be around 22000 rupees. Since Sandhya could not afford this cost, her husband enquired about hospitals where RSBY card could be used to get surgery done at subsidized rate. The doctor who operated upon Sandhya did not even examine Sandhya before surgery. He scrutinised the reports of her investigations and fixed the date for surgery. Sandhya was feeling miserable that her family had to suffer a lot because of her health problem and hence accepted the surgery as a permanent solution for her menstrual problems.

Sandhya is 43 years old respondent from Purandar Block of Pune district operated at the age of 41 years

Sandhya’s case study indicates that in the community, dysmenorrhoea is not associated with fatal complications like cancer whereas menstrual irregularities are considered as serious illnesses and treated immediately. Sandhya spoke about the
negligent attitude of doctor, as he didn’t examine Sandhya before surgery. Sandhya felt that since she was poor, the doctor ignored her.

Case story of Maya who underwent hysterectomy after a single episode of pain in abdomen

Maya, 36 years old respondent from Purandar block of Pune district has undergone hysterectomy for pain in abdomen at the age of 30 years. Maya who belongs to Hindu Maratha family; has studied up to 9th standard and works in the field owned by the family which is around one acre in size. Maya had a history of seven pregnancies. In two of the pregnancies, she had done MTP. She has four daughters where youngest daughter is 10 years old. During one of the pregnancies, there was still birth.

One night, Maya had severe pain in her abdomen, for which she was admitted in the hospital in nearby town, Jejuri. Doctor gave her injection and Intravenous fluids.

Maya describes that the pain was as severe as labour pains. Next day the doctor performed Ultra sound and told Maya that there are fibroids on the uterus for which hysterectomy would be required. If surgery is not done then the fibroids will grow and may lead to cancer. Maya’s husband consulted other doctors while Maya was in hospital; however, other doctors also said that the fibroids will grow in size.

During interview, Maya sounded upset because she could not give sons to her husband. She considered herself unfortunate. One of the major concerns riding on Maya’s mind was that she has four daughters and if she dies who will look after her daughters. Under these circumstances, Maya and her husband decided not to delay the surgery and within 15 days of first episode of pain in abdomen, Maya underwent hysterectomy.

7.2.4 Respondents’ Perceptions about the Cause of Illness

Respondents were asked about their perceptions about the cause of their reproductive health problems. Most of the respondents felt that the health problems are occupational in nature. Work in the field requires carrying heavy loads or strenuous activities, which leads to these problems. Along with the occupation, the respondents also mentioned that previous reproductive events such as deliveries or use of contraceptives or the tubectomy could have caused the health problems. Meena (41 years old respondent from Velhe block operated at the age of 32 years) had delivered twins, according to her, the uterus started coming down after the twin delivery. She felt that the opening of the uterus increased in size after the delivery of twins and hence the uterus prolapsed. (pishviche tond mothe jhlae hote) Repeated MTPs which
is called as *pishavi Dhune* which literally means ‘washing bag’ were seen as another cause of reproductive health problems. Respondents who had delivered at home believed that during delivery, they had not received proper care which led to health problems subsequently.

In case of Madhuri (37 years old respondent from Purandar block operated at the age of 33 years), the doctor had forgotten to remove copper T at the time of tubal ligation; hence the Cu-T was inside for a long time. She said, ‘*I think it is because of that CuT which remained inside for long, may be because of having sex with CuT inside, this fibroid must have happened, and plus there is swelling on intestine....’*

Laparoscopic tubectomy was perceived as the cause by some of the respondents. In fact, in some areas women believed that laparoscopic surgeries lead to these health problems and thus they demand open surgery for tubectomy. In case of problem of dysmenorrhea, it was considered that this could be a hereditary problem as the mother of the respondent was also facing similar problem. Several respondents felt that early marriage and having children in very young age could have led to these health problems. One of the respondent also cited that the age difference between her and her husband was more than ten years which could have caused problems. There was a perception that if the woman does not bleed enough after delivery, she may face bleeding problems later on.

Living in rural areas mandates very strenuous work as women are entrusted with the responsibility of household chores as well as farming. In this situation, women cannot take adequate rest after delivery or during pregnancy. Many respondents had imbibed the feeling that they have neglected their health during important reproductive events such as deliveries which has resulted in to these morbidities. In some cases, it was reported that the doctors told respondents that since they did not follow proper menstrual hygiene i.e. they use rags during menses, which causes these reproductive infections. It is important to note that none of these situations are under control of women, they are either culturally constrained to follow the menstrual taboos or the gender division of labour compels them to contribute to the agricultural activities. However, the doctors spoke in a victim blaming approach where women were held responsible for their health problems. The respondents also sounded like they
considered themselves to be victims of situation where they can’t take any decisions regarding their life such as when they should marry or when to have children.

Lifting heavy workload is one of the major reasons for the prolapsed uterus. Out the present sample of twelve women who had prolapsed uterus, seven were working the agriculture whereas remaining were either home makers or were doing non-agricultural work. Multiple pregnancies is another known cause of prolapsed uterus. Hence, obstetric history that is the history of pregnancies and child births was checked for those respondents who had reported prolapsed uterus. Out of the twelve respondents who had prolapsed uterus five respondents had four children each. In addition, these respondents reported complications during pregnancy such as intrauterine death of foetus, premature delivery, spontaneous abortion, caesarean section, jaundice during delivery and post partum haemorrhage.

A study conducted in Nepal by Earth B., Sthapit S. (2002) had investigated the role of gender-skewed cultural practices to the high prevalence of uterine prolapse among rural women in Nepal. The study had brought out factors such as difficult geographical terrain, heavy workload during pregnancy, lack of proper antenatal health services and lack of autonomy for decision making as some of the factors responsible for high prevalence of prolapse in this region. Similarly, the study mentions that push and pull methods are used to deliver the baby when the deliveries are conducted by inadequately trained personnel, and post-delivery women are not entitled to adequate rest all these results in the prolapse of uterus. In the same paper, the explanation regarding the mechanism of prolapse of uterus is noted. According to Bhat (1997 cited in Earth B., Sthapit S. 2002), damage to the muscles of pelvic floor results from overstretching of the perineum; obstructed labour; delivery of a large infant; delay in episiotomy; and/or imperfect repair of the perineal injuries. This damaged pelvic floor then cannot support the uterus and the only support to uterus is of ligaments. These ligaments are also prone to tear if they are subjected to pressure beyond their capacity. The pressure inside abdominal cavities increases at the time of pushing the baby down during the delivery process as well as performing work which requires lifting of heavy loads. Most of these factors were even reported by the respondents in the present study.
In the rural areas, there is a belief that work done during delivery enhances the chances of easy delivery and there is hardly any rest post-delivery. Thus the reproductive organs do not get the required rest for six weeks to return to their normal state. All these increase the chances of reproductive morbidity subsequently.

Regarding acknowledgment of reproductive health problems, prolapse of uterus is one of those problems where there is high correlation between self reported and clinically diagnosed condition. Opposite to prolapse, menorrhagia is found to be a subjective illness where the symptoms reported by women may not correspond with actual blood loss and women felt that menorrhagia impacted family life more than physical health. (Grant C. et al., 2000; Clarke 2010) In the present study also sometimes the reporting of blood loss due to menorrhagia was found to be on higher side. For e.g. one of the respondents said she had to change the pad every half an hour.

7.2.5 Respondents’ Perceptions about the Severity of Health Problems

In the study, the respondents were asked about at what stage they felt that the illness is serious and they need to seek care.

Respondents with menstrual problems such as continuous bleeding or heavy bleeding faced weakness as the loss of blood would have resulted in anaemia. Respondents mentioned that in that state of weakness, due to continued bleeding they had to wash the rags several times in day. Some of them were fed up of frequent washing of clothes and continuous bleeding. In case of prolapsed uterus, as the degree of prolapse increased, women started facing problems with passing urine as the prolapsed uterus was obstructing the flow of urine. In addition, there were lesions on the mouth of uterus due to constant rubbing. Both these problems had significant impact on the daily lives of the respondents. In some cases, the bleeding problems incapacitated them for doing any agricultural work.

In some cases, initially there was only one problem like either pain in abdomen or white discharge but many a times subsequently other problems like bleeding problems started which was perceived to be serious by the respondents. Foul smelling discharge was most of the times considered as one of the symptoms indicating that the underlying health problem is serious. Sometimes the ultrasound
showed that the size of the fibroid has increased. The respondents perceived this to be serious. In many cases, the relief due to medicines was found to be temporary as the problems like bleeding as pain used to resurface once the medicines were stopped. Recurrence of the health problems was also perceived to be indication of underlying grave problem. To describe the severity of pain in abdomen, it was likened with labour pains as labour pains are considered to be most severe pains.

After the findings related to the acknowledgement of health needs by the respondents, the subsequent chapter now describes the household level processes at the time of decision making regarding hysterectomy.

SECTION III- INTRA-HOUSEHOLD DECISION MAKING PROCESSES PRIOR TO HYSTERECTOMY

Once the barrier related to acknowledgement of health needs is crossed, then the second barrier faced by women is getting permission from the family for accessing health services. In the present study, the respondents were asked about the response of the family when they disclosed their reproductive health problems and about the intra-household decision making processes before undergoing hysterectomy. In this section, information related to following aspects has been given-

1. Who was the first person to whom the respondents revealed their illness?
2. What was the response of the husband when he came to know about the illness?
3. Given the culture of silence around reproductive health issues, how did the respondents overcome this barrier?
4. Who accompanied respondents during visits to health care facilities?
5. What discussions happened within the family when the doctor advised hysterectomy?
6. Who all were consulted before taking the decision about surgery?

7.3.1 Disclosure of Reproductive Health Problems

Out of 44 respondents, 21 had first revealed the illness to their husband. Remaining respondents had spoken first to family members other than husband and then later on they shared their health problems with the husband. The respondents were asked about the response of husband when they shared their health problems with him. Out
of 36 respondents who shared their reproductive health problems with their husbands, in most of the cases, the husbands immediately took their wife to the doctor for treatment. Only in one case, there was some delay as the couple did not have enough money to seek care. There was a sense of fear of death due to reproductive health problems even among the husbands.

Respondents mentioned that in previous generations, women were not taken to the hospital, but now people are fearful about serious complications of such illnesses hence there is no delay in treating these illnesses. Respondents also quickly added that they directly seek care from doctors prescribing modern medicines and do not resort to herbal medicines for these illnesses. Sometimes the promptness in seeking care was also to avoid the practical difficulties, for e.g. one of the respondents said that if she is unwell she can’t cook (tukdyache vande hotat) which is a problem for the family and hence the husband immediately takes her to doctor. The respondents expressed that in this generation, the husbands are more concerned about wife’s well being and they take notice of wife’s health problems.

Majority of the respondents (26) were taken to the doctor by their husband. Six respondents told that they were not accompanied by anyone when they went to see the doctor. Natal relatives like mother or sister accompanied six respondents whereas remaining six respondents were escorted by either children or mother in law.

Involvement of men in the decisions related to family planning and responsible parenthood has been identified as essential for improving women’s reproductive health. (Santhya and Dasvarma 2002) Better spousal communication is needed for shared decision making. Santhya and Dasvarma had shown that elderly women had better communication with their spouse. In the present study also it was seen that elderly women were open to talk about the reproductive illnesses as compared to younger ones. Reasons noted by Santhya and Dasvarma (2002) for poor communication by younger women were shyness, fear of husband’s reaction and acceptance of normalisation of gynaecological illnesses. Along with age, education was found to be positively associated with better spousal communication.
7.3.2 Crossing the Barrier of Shyness

In the study the respondents were specifically asked if they felt any awkwardness or shyness to talk about these health problems. Majority of the respondents (24) said that they did not feel awkward in sharing their problems with their husband or other family members. Increased awareness about women’s health problems in the society was cited as one of the reasons by the respondents, which made it easier for them to share the reproductive health problems. Respondents said that now everybody is aware about these problems, even the young people know, so there is no awkwardness in sharing. They also felt that there is more receptiveness in listening to these illnesses as compared to earlier days. Some of the respondents said that if we hide these problems, then the delay (in seeking treatment) can cost you your life, hence if we face the problem, we have to share it with the family as there is nothing more important than your life.

It was felt that young girls may feel shy to talk about these problems, but since these women already have children, they are more open to discuss these health problems without getting awkward. In some cases, as the problem was first shared with other women in the family like mother, mother in law or sister, hence there was less discomfort in talking about reproductive health problems. Respondents expressed that the family has quite open culture and hence there wasn’t much problem.

However, some of the respondents (14) did express embarrassment in discussing reproductive health problems with the family members which had led to delay in disclosing the illness. In these cases, women did not talk about the health problems until the problems became noticeable to others.

‘see, initially it was difficult to talk, but have to tell na, people could guess that I am having some problem, I could not eat, so people believed that I really had pain, I could not work in field, so had to sleep, (katkat hotech na gharat, sarakhe kase dukhane) the family will complain na.. if you are always unwell...’ (Jyoti, 45 years old respondent from Wai block operated at the age of 39 years)

Sonali from Velhe narrates her situation about delay in seeking care despite having severe bleeding problem.

‘I had problem of continuous bleeding, see usually when we get periods, we have bleeding for 4, 5 days and then we take head bath and the bleeding stops. But once
it just continued, I thought it will stop today or tomorrow but it didn’t stop. At that time, my daughter's marriage was fixed so I did not pay much attention to this problem. My son is mentally retarded, I have lot of workload so I could not go out (and see a doctor). After my daughter's marriage there was no one to look after my son, so I did not tell anyone, then other women started asking me why you look so ill. Is there any problem? I had continuous bleeding for one year....’ (44 years old respondent from Velhe block of Pune district, operated at the age of 39 years.)

Women were hesitant to reveal their problems, but the severity of pain or bleeding forced them to talk about it. Sometimes the family members were annoyed due to their inability to perform household chores due to recurrent episodes of bleeding or pain.

Though most of the respondents expressed less discomfort in talking about reproductive health problems, the situation was different for young women.

‘I did not talk about it for two year..., I thought that I have recently recovered from delivery, how should I immediately talk about this problem so I hid it...’ (33 years old Nasreen from Khatav block who was operated at the age of 30 years)

Nasreen did not want to be seen as the one who is all the time complaining about one or the other health problem and hence she delayed talking about the problems. This indicates that getting cared by the family is considered as privilege by women and not as their entitlement.

Sandhya (43 years old respondent from Purandar block, operated at the age of 41 years) had problem of severe dysmenorrhoea, however, for several years she tolerated this problem which made her very sick during the days of menses. Everyone in her family knew about her problem and several different treatments were being tried to alleviate the pain. Her pain was so severe that she was incapacitated to do any work during menses. After the marriage of her daughter, she started feeling very awkward because she did not want her son in law to know about her menstrual problems and hence opted for surgery as a permanent solution.

Similarly Madhu (45 years old respondent from Velhe block, operated at the age of 44 years) who was suffering from menorrhagia reported she felt embarrassed to discuss menses related problems in front of grown up sons. Hence, one can say that though there is some progress in terms of more openness in discussing menstrual problems, however, this openness is limited to discussing with spouse or women and not with
other men even if he is a son. If some other family members had already undergone hysterectomy, then it was easier for the respondents to share their problems as the family was already aware about the need for treatment in such cases.

‘My mother in law was also suffering from bleeding problem, but my father in law never paid attention, you know in those days even husband used to neglect his wife.....finally she had to be given blood from two other men.. then her surgery was done..since my husband had seen this he immediately took me to doctor.’ (Maya, 35 years old respondent from Purandar block of Pune district operated at the age of 29 years for the problem of pain in abdomen)

I had pain in abdomen... I was eating medicines, but the pain did not stop, so the family members started saying that why are you bearing so much of pain, get it removed, my mother in law also had done hysterectomy, she said remove it if you are having so much of trouble (Madhuri, 37 years old respondent from Purandar block of Pune district operated at the age of 33 years for the problem of pain in abdomen)

In many gender-stratified societies, women do need the approval of their spouses and families in order to seek treatment. For example, in India, as high as 50% of the symptomatic women in a tribal area of Gujarat who had agreed to be examined and treated at a health camp, backed out because the male family members did not allow them to attend the camp (Khanna et al. 1998 cited in Santhya K.G., Dasvarma G.L (2002) Two studies reported that symptomatic women often did not inform their husbands about their gynaecological symptoms (Bang and Bang 1994, Ramasubban and Rishyasringa 2000). Ramasubban (1995) notes that women are afraid and confused to talk about their illnesses because they are not supposed to have such problems in the first place and also because they are socially deemed to be polluters, the originators of sexual problems.

Santhya and Dasvarma (2002) note that women are told that the occurrence of reproductive symptoms is normal at some stages of their lives. In her adolescence, she is told 'once you get married, you will get over it'; in her initial years of marriage, she is told 'it happens to all women sometime' and in later stages, she herself starts believing 'it just happens'.
7.3.3 Intra-Household Decision Making Processes before Undergoing Hysterectomy

A study conducted by Wu et al. (2005) to probe the decision making processes prior to hysterectomy revealed that women who can overcome the fear of benign fibroids turning into malignant ones, decide against surgery. Whereas, women who faced irrational psychological obstacles, who were unable to bear the physical discomfort and in whom the fibroid size was increasing, opted for surgery. The study revealed that fear of fibroids turning malignant was the best predictor of the decision. These women also believed that uterus is merely an organ for producing children, hence thought it was useless after having children. The findings of the present study also reveal similar considerations by respondents before accepting hysterectomy as treatment. Another study by Cabness (2010) had indicated that women’s pre-surgery physical experiences were the most critical factor in their decision-making. Women reported that frequent bleeding episodes affected their social life and also made them irritable, moody, depressed, scared or fearful. Due to this physical as well as emotional disturbance, they opted for surgery.

In this part of Maharashtra, hysterectomy as a treatment for gynaecological problems has gained wide acceptance. During the fieldwork I came across several women who had undergone hysterectomy before 45 years of age but they were not included in the study as their age the time of interview was more than 45 years which was cut off for this study. During the informal discussions with women, it was seen that hysterectomy was anticipated in case of women who start suffering from gynaecological problems. There were myths associated with modern medicines such as painkillers cause swelling or the hormonal tablets cause heat in the body, whereas hysterectomy was considered as permanent solution for all gynaecological problems. Due to this wide acceptance to hysterectomy as a best treatment, the respondents hardly faced any barrier at household level for seeking permission in the family to undergo hysterectomy. In none of the cases, the family members opposed the respondent from undergoing surgery. The surgery was delayed in case of some of the respondents as they did not have enough money for surgery; however the family was convinced about the need for surgery.
Case story of Madhu who underwent surgery under pressure from the family members and neighbours

Madhu, 45 years old respondent who operated one year back is a resident of Velhe block. She has never been to school. Her husband is educated up to 7th standard. Both the husband and wife work in their field. When Madhu was around 42 years old, she started suffering from heavy bleeding during menses. Till then, her periods were normal and she never felt troubled during menses. When the problem started, the bleeding was so heavy that Madhu had to change pads several times in a day. Initially she went to a private clinic in her area; the doctor gave her injection which provided relief for next few months. However, later again the problem of bleeding started. Then the doctor did curettage to stop the bleeding and gave medicines. After this curettage, there was relief from bleeding for two, three months, after which the problem again started. Then she sought treatment from a nearby Trust hospital, where she was admitted for ten days. Madhu felt that the medicines were causing weakness and burning at the time of passing urine. Overall this problem continued for two years. During this period, other people in the neighbourhood started blaming the husband for not consulting a good doctor. According to them if the doctor was not suggesting hysterectomy for the bleeding problem, then they considered him to be incompetent doctor who doesn’t know proper treatment. Even the family members started pressuring Madhu’s husband to take her to a doctor who will advise hysterectomy. Madhu’s sons were grown up and Madhu was feeling very embarrassed that her menstrual problems were being discussed in front of them. By now, Madhu’s husband and sons also started feeling that they need to see a doctor who will advise hysterectomy. Finally they took Madhu to a doctor in Pune city who performed hysterectomy. The doctor had said that there is no problem with the uterus, however, since bleeding continued, surgery was done. After the interview, Madhu’s husband shared that due to the constant pressure from other family members and the neighbours to take Madhu for hysterectomy, he had started feeling guilty of not providing good quality care to his wife. Succumbing to this pressure, Madhu’s husband took her for hysterectomy.

In cases where the children were grown up and were educated, they were also seen to participate in the decision about hysterectomy. In fact, Bharati (45 years old respondent of Wai block operated at the age of 40 years) was suffering from complete prolapse of the uterus and was advised hysterectomy long back. However, since she could not afford the expenses of the surgery she had delayed the decision. As soon as her son finished his education and got a job, first thing he did was to get his mother treated. The son managed all the expenses of the surgery.

Overall the husband or other relatives such as mother in law or mother were very supportive of the decision to undergo hysterectomy. Several respondents said that their husband never delays the treatment once it is suggested by the doctor. As soon as the doctor advised hysterectomy, the husband agreed for it. In some cases where
the husband was working in some other town, the respondents had confided with mother in law, who had also readily agreed for surgery. As mentioned above, in every village there are women who have undergone hysterectomy, many a times women in the close relationship like either mother or the mother in law or sister in law had been operated earlier, so the family is aware about the surgery. Overall perception about hysterectomy is that it is a safe surgery and hence there is not much reluctance in taking decision in favour of it. Sometimes the decision of surgery was necessary as the family was suffering practical difficulties in managing work due to the recurrent illness of the respondent.

Decision of surgery was also favoured because it was thought that since hysterectomy is a permanent solution, it will reduce the number of visits to doctor for medication.

'if we decide to go for medication, then we will have to go to hospital every time, secondly if there happens any problem after taking pills then what will we do? He said it’s better to get operated (direc aapan pishvich kadhun taku)' (Bhagyashree, 40 years old respondent from Purandar operated at the age of 32 years)

The timing of the surgery was adjusted considering the school vacations as the surgery was going to incapacitate the respondent for some weeks. Hence, in some cases though doctor had said that there is no hurry for getting operated, the respondents underwent surgery taking into consideration holidays for children which would give her time to recuperate.

Urgency for surgery was also due to the perception that the delay in treatment may lead to fatal or serious complications later. As Mukta said, ‘my family gave permission to do surgery... mother in law said that rather than anything going wrong, (just kamee kahi hounaye), get it done..' (35 years old respondent from Wai block operated at the age of 35 years)

Recurrent nature of reproductive health problems was also one of the reasons behind the family giving permission for surgery. Priti reported that her husband said that ‘we have to do the surgery, its’ better than going to doctor all the time. (karayache mhanje karayache, eksarkhe nako he jhanjhat) (39 years old respondent from Velhe block operated at the age of 39 years)
In most of the cases, the husbands were also fed up of wife’s recurrent illness and hence readily agreed for surgery.

Since in many cases the doctors had said that the delay in surgery can lead to life threatening complications, the family members did not want to take risk of that. In some cases, the permission for surgery was granted mostly out of practical purposes.

‘.... the mother in law had said that it would be better if you get operated soon, because if the delay in treatment costs your life (kahi bare vacet jhale tar), then I will have to look after your children, so it’s better that you get operated. (Geeta, 42 years old respondent from Velhe block operated at the age of 35 years)

In those cases, where the doctor had asked to undergo hysterectomy immediately, there was not much scope for discussions as in such cases surgery was perceived as an emergency and delay was considered life threatening. For e.g. Suchitra (42 years old respondent from Purandar block operated at the age of 37 years) had an inflamed appendix as well as there was problem with the uterus so the doctor had asked to undergo surgery for both these problems. In this case surgery of inflamed appendix was needed at an urgent basis and hence the couple did not give much thought about it as doctor had said that if you delay the appendix may burst.

Though some of them were wary about the possible implications of hysterectomy, they preferred to get immediate relief from the reproductive health problems they were facing and considered hysterectomy as a measure of respite. (sutaka)

‘what we thought that now I am going for surgery, that is good for me, let’s see what happens later, since I am facing so much of problem, it’s important to get relief (sutaka) from this...’ (Sonali, 44 years old respondent from Velhe block operated at the age of 35 years)

After the preliminary discussion with the husband, most of the respondents discussed with other relatives as well. In most cases, mother or other relatives from natal family were consulted as mostly the mother of the respondent had provided support required to manage the household chores after surgery when the respondent was incapacitated. This also indicates that despite several years of marriage, the illness of woman is considered as responsibility of her natal family. In this part of Maharashtra, it is customary that the expenses of marriage and first delivery are
entirely borne by the girl’s family. Similar custom was seen even for the treatment of reproductive illnesses, where the post-surgery support was mostly given by mother.

Narrative of Neelam which typifies the decision making process at the time of hysterectomy

Neelam is a resident for Wai block in Satara district. She is 36 years old at the time of interview and was operated six months before the interview was conducted. This is how Neelam narrates her story...

I have two children, (daughter 15 years old and son 11 years old) both the times my deliveries took place in a private hospital. This problem started in the month of May last year....see, I had gone to work in field at that time.... you know our work involves lifting heavy loads.. we have to do it....we also carried heavy loads during pregnancy, so why should it be a problem if I carried weight after almost 8,9 years of my delivery....that was sixth or seventh day of periods.. I felt like there was some discharge... I checked when I came home... it was white discharge.... it happened two-three times. I thought it must be because I had done heavy work at that time...after some days the discharge became smelly and I also started getting backache.......so we went to Dr. P (lady doctor) ...she said this may be because of lifting heavy loads...slowly the discharge was more and more... it also started itching by then....I felt like my stomach was distended, my legs were paining... periods also came from time to time...there was not much relief with medicines....the neighbours also started saying that why don’t you see some other doctor...so we went and showed to Dr. S. He also said that this will go with medicines....he gave me medicines to be inserted from below....I ate the medicines but there was hardly any relief...slowly the tummy started looking more bloated like eight month pregnancy.... there is one lady in our area she has also had hysterectomy, she asked me to go and see Dr. G. By then the discharge was really foul smelling, I was worried whether it can be smelt by others who sit beside me.....Dr. S had not said that I will have to remove bag....but there was no relief from the problem... every time he gave tablets....then once we went to Dr. G who did sonography....before that also we had done sono graphic.... they had said that there is no problem with the bag....but when Dr. G did the sonography, it pained a lot. He also did internal examination and said that you will have to get operated. He showed me the bag after surgery.....it was total white....see the earlier doctors were giving me very powerful medicines..... the cost was almost two thousand rupees per week, but there was no relief...we thought that the body may swell due to medicines....but Dr. G gave some medicine which costed only 100 rupees but I got some relief.....Dr. S had told me not to have sex... I followed it but still there was no relief....we did everything that the doctors said but if you don’t feel better...how can you trust the doctor....finally I went for surgery when my children had school holidays....what we (me and my husband) discussed was that it’s Ok if we have to spend 20000 now, we can always work and earn that money.... but tomorrow if I get cancer.... do we have two-three lakh rupees for the treatment...after spending so much also the person will die.......I know women who have died of cancer....if the doctor says that you have to remove bag then we have to do the surgery....if we say that I don’t want to remove my bag then the doctor will say that if you have so much of knowledge, then why did you come to me?
The case story of Neelam illustrates how failure of relief due to medicines then leads to surgery. It also brings out the myths such as use of high power allopathic medicines and that the reproductive health problems may lead to cancer.

### 7.3.4 Discussion with Other Women Who Had Undergone Hysterectomy

In the rural areas, women have very limited access to sources of information such as internet or other health related literature. In this situation, women often consult other women from the neighbourhood before undergoing surgery. In the study, 16 respondents had spoken to other women in the village before undergoing surgery. In case of some of the respondents, other family members like mother in law or sister in law had undergone hysterectomy; hence they convinced the respondent to undergo hysterectomy saying that there is no risk in this surgery.

Some of the reasons given by the respondents for not discussing with other women before surgery were as follows-

Ashwini (43 years old respondent from Wai block operated at the age of 33 years) said that she was the first woman to get operated in her wadi (neighbourhood), hence could not discuss with other women. In the rural areas, the neighbourhoods are designed in such a way that households belonging to same caste usually reside close to each other. The families from similar caste constitute one neighbourhood and most of the interactions take place within this close knit group of families. Hence the respondent did not consult other women before surgery. In some of the cases, the decision of hysterectomy was taken in a short span of time thus the respondents did not get time to consult other women. As Jyoti said that it was a matter of life and death for her (jeevala aala hota) and hence she did not think it was necessary to discuss with others. (45 years old respondent from Wai block operated at the age of 39 years) Prachi said that if we are convinced about surgery (aaplya manachi khatri aahe na), then there is no need to talk to other women. (43 years old respondent from Velhe block operated at the age of 38 years)

Those respondents who consulted other women had mainly asked about the problems associated with surgery. Most of the respondents had received positive feedback about surgery from other women. Those respondents who had heard about negative aspects
of surgery had been told about pain after surgery, weight gain after surgery. Women had spoken about backache as a result of surgery. But the negative responses about surgery were very few. Respondents who were scared about the surgery said that they discussed with other women to know their experience of surgery like how anaesthesia is given or does it pain during surgery. In an ideal doctor-patient relationship, all this information should be actually given by the doctor before the surgery. However, doctors were seldom seen to discuss the details of the surgery with the patient.

Other women also try to convince about the surgery saying that rather than any complications later on, it’s better to get operated. In these communities, fear of cancer was widespread and hence women considered hysterectomy as preventive measure for avoiding cancer.

7.3.5 Duration between Doctor Advising Hysterectomy and Actual Hysterectomy

Out of 44 respondents, one got operated within seven days of onset of problems; four got operated within one month indicating that the doctors immediately advised hysterectomy and the respondents also took quick decision. Out of these five respondents, three were told about the possibility of cancer by health provider.

Generally it was seen that doctors gave a period of three to four months to decide the time of surgery. Depending on the severity of health problems and the family level engagements such as agricultural work or any wedding in the family, the respondents decided the time of surgery.

‘he (doctor) said you can do it in next 2 months, do it when you have time (fursat ghaval tasa kara) but in our fields harvesting was going on (kadhani chalu hoti) then we would not have been able to do it for next four months, there was no relief with medicines also.. (Jyoti, 45 years old respondent from Wai block operated at the age of 39 years)

Almost one fourth of the respondents said that the doctor had said that there is no hurry, you can take your time for deciding but surgery would certainly be required. Only one respondent said that even if doctors ask you to do the surgery urgently, you should take your time and decide.
‘doctor said do it immediately, see doctors ask us to do immediately, but we should think of our life, what is the use of hurrying in such cases, we should enquire properly, we did not have time because of field work, so we did after one or two months of doctor telling...’ (Shilpa, 37 year old respondent from Khatav block operated at the age of 31 years)

To summarise the findings in this chapter, one can say that though the respondents had negative attitude towards menstruation and called it as inconvenient thing, still they were able to manage if the bleeding was within normal range. However, problems such as frequent menstruation or menstruation were found to be difficult to manage. Given the hindrance caused by these gynaecological problems, the respondents shared them with their family members, who were supportive and thus the health care was sought immediately. The next chapter would now describe the interactions with the health care providers.