CHAPTER 10

RESPONDENTS’ EXPERIENCES OF THE IMPACT OF HYSTERECTOMY

Reasons behind acceptance of hysterectomy and the impact of hysterectomy on women’s lives, these are the two key areas explored in this study. Previous chapter has delineated the reasons for acceptance of hysterectomy with details of individual level, household level, community level and health system level factors that lead to this acceptance. This chapter narrates women’s experiences of surgery and its impact on various aspects of their lives.

The chapter delves into following aspects of the experience

1. Experience of actual surgery
2. Immediate post operative health problems faced by the respondents
3. Long term implications of hysterectomy on their physical health
4. Impact of the surgery on family life
5. Women’s perceptions about self image after the removal of uterus

10.1 Experience of Surgery

Majority of the respondents expressed that they were scared of surgery. Some of them expressed their dilemma at the time of surgery. On one hand, they were worried about the consequences of delay in surgery, mostly considering that the reproductive illness would lead to cancer; on the other hand they were scared of the procedures associated with the surgery. The anxiousness expressed by the respondents was due to several reasons such as -

10.1.1 Apprehension about the Procedures Associated with Surgery

Respondents expressed that they were fearful about the different procedures associated with surgery such as spinal anaesthesia or pre-operative check up like taking ECG. The reason for the fear is that the health care providers do not adequately explain about the procedures that are going to take place leaving things for the
imagination of patients. Also the entire atmosphere of the hospital and especially the operation theatre is quite alien for the patients. Hence, in absence of any proper source of information, the patients rely on the informal talk with other patients. Lack of information thus leads to feelings of anxiety and fearfulness.

In case of Nandini (31 years old respondent from Khatav block operated at the age of 22 years), the fear was so gripping that she had fled from the hospital. However later, other people pacified her and tried to alleviate her fear of surgery. Once again it is important to underscore that it is the responsibility of the doctor to counsel patients and adequately prepare them mentally as well as physically; however given the cryptic nature of communication that takes place between the doctor and the patient, the patients do not get any opportunity to get information which would alleviate their fears.

‘..I was scared, because they give anaesthesia in the spine, I thought my back will be injured (Kambar janar kaayamchi), because of injection in spine, it was the first time that I was going to take anaesthesia, my nature is bit apprehensive, so I was very scared....the doctor told me that if you get anxious then your BP may rise.....’(Dhanashree, 40 years old respondent from Wai block operated at the age of 31 years)

‘I was scared of those machines and injections and saline, I had to be given anaesthesia twice...’ (Neeta, 40 years old respondent from Wai block operated at the age of 35 years)

10.1.2 Anxiety about the Success of the Operation

Though the respondents had decided to undergo hysterectomy, they were nervous about the outcome of the surgery. Several of them expressed that they were worried about death during surgery.

Shilpa said, ‘operation madhe kaay kele doctor ni aani aapla jeev beev gela mhanje asa vatat hote- I was worried that if doctor does something wrong during surgery, what if I die during surgery...’ (37 years old respondent from Khatav block operated at the age of 31 years)

‘I was so scared thinking what will happen? They will cut me, whether I will come out alive?’ (Ashwini-38 years old respondent from Khatav block operated at the age of 34 years)
'I was scared; I could not sleep whole night before surgery..... I was thinking if doctor does anything wrong during surgery and if I die....I was scared, I thought there is no blood inside me, whether my surgery would be alright.... whether I will be able to work after surgery....' (Bharati-45 years old respondent from Wai block operated at the age of 40 years)

10.1.3 Anxiety about Children’s Future in case of Death during Surgery

The respondents were more worried about the future of their children in case of their death, rather than being worried about their death itself. Women’s indoctrination about their role as mothers is so deep that rather than getting concerned about their health or their right to live healthy life, they are constantly worried about their children especially about not being able to fulfil their responsibility as mother.

‘I had tension, I thought even if I die it’s Ok but my children should be happy (sukhi), anyway I would have died of the illness so it doesn't matter if I die during surgery.....’ (Gayatri-41 years old respondent from Khatav block operated at the age of 38 years)

Similarly, tension was expressed about how the hysterectomy would hinder them from fulfilling their role as home maker. The respondents were aware that at least for some period they would not be able to manage the household responsibilities in a full-fledged manner as the surgery would incapacitate them for doing so. Hence, besides death, impact of surgery on their capacity to work was another reason of concern before the surgery.

‘I was tense (tension aale hote) who will do the household chores, it was difficult not to lift heavy weights, but since my daughters were not married, they did household chores......’ (Jyoti-45 years old respondent from Wai block operated at the age of 39 years)

Some of the respondents said that they had made up their mind for surgery hence there was not much anxiety. Others felt that the existing health problem was so troublesome that the surgery was better than suffering from this health problem even if the surgery has any untoward complications.
‘I have faith in God....I thought if he wants to kill me, he can kill me.... if he wants to keep me alive, he will keep me alive.....but relieve me of this problem, I was facing very severe problem...’ (Manju-41 years old respondent from Velhe block operated at the age of 40 years)

‘I was not scared, here I was dying (jeev challay) and why should I feel scared, I was suffering so much that I thought it was better to die than suffer...’ (Nilima-43 years old respondent from Velhe block operated at the age of 36 years)

10.2 Immediate Postoperative Complications

Medical journals are replete with the studies that discuss the long term and short term consequences of the surgery. Bleeding during surgery, injuries to organs such as bladder, ureters and bowel, post-operative bleeding, retention of urine, urinary infection, wound infection, fever are the reported complications after hysterectomy. (Brummer et al., 2011) Complications such as urge incontinence defined as experience of urine leakage related to the feeling of urgency and difficulty in emptying the rectum, were observed more in the patients who had hysterectomy through vaginal route than patients who had through abdominal route. (Roovers et al., 2001) But the chances of injury were found to be lower in cases where the vaginal hysterectomy was done for prolapsed uterus than vaginal hysterectomy done for other conditions. (Dorairajan et al., 2004) The rate of serious postoperative complications of hysterectomy is about 10%, and long convalescence periods are required. Hospital stay and time to resumption of normal activities are long for hysterectomy. (Clarke, 2010)

In the present study, out of 44 respondents, almost half of the respondents reported that they faced post operative health problems. Some of the common health problems reported by the respondents were moderate to severe pain in abdomen, difficulty in passing urine, giddiness, weakness, loss of appetite, headache, nausea, vomiting and back ache. Given the fact that hysterectomy is one of the major abdominal surgeries, it is anticipated that there would be some health problems immediately after surgery, however, the doctors never discussed about the possibility of any immediate or long term health problems that could ensue after surgery. The respondents felt that probably the doctors do not tell this information to avoid creating fear in the mind of
patient. However, in order to make informed decision it is essential that the patient takes the decision of surgery after knowing all possible complications of the surgery. Most of the respondents who reported any health problems immediately after surgery were operated in last five years. There is a possibility that the respondents who were operated long back did not remember if they had any health problems after surgery. Two respondents reported that due to inadequate effect of anaesthesia, they could feel pain even at the time of surgery. Another respondent reported that the doctor had forgotten to remove the vaginal pack kept during the surgery which made it difficult for her to pass urine postoperatively. Longest period of for which the respondent suffered from post operative health problems was six months.

Following narratives describe the health problems faced by the respondents immediately after surgery-

‘I had pain in abdomen, which got relieved after taking injection. I took several injections; finally sisters told me that if you take so many injections, you will get pain at the site of injection. I had very low pain tolerance at that time, so I used to take tablet immediately when I felt pain....’ (Vrinda- 35 years old respondent from Wai block operated at the age of 33 years)

‘The anaesthesia effect wore off at the time of surgery. I was given saline for eight days, I could not even sit for eight days. I had tingling sensation in my head, lot of weakness, giddiness, I felt giddy as soon as I got up. I also had problem of acidity which is still there....’ (Neeta- 40 years old respondent from Wai block operated at the age of 35 years)

10.3 Post- Surgery Recuperation

During the interview, the respondents were asked about the time period for which they could take rest after surgery. Out of the 44 respondents, response was not given by two respondents, out of them one was operated only eight days back. Out of remaining 42 respondents, 16 respondents i.e. almost one third of the respondents mentioned that they had to start doing household chores within one month of surgery. Most of the respondents who had to resume work after surgery were less than 35 years age at the time of surgery. Majority of the respondents (21) said that within 2, 3 months after surgery, they resumed routine work and five respondents reported that they took rest for more than four months. The period of rest varied depending on the availability of support from the family members. Most of the respondents differentiated between heavy work and routine work. The activities which needed
lifting weights were avoided for at least 2 to 3 months, whereas routine work such as cooking and cleaning utensils was resumed after short period of rest. Agricultural work was resumed taking considerable gap after surgery.

Ashwini- 38 year old respondent from Khatav block who was operated three years back and had no family support said, “I am working from the day I am back from surgery. Only thing I did not lift heavy weight. I still don't lift weight on my head. I only bring pot of water. I do household chores as well as wage labour. I did wage labour work for three months but now I don't feel like doing it. All this is paining especially in the lower abdomen. I am sitting at home complaining about pain.’

10.3.1 Support from Family

During the period when respondents were unable to do household chores, the responsibilities were shared by other family members. In some cases, doctors had not specified any particular period for which the rest is essential after surgery. Sunita (40 years old respondent from Wai block operated at the age of 33 years) said that since doctor had not mentioned any specific period, on her own she decided to take rest for a month. However, rest meant that she only cooked food for the family and rest of the chores were managed by other family members especially her mother. Those women who went to their natal place could take complete rest at least for few days after surgery; others who stayed at their marital place had to contribute in some way in the household chores. Madhavi (42 years old respondent from Wai block) said that the daughters were forthcoming in doing household chores, whereas sons rarely offered any help. The gender division of household chores expected the girls to take over mother’s share of responsibility but the sons were let off.

Priti (39 years old respondent, who was operated six months back) said that she rested only for three days after surgery. On fourth day, she washed a bucket full of clothes. She was not even following restrictions regarding lifting heavy weights. Those respondents who did not have any family support after surgery expressed their helplessness regarding taking adequate rest after surgery.

The respondents were asked about how the family managed in their absence and the implication of the surgery on the family. Some of the respondents told that to accomplish the agricultural work, they had to hire labourers.

Maya recalls, ‘I started routine work after 6 months, I did not lift any weight till then, we did not sow any crop that year, only wheat, we employed a labourer, I
used to instruct him. It’s not easy surgery..... after six months, I started doing things regularly.....’

Those women who lived in nuclear families were sometimes helped by neighbours by cooking food for their family in their absence. Respondents felt that the family had to bear the load of work as they could not work. Most of the respondents also mentioned that their husbands were supportive during the period after surgery and never complained about their wife’s inability to work after surgery. Geeta said that her family believes that surgery is like a new life. (navin janm)

‘I started doing household chores after 5,6 days. Who else will do our work but did not go to field for almost a year. My husband worked (alone) in the field all this time, I did not get any rest after surgery.’ (Shraddha 43 years old from Khatav block operated at the age of 34 years)

It is interesting to note that almost one third of the respondents told that after surgery, their mother had come to help them for doing household tasks or some of them had gone to natal place for taking rest. This indicates that whenever a woman faces illness, it is considered the responsibility of natal family to look after woman’s health in case of illness. Whereas when she is healthy, her contribution to economic labour is to be given to the marital family.

10.4 Respondents’ Experiences of Impact of Hysterectomy on Their Health

In the literature, it has been seen that the hysterectomy not only has implications on physical health, but also has an impact on mental health. A study conducted among Chinese women had shown that 4.8% had experienced depression after hysterectomy. Economic stress faced due to surgery was one of the main reasons for the depression. (Wang, Lambert and Lambert, 2007) Due to the disruption of the blood supply to the ovaries, their function of producing oestrogen gets hampered.

Kameswari and Vinjamuri (2007) mention that often doctors recommend the removal of ovaries at the time of hysterectomy to prevent the ovarian cancer, however, the possibility of ovarian cancer is very low, only 3% of the cancers are of ovaries. Thus, removal of ovaries does more harm than benefit and hence is not recommended. Post
hysterectomy, the remnant ovaries can still produce androgens that can convert into estrogens providing protection to the bone and blood vessels.

It is also well established that women with long-term oestrogen deficiency face increased risk of osteoporosis and heart disease, stroke, hip fracture, depression and anxiety. (Conway, 2000; Sharma, 2011) Cochrane review of hysterectomy versus hysterectomy plus oophorectomy for premenopausal women done by Orozco et al. (2008) also confirmed these findings.

In the present study, an attempt was made to view the discharge card to see how many women have undergone hysterectomy along with removal of ovaries. Out of 44 respondents, only four could provide some record about surgery. Overall it was seen that the respondents did not think it was important to retain the card as an important document about the surgery they had undergone. Hence, there is no way to find out how many of these respondents had undergone removal of ovaries.

Though there are no official records about the removal of ovaries, the narratives of the respondents bring out the gravity of the situation as several of them report depletion of energy and vigour. The hysterectomy had converted these women into morose individuals who are struggling to work and fulfil their responsibilities. Out of forty-four respondents, barring five respondents, all the respondents narrated health problems that they were facing after surgery.

As mentioned previously, the respondents were divided into two groups based on their age at the time of interview. Respondents between 30 to 37 years were in one group and respondents above 37 years were in another group. In the first group, there were sixteen respondents; out of them four respondents said that they did not have any health problem at the time of interview, whereas remaining respondents in this group reported that they were facing health problems like backache, pain in hands and legs, pain in abdomen and heaviness due to weight gain after the hysterectomy.

‘I have pain in both the flanks, this problem is similar to the problem before surgery, there is no difference only bleeding has stopped...’ (Rupali-31 years old respondent from Purandar block operated at the age of 27 years)

‘I feel throbbing pain (thasthasate) after working full day; I don't feel like doing anything at the end of the day...’ (Neelam-36 years old respondent from Wai block operated at the age of 36 years)
‘I feel breathless, chest pain. I have put on weight especially around tummy. Now again I am facing problem, I am again facing prolapse...’ (Vrinda- 35 years old respondent from Wai block operated at the age of 33 years)

‘Earlier I was not so obese, but after surgery my weight increased. Now I feel heaviness while working. When I do more work, I feel pain in body. My calcium has gone down. I went to see another doctor in Karad for this complaint; he told that you have done a mistake by operating that is why you are suffering from this problem. I ate calcium tablets but I started getting swelling, the tablets did not suit me, so now I eat Ayurvedic medicines for this...’ (Shilpa-37 years old respondent from Khatav block operated at the age of 31 years)

Interestingly, doctors talk about surgery being unnecessary if it is done by another doctor, or once the woman has undergone hysterectomy, she is told that the surgery should not have been done, whereas when the patient comes to seek treatment for gynaecological problems, hysterectomy is often suggested as an ultimate and permanent solution for gynaecological problems. Problems related to hysterectomy in young age are seldom discussed prior to surgery but post-hysterectomy fear is created by saying that since the hysterectomy has been done at a young age, these problems are bound to happen.

Out of 28 respondents in the age group between 38 to 45 years, only one respondent said that she has no health problems whereas others reported of suffering from various health problems. Almost half of the respondents reported they were suffering from backache.

‘I have backache, but this is bound to happen, we have to do work in bending position such as sowing, so it pains.....’ (Nilima-43 years old respondent from Velhe block operated at the age of 36 years)

From this quote, it is apparent that there is acceptance about the problems associated with surgery. The nature of work of these respondents mandates working in bending position for longer hours, thus backache is an occupational health hazard for women who are engaged in agricultural activities, in this situation, the hysterectomy related problems such as osteoporosis further lead to weakening of musculo-skeletal system intensifying the problems like backache and hands and leg pain.
Backache and hand and leg pain were cited as one of the major health complaints by fifteen respondents. Some of them also related it to the spinal anaesthesia given at the time of surgery. Another major health issue was significant weight gain after surgery. Because of increased weight, respondents felt that their ability to work had gone down.

‘I get tingling sensation in my legs, my vision has diminished, earlier my weight was 46, 47 kgs now it’s almost 60 kgs, I don't feel agile (chanchalpana) earlier I was very slim, sometimes I feel fresh sometimes not.....’ (Dhanashree 40 years old respondent from Wai block operated at the age of 31 years)

‘I am suffering from backache, dim vision, weakness, weight gain, I put on weight but have lost stamina, people think that I am hefty but with no strength, there is a difference between how much I worked earlier and what I can do now.....’(Meena-40 years old respondent from Wai block operated at the age of 32 years)

After lifting heavy weights, some of them felt strain at the scar of surgery. (rag laagte) After strenuous work, there was throbbing sensation at the scar. Most of the respondents said that our work needs lifting weights so we can’t avoid it even if it is painful or distressing.

Sandhya (43 years old respondent from Purandar block operated at the age of 41 years) described that prior to surgery, she was working with lightening speed, but now she cannot move swiftly and feels a lot heavy.

Arti said, “I still feel the problem of prolapse, I asked them after 4 months, then the doctor said this is not uterus, all women face this problem. Now it comes out almost four fingers, especially at the time of passing motion.” (45 years old respondent from Wai block operated at the age of 38 years)

In addition to the previous problem now there is significant weight gain after surgery which has given rise to knee joint pain. Prolapse of vaginal vault is a common complication of hysterectomy, repair of which again requires another surgery. (Dawn, 2000)

Jyoti narrated her experience of hot flushes, (umasa, garam vhayche) she felt very hot at times alternating with chills.

She said that after surgery, I can't tolerate cold or heat. It’s really difficult. When I feel cold, I feel as if my body has become like ice, when it feels hot, I feel like removing everything. After surgery, only pain in abdomen has gone, but the
Since doctors had not spoken about peri-menopausal problems, respondents had no idea about such changes.

10.5 Implications of Hysterectomy on Family Life

Overall, given the acceptance of hysterectomy and the conviction that this is the best treatment for gynaecological morbidities as well as the belief that it is essential for preventing the morbidities leading to cancer, most of the family members cooperated with the respondents post surgery. In fact, Sheetal (33 years old respondent from Velhe block who had surgery at 26 years) said that her husband was happy after she underwent hysterectomy. The reason for the happiness was that because of hysterectomy his wife would no longer get menses, and thus he will not have to cook which he had to do earlier during wife’s menstrual period. Majority of the respondents said that their husbands were cooperative. Priti (39 years old respondent from Velhe block who had surgery at 39 years age) said that before surgery, she felt sick all the time and was complaining about her health problems often. But her husband never complained about anything (kitkit nahi keli). Most of the respondents also said that husbands were willing for surgery and none of them were asked to delay the surgery. Husbands were also happy that their wives health problems were alleviated after surgery.

Madhuri (37 years old respondent from Purandar block operated at the age of 33 years) mentioned about her husband’s irritation as doctor had asked the couple to avoid sexual contact for at least six months after surgery. Few negative voices were also heard on the aspect of impact of hysterectomy on family life. Some of the respondents expressed that since their strength and ability to work had reduced, the family is getting affected.

Vrushali said, ‘I think it (surgery) caused stress to my husband, he is not at home even for a single day, see the expenses for children’s education are also huge.’(Vrushali-38 years old respondent from Wai block operated at the age of 38 years)
Husbands at times disapproved that the wife is not working as much as they expected. Since after surgery, women were not allowed to lift heavy weights, hence the husband had to fetch water. Women also said that in rural set up, most of the work requires lifting loads, hence the husband felt burdened.

Yogita narrates, ‘there were fights at home, my mother in law was not considerate, she made me work, I got rest only at my mother's place. I started doing heavy work after returning, she made me bring water, wash clothes, remove dung.....’ (34 years old respondent from Purandar operated at the age of 30 years)

Only few of them spoke about how the surgery affected their sexual life.

Namrata recalled, ‘Doctors don't tell you anything like that (not to have sex). Women tell each other that you should not have intercourse for 6 months to one year. We followed for 6,7 months as I had problems, but my husband never got irritated.’ (30 years old respondent from Khatav block operated at 28 years)

Dryness in vagina, decreased libido and dyspareunia i.e. painful sexual intercourse were reported by few other respondents. Most of the respondents said that they refrained from sex at least for 5 to 6 months. Two of them said that the surgery had no impact on their sexual life.

The studies which have looked into impact of hysterectomy on sexual life have shown positive as well as negative impact. One of the hypotheses is that during hysterectomy, the local nerve supply and anatomical relations of the pelvic organs get disrupted and thus, there could be a possibility of sexual functions getting affected after surgery. Since different techniques are used for performing hysterectomy, it was hypothesised that the impact of hysterectomy on the sexual pleasures would differ according to the technique used for surgery. However, a study conducted by Jan-Paul W. R. Roovers et al (2003) found that sexual pleasure improves after hysterectomy and the sexual wellbeing does not depend on the surgical technique.

10.6 Respondents’ Perceptions about their Level of Fitness

Respondents were asked to describe their perceptions about their level of fitness presently. The responses were separated according to the time period after surgery. Out of the 16 respondents who were operated more than five years ago, 11 respondents gave response to this question. Out of 11 responses, one was positive
saying that she felt healthy and enthusiastic about work even after surgery. All the remaining respondents complained about lack of energy and feeling tired.

Bharati (45 years old respondent from Wai block operated at the age of 40 years) said that earlier she felt very energetic, but now she feels tired. However, according to her the weakness is because of surgery as well as because of age. She felt lack of agility (chalakhi) in her work. Due to early marriage and early deliveries, women in rural areas become grandmothers at very age. Becoming a grandmother (Aaji) is considered as a sign of being aged. Thus we can see that at the age of 45 years, Bharati attributes her health problems to ageing process rather than attributing then to hysterectomy. Bharati also described that she felt hollow (khadda) inside as if there is no support to the back because the bag is removed.

Decreased ability to do even routine work was also mentioned by most of the respondents. Sheetal who was operated at the age of 26 years told that she feels excessively tired and very often she goes to local doctor to take injection. At the time of interview Sheetal was just 33 years old. Reduced strength was one of the major complaints. Respondents said that mentally they feel enthusiastic to work, however their body cannot match this enthusiasm.

Gayatri used the term ‘dhilli hote’ which means that the support to the back loosens. She said, ‘what strength? (taakat kasali domblyachi) once the strings of bag are torn then women's life is gone. Those who have good nutritional status, they can say that they are not affected by surgery, others can’t. After surgery also, one should get good nutrition. Doctors should tell the family members that if you are going to feed her properly then only she should get operated at young age.’ (Gayatri 41 years old respondent from Khatav block operated at the age of 38 years)

Respondents used the terms such as hurup vaatat nahi to describe that they lacked vigour.

Shraddha said, ‘I can't work at all, even if I go for weeding (khurpayala) I have to sit on the floor, I feel enthusiastic to work but can't work physically. I just can't finish my work.’ (43 years old respondent from Khatav block operated at the age of 34 years)

Madhu said, ‘I don’t feel energetic, I feel loose inside, in my mind I feel that I will do this, I will do that but I can't even complete half the work.’ (45 years old respondent from Velhe block operated at the age of 44 years)
Respondents described constant morbid feeling in the form of back ache or at times feeling feverish which led to loss of stamina to work. Severe weakness was causing hindrance to work in many cases. Tingling sensation in extremities, swelling on face, problems with passing urine were some of the other complaints described by the respondents. Two of the respondents told that they started facing problem of excessive sweating (davdav gham nighato) after surgery. The doctor told that this problem will last for couple of years. Respondents were also fed up of eating medicines as they suffered from hyperacidity due to these medicines. Severe weakness was described as shakti laee kamee vatate. Lack of strength led to reduced ability to carry heavy loads.

Seven respondents were operated in last one year. Out of these seven respondents, two felt good after surgery.

Prachi said, ‘Right now I have strength but who can say what will happen in future, I do as much work as I did before surgery, means I do that much, I don’t feel weakness.’(43 years old respondent from Velhe block operated at the age of 38 years)

However other five respondents complained about health problems.

Gauri said, ‘I don't feel fit. I don't feel same as when the bag was inside. I feel light. I have lost weight. The doctor has said that there are bubbles on the pancreas.’(45 years old respondent from Wai block operated at the age of 30 years)

Sunita narrated that now she has to take a short nap between two chores. Earlier she used to finish her work and go to chat with women in the neighbourhood but now she just feels like resting and not going anywhere. (40 years old respondent from Wai block operated at the age of 33 years) Maya said that after surgery she has stopped working in others’ field. She has decided to sell off her cows as her hands start paining due to milking the cows. She has no energy left to do all these tasks. One of them was aware of effect of surgery on hormones, she said, ‘the hormones decrease, so I feel dryness.’
Nandini considered that working as much as a man as the benchmark of level of fitness.

She said, ‘Still I work as much as a man does. But, I feel tired in the evening’ (31 years old respondent from Khatav block operated at the age of 22 years)

Five respondents had no complaints after surgery. They said that they felt fit and energetic.

Some of the respondents regretted having undergone surgery but felt it is of no use lamenting now since the surgery is already done. Though the respondents could not work strenuously, there was no other option as they had to do the household chores and the fieldwork.

While describing the decline in strength, Ashwini said, ‘earlier I used to offload 20 bunches of hay (Pendya) at a time but now I can't even lift a pot of water. I force myself to work.’ (43 years old respondent from Wai block operated at the age of 33 years)

Shraddha said that women who haven’t had surgery are fit (tantani) but I feel dispirited (khachliye) after surgery. (43 years old respondent from Khatav block operated at the age of 34 years)

Respondents expressed their obligation to work despite weakness. They said there is no point in saying that my strength has gone down.

Suman felt , ‘I think I have less strength than other women. If I would not have gone for operation, then I would have done much more work.’ (38 years old respondent from Velhe block operated at the age of 35 years)

From these narratives, it is apparent that excessive fatigue hindered the ability of respondents to perform normal activities, and enjoy life.

10.7 Respondents’ Perceptions about Loss of Uterus

Seminal work on impact of hysterectomy on women has been done by Jean Elson in New England. One of the theoretical questions investigated by Elson (2003) was about the specific symbolic significance of ovaries to gender identity. Elson’s research intended to determine the role of gendered body parts in the individual's perception of gender identity. Elson’s research revealed that several respondents
associated hysterectomy with loss of fecundity but oophorectomy was associated with losing femaleness. Another study conducted by Abramson (nd) underscored the need to recognize the multiplicity or diversity of standpoints women experience with hysterectomy.

Out of 44 respondents in the study, 11 respondents could not answer the question regarding how they felt about losing their uterus.

Sixteen respondents had expressed relief after the removal of uterus as it relieved them from thinking about any possible complication of the health problem since they felt that they have treated the root cause by removing uterus. Those who were annoyed by the health problems they were facing, surgery offered them relief. Seven respondents expressed sadness about loss of one of the body parts, whereas remaining 10 respondents expressed mixed feelings post surgery. On one hand, they were feeling relieved from the health problem but at the same time they also were regretting loss of an organ.

Out of those respondents who had only negative feelings, one respondent reported that she feels that her strength has gone down after surgery, she felt feeble (khachlyagat vatate). Respondents expressed that every month after menses, one feels light and agile; however as they are not getting menses anymore, their body feels heavy. Respondents expressed that the decision of surgery was not in their hands as they had to follow doctor’s advice of surgery. (Fate accompli) Some of them also expressed anxiety about removing uterus at young age. Respondents expressed their feeling of void (mokale vatate) inside after surgery. They said woman with bag inside feels full. One of them said that it feels like a pit inside. Some of them said that they were missing their menses. Some of the respondents expressed that in their life everything happened before time like they were married off at very young age, had children very early and now they are also operated at young age.

One of the perceptions about role of uterus that came up in the study was that uterus is responsible for maintaining balance.

Dhanashree says, ‘I think I have lost balance of my body. See, our entire balance depends on our body. See, I think there must be strings attached to the bag inside body (shira joined asanar na), now these strings may have become loose, that’s why sometimes I get tingling sensation in my legs, there is severe leg pain, but in my mind I feel that I have lost one of my parts, that’s now I can't maintain balance,’ (40 years old respondent from Wai block operated at the age of 31 years)
Another perception was that after hysterectomy, the weight increases because one does not get menses. Neeta told that she has almost doubled her weight after surgery. Prior to the surgery, her weight was 35 to 40 kgs, after surgery, she weighed almost 70 kgs. She thought that because she is not getting menses now, that is why her weight is increasing. (40 years old respondent from Wai block operated at the age of 35 years)

Women also felt that getting regular periods makes them feel light, fresh and agile, since after hysterectomy they stopped getting periods, they were feeling heavy. Namrata said that when the uterus is inside, our body makes calcium, once we remove the uterus, the calcium is not prepared, so I feel (bad) but had to remove as there was no option. (Khatav block, 30 years age at the time of interview and 28 at the time of surgery)

Ten respondents expressed relief and sadness concurrently. When asked about feelings after surgery:

Neelam said, ‘what do you mean? The bag had rotten so it was good that my disease is gone now. If my bag had been in good condition, then who will spend so much money? This is one of our body parts, because of which there is some sturdiness to the back (kamreli jeev asato), when the bag is there, one can work whole day but now I don't have that much strength. I can't lift heavy weights now. I feel like emptiness inside. (Wai block, age at interview and surgery was 36 years)

Some of the respondents had expressed that even after surgery, for few months they could feel the changes before the date of menses like heaviness in the breast, which waned subsequently. Losing a body part (avayav gamavala) was very frequently mentioned by the respondents.

**10.8 Respondents’ Perceptions about Positive Aspects of Hysterectomy**

Sunita (Wai block) said that she feels relieved that she does not have to bother about menses coming during festival period. Before surgery, she faced lot of problems if her menses came at the time of festival as there was nobody else to manage work at home and the restrictions during festival are even more stringent. Dhanashree (Wai block) also said that she was happy to get rid of the heavy bleeding during menses. As she was using rags during menses, she faced lot of problems as the cloth became hard after soaking blood and caused peeling of the skin. So she felt relief as now she does not have to face this problem.
10.9 Respondents’ Perceptions about Negative Impact of Hysterectomy

Neelam (Wai block) expressed that she felt that she is permanently disabled now (kaayamswarupi adhu jhale) after the bag is removed. She felt like a pit inside which has not yet filled. Sonali said it is obvious to feel bad. Till the bag is there, woman feels full (bhargacchapana), after the bag is removed, one loses strength (kambarkhachati, takat rahat nahi) earlier we could lift so much weight, now I can't do that, earlier I felt strong Bhakkam vatayache, now I feel light, after this surgery, woman gets this loose feeling inside.

Although the implications of hysterectomy on physical health and mental health have been well established through various studies, the social impact of this surgery varies with the social context. Study conducted by Jean Elson (2003) in New England which is a different social context than India had shown that women placed significant value on ovaries as the source of female normality. In Elson’s study, it was seen that women considered uterus as an important organ for producing children, whereas the ovaries were considered as an organ responsible for producing female sex hormones. Women identified removal of ovaries with losing something essential to their sense of femaleness. Whereas in the present study, it was seen that women were not aware about the role of ovaries. In fact, women were never given any information about the reproductive organs and their functions. In the area where the present study was conducted, women often referred to uterus as ‘bag (pishavi)’ and believed that the role of uterus is to carry child. In Indian context, role of women’s reproductive health system is often confined to its function as child producer.

Despite the fact that removal of ovaries leads to decrease in the production of female sex hormones, thus affecting women’s sexuality negatively, neither the doctor nor the women or their husbands raised any concerns regarding the impact of hysterectomy on women’s sexuality. On the contrary, it is seen that in case of men, their reproductive system is strongly associated with their sexuality. There is a misconception that the male sterilisation surgery (vasectomy) affects sexual potency in men and thus very few men come forth for vasectomy which is a simpler permanent method of contraception as compared to tubectomy which requires opening of abdomen. (Biradar and Bhov, 2013; Saoji et al., 2013) This indicates gender bias prevalent in community.
In another study, Elson (2002) had looked into whether premature termination of menstrual function negatively affects women’s subjective gender identities. In her study, it was seen women closely associated menstruation with their gender identity and hence regretted losing the menstrual cyclicity as it was a regulator of their daily lives. In the present study, women did not express that if they are not menstruating then they feel that they are less of a woman. In Indian context, ideal woman is the one who fulfils domestic responsibilities and produces heirs for the family and women did not seem to be bothered about not getting menses.

10.10 Respondents’ Advice to Other Women Who Are Contemplating Hysterectomy

In the previous section, it has been reported that the respondents spoke with other women in the community who had hysterectomy to get more information about hysterectomy. None of the respondents who discussed with other women got to know about negative health impact of hysterectomy, on the contrary, there was an overall wide acceptance of hysterectomy as best treatment for gynaecological morbidities. Hence, the respondents were asked about what advice they would give to other women who are contemplating surgery. It is interesting to note that some of the respondents said that they would only talk about positive aspects of surgery as they do not want to create fear in the mind of other women who have been advised hysterectomy.

10.10.1 Advice Cautioning about Surgery

Those respondents who said that they would caution other women at the time of doing hysterectomy mainly said that they will share the health problems that they face and would ask to reconsider hysterectomy especially if medical treatment is going to help.

‘I will tell others not to take the decision in hurry, because I am suffering now....If the problem is severe and doctor is suggesting surgery, then only do it. After surgery, you can feel heaviness.’ (Shilpa, 37 years old respondent from Khatav block of Satara district operated at the age of 31 years)

‘Go for surgery only when the problem is severe..... as far as possible avoid surgery. Those who have attained menopause can go for surgery but those who are still getting menses should avoid surgery.’ (Kirti, 31 years old respondent from Khatav block operated at the age of 29 years)
'I tell everyone that this operation has no use. I am facing same problem again. I am regretting that I have done surgery (pastavale), I was better earlier. The surgery only benefits the doctor and not the patient (karnaryala faayda), I was telling her not to do...' (Arti, 45 years old respondent from Wai block operated at the age of 38 years)

'I tell them if there are medical treatments then go for them. Don't go for surgery. See my example, when I start walking, I feel breathless. At this age, my condition is like a woman of 65 years age.... my mother has more stamina than me....she looks as if she is my sister....' (Shradhha, 43 years old respondent from Khatav block operated at the age of 34 years)

'I tell them these are the problems after surgery, initially you feel good but later on there are other problems.... the bag is removed from the body, so there is weakness in the body....' (Bhagyashree, 40 years old respondent from Purandar block, operated at the age of 32 years)

'I will tell them that these problems occur after surgery, like because of the spinal injection, you get back ache, hands and legs pain, your vision diminishes...’(Meena, 41 years old respondent from Velhe block, operated at the age of 32 years)

'If the bleeding is severe, then only you should go for surgery. One should not remove bag unnecessarily. Our life depends on it. Our vigour (tarunya) is on uterus and spine.....'(Gayatri, 41 years old respondent operated at the age of 38 years, residing in Khatav block)

‘Women go for surgery out of fear.... a woman is half finished after her surgery...' (Sangeeta, 37 years old respondent from Velhe block operated at the age of 33 years)

‘I will say if the problem is severe then only one should think of removing the bag..... It’s good to get menses; your body remains light...’(Sunita, 40 years old respondent operated at the age of 33 years, staying in Wai block)

‘I will tell others that there is no use of surgery.... I am again facing the same problem..But if I would not have removed the bag, I would have been very weak by now (due to bleeding), I still have pain.... (Rupali, 31 years old respondent from Purandar block operated at 27 years)
‘...after surgery, my first problem is as it is... I will tell other women that they give you injection in spine, because of that we cannot work, we feel tired, it feels as if you are always unwell... . I feel like resting but we are farmers, we have to work, if we don't work, we will not get single rupee, if we work then only we can eat,’ (Suchitra, 42 years old respondent operated at the age of 37 years, residing in Purandar block)

Overall it was emerging that for several respondents, post-surgery morbidity was also quite significant and hence they had negative experience associated with the surgery and thus they had said that we will talk about our problems candidly if someone comes to seek our opinion.

10.11 Respondents Giving Positive Feedback about Surgery

Though several respondents spoke in a cautionary voice, there were few positive voices as well. Given below are the quotes of the respondents who spoke positively about surgery-

‘I will say if the problem is severe, they should go for surgery.... I did not take proper care, so my health deteriorated.... there is no point in blaming doctors...’(Priti, 39 years old respondent from Velhe block operated six months before interview)

From what Priti says, one can see that when there is negative consequence of surgery, women take the onus on themselves and feel that the hysterectomy did not cause problems but that they could not take proper care is the reason of negative consequences. Given the demanding nature of women’s work in rural areas, most of them cannot take adequate rest and thus internalise that they are responsible for their post surgery health problems.

‘Rather than delaying, they should consult doctor immediately, I will tell them that go to good doctor, if you have pain in abdomen or bleeding, you should take it seriously, I did not have problem after surgery...’ (Maya, 35 years old respondent operated at the age of 29 and residing in Purandar block)

Maya’s quote exemplifies how deeply the myths about reproductive problems being fatal or leading to serious complications are ingrained and the way they get propagated in the community.
Some of the respondents said that even if we faced negative consequences of surgery, we will not share them with other women as we do not want to create fear in their mind about surgery.

‘why will we create fear in their mind, I will say that there is no problem with the surgery, see if some woman is going to get cured, why will we tell her anything against it, but if the problem is not so severe, then we will off course tell that it’s not so easy to get operated...’ (44 years old respondent from Velhe block operated at the age of 39 years)

‘I will not tell bad to anyone, we should tell its good, there is no need to worry, why should we talk about our problems, they will come to know later what the problems are. If there is any problem, then one should wait for six months and then if the problem is severe they should go for surgery...’(38 years old respondent from Khatav block operated at the age of 34 years)

As discussed previously, the doctor-patient relationship in India is mostly paternalistic in nature, which gets confirmed from the quotes of Neelam and Vrushali, where they speak of following doctor’s advice without much critical thought. Respondents considered that if the doctor advises hysterectomy then it is inevitable.

‘...you have to follow doctor's advice, if the problem is severe, go for surgery...’ (Vrushali, 38 years old respondent from Wai block, operated seven months before the interview)

‘Every woman has different problem, some get white discharge, some have bleeding, someone feels awkward to sit outside during periods, then when they go to the doctor, then they have to do as doctor says. Suppose, we tell someone not to go for surgery and if anything goes wrong, then she will hold us responsible, so whoever faces problems will have to do decide about the surgery......’ (Neelam, 36 years old respondent from Wai block operated six months before the interview)

One of the primary reasons to seek health care is to resume the healthy status. Hence, one can say that though all these women had sought health care with the hope that they would alleviate their health problems and get back to their work in a more productive way, in reality they were feeling even more crippled and were experiencing loss of stamina to accomplish the arduous tasks that they are expected to do. Moreover, these women were already feeling burdened because they felt that the family has spent considerably on their health problems and has suffered during
their recuperation period; hence, they were hesitant to talk to about their post surgery health problems.

The family also expects that after the surgery is done, there should not be any reproductive health problems as the root cause has been treated. As Arti has clearly articulated, the benefits of hysterectomy are reaped only by the doctors as they lose nothing, but the women and the families suffer significant losses in terms of finances as well as loss of health. Yet the hegemony of medical system is so deeply ingrained in the minds of people that there is reluctance to share their experiences and caution other women.

Till here, the thesis has presented the key findings of the research along with the discussion of these findings. The last chapter reflects on the overall findings and tries to explicate these findings in the broader framework of access to healthcare.