CHAPTER 8
ACCESSING HEALTH CARE SERVICES

Previous chapters have given details of the ways in which women acknowledged their health needs and how they overcame the barrier of seeking permission from the family. This chapter provides answers to the following research questions.

1. What is the role played by the health care providers in creating acceptance for hysterectomy?
2. How informed is the decision of undergoing hysterectomy?
3. What are the factors which facilitate physical access to health services?

8.1 Number of Health Care Providers Consulted By the Respondents

In the present study, out of the 44 respondents, total 92 health care providers were consulted by 44 respondents. Eighteen respondents had consulted one health care provider, 15 had consulted two healthcare providers, and three had consulted three health care providers, whereas six had consulted four healthcare providers. Two respondents had consulted five and six health care providers each. This indicates that more than half of the respondents had sought treatment from more than one source before undergoing hysterectomy, whereas 18 respondents had relied only on single opinion.

Kirti, who had consulted four doctors, narrated her story as follows-

‘I took lot of medicines for swelling on the uterus, changed many doctors.....first I went to Dr. “L’ in Dahiwadi, I got some relief after medicines but problem again started after stopping medication. Then I went to Virar (Mumbai) there the USG showed fibroid, he gave medicines for a month, then I went to Katarkhatav PHC, I was taking medicines for five years at least. Then I went to Dr. ‘M’, I was fed up of taking medicines repeatedly. I was getting swelling on the entire body because of the medicines, they were giving me pain killers. Then Dr. ‘M’ did USG and said that your bag has become hard (pishavi kadak jhaliye) and it has become big.....finally I got operated at Dr. M’s hospital’ (31 years old respondent from Khatav block operated at the age of 29 years)
8.2 Place of Surgery

Out of 44 surgeries, 39 were performed in private hospitals, two in public hospitals and three in trust hospitals, indicating that private health sector was mostly preferred for hysterectomies. Both the respondents who got operated in public hospital were from Velhe block of Pune district, whereas out of three respondents who got operated in trust hospitals one was from Khatav block of Satara district and remaining two were from Velhe block. All the four respondents from Pune district had first consulted a private doctor, but the actual surgery was conducted at the public hospital or trust hospital since the expenses quoted by the private doctor were found unaffordable. Shraddha, (43 years old respondent from Khatav block operated at the age of 34 years) was suffering from white discharge and prolapsed uterus for almost four to five years. Initially she had consulted two private doctors and sought treatment from nearest PHC as well, however since her problem was not alleviated and she could not afford the treatment at private hospital, she started seeking care from nearby trust hospital, where the entire treatment was done free of cost.

In Wai block, out of the 14 respondents, 5 were operated by one particular doctor. All those who sought care from this doctor were directly advised to undergo surgery. Similarly, in Khatav block one hospital was named by several people in the villages. Out of 9 respondents in Khatav block, 4 were operated in this hospital. It was seen that in Wai and Khatav blocks, generally the respondents consulted mostly single health care provider. Whereas in Pune district there were more options available and rarely respondents cited name of the same doctor.

In the study, information about health care access for deliveries was sought to see if there was any difference in access for hysterectomy and caesarean sections. It was seen that out of 113 deliveries reported by 44 respondents, 47 deliveries (41.5%) were in private sector, similarly only one third of the sterilization surgeries were in private sector whereas in case of hysterectomies more than three-fourth of the hysterectomies were conducted in private sector. This indicates women’s preferences for private sector for the treatment of gynecological morbidities. One of the reasons for preferring private sector for the treatment of gynecological morbidities in private
sector could be lack of availability of these services in public sector. (Desai et al. 2011)

8.3 Reasons for Choosing a Particular Health Care Provider for Surgery

To understand women’s preferences for choosing health care provider, they were asked why surgery was done at this particular hospital. Following responses were received -

8.3.1 Preferred Doctor in the Neighbourhood

In Satara district, it was seen that one or two hospitals in each of the blocks studied were mostly preferred by the respondents. Since most of the women in the neighbourhood get operated in this hospital, the doctor earns reputation of being a competent doctor and then everyone in that area prefers to get operated by that doctor. For e.g. Suvarna, a respondent in Wai block narrated that the doctor who did her hysterectomy is a famous ladies doctor in this area. Most of the deliveries, caesareans and other surgeries like appendix are conducted here. Suvarna told that the day she got operated, there were 4 other patients for surgery, the doctor performed 4 surgeries starting from morning 5.30 to 11.00 am indicating that this particular facility was preferred by most of the women in this neighbourhood.

8.3.2 Previous Experience of the Health Facility

In some cases, the same doctor who had preformed deliveries of the respondent was preferred for hysterectomy as well. In such cases, respondents believed that the doctor knows their past history well and they are also well acquainted with the hospital setting. Similarly, there is more trust as compared to other doctors which is built through their previous interactions with the same doctor during deliveries. Owing to this trust, the respondents preferred to seek care for gynaecological morbidities from the same doctor who had provided obstetric services.

8.3.3 Acquainted With the Doctor or Hospital Staff

In some cases, either the doctor was a relative or some other staff of the hospital was relative of the respondent and hence that hospital was preferred. Often it is experienced that the quality of care in terms of providing personal attention or is better when one knows someone from the hospital staff. Navigating in the hospital and personal
negotiations for reducing cost of surgery is also facilitated by the relative and hence such hospital was preferred for conducting surgery.

8.3.4 Doctor’s Treatment Provides Relief - ‘gun yene’

In cases, where respondents had sought care from multiple health care providers, the provider whose treatment offered relief was the provider who conducted the surgery. In colloquial terms, effectiveness of medicines is termed as ‘gun yene’. Most of the conversations about medical treatment from a doctor mention this term. When the treatment provides relief, the trust in the doctor is enhanced and then the advice given by the doctor is rarely doubted. And hence the surgeries advised by these health care providers were readily accepted by the respondents.

8.3.5 Doctor giving Concession in fees

In case of respondents who were not able to afford the cost of surgery, getting financial concessions was a major consideration at the time of choosing health facility. Thus, in such cases, surgery was conducted at a hospital where the doctor gave concession in the bill.

8.3.6 Hospital Proximal to Residence

Proximity of the hospital to the place of residence was another consideration while selecting the hospital. Gauri (45 years old respondent from Wai block) who got operated at the age of 30 years that since her younger child was very small, she preferred the hospital within the vicinity of residence.

Very few respondents had tried to seek care from public health facilities. One of the reasons could be that at present, though the services related to treatment for gynecological morbidities are mentioned in the RCH programme, in reality the RCH programme focuses only on services such as contraceptives and services related to deliveries. Within contraceptive services also, the focus is mostly on sterilizations that too in target oriented manner. Once women have undergone sterilizations, they fall outside the ambit of services provided by the public health system. The dominant thinking of the public health system is to control the population. Once woman’s fertility is controlled through sterilization, then the public health system loses its interest in those women and the services related to treatment of gynecological
morbidities are rarely provided with the same emphasis as the sterilization drive takes place. Due to vacant posts of specialists in government hospitals, most of the public hospitals are not equipped to perform major surgeries like hysterectomy. Thus, hardly any rural hospitals provide services like hysterectomy; hence they are not the places of choice for any surgical treatment.

Preference for seeking care from private health facilities has been noted by other studies in Maharashtra as well. (Ganatra and Hirve 1994 cited in Ensor & Cooper 2004) Perception that the services from private sector are of better quality than public health sector facilities is one of the important reasons for this preference to private health facilities. (Bhatia 2001 cited in Ensor & Cooper 2004) In the same paper, the authors state that patients’ decisions about choice of health facility is also influenced by the nature of the health problem and their assessment of the particular facility about its performance in providing effective treatment. Hence, though patients are not in position to influence or challenge treatment, they apply their judgement in the choice of facility. (Leonard, Mliga et al. 2001 cited in Ensor & Cooper 2004) Some of the factors which are considered while preferring a particular facility are like past experience of the health facility or knowledge provided by friends and relatives. (Hutchinson 1999 cited in Ensor & Cooper 2004) In the present study also, doctors who had performed deliveries were preferred as well as doctors where treatment was sought by neighbours or relatives were also given preference by the respondents.

In the present study, out of 92 providers consulted by 44 respondents, only few were female doctors. Only one respondent had insisted that her surgery should be done by a female doctor, in which case the doctor wife of the gynecologist who was treating the respondent had performed the surgery. The paradox is that non-availability of female doctors in public health facilities is often cited as one of the reasons for not seeking treatment for gynecological problems from the public health system; however this did not prove to be a barrier for seeking health services from the private health sector. This indicates that if the patient has assurance that the doctor will cater to her needs and will be available when she visits the health facility, then whether the doctor is a male doctor or a female doctor is not an important consideration for seeking care from that facility.
8.4 Physical Accessibility of the Health Care Facility

The questions related to the mode of transport and the distance between the health facility and residence are pertaining to the health facility where the surgery was conducted. Hence, though several of the respondents had sought care from more than one provider, the following information is with respect to the place of surgery.

8.4.1 Distance between Residence and the Hospital

Median distance covered by the respondents was 13 kilometres and the distance covered ranged from few meters to 40 kilometres. It was seen that in Pune district, respondents travelled longer distances whereas in Satara district shorter distances were travelled to seek care. The villages in the Purandar block are well connected to three towns such as Baramati, Jejuri and Saswad and hence the respondents here had more options to choose from, whereas for the respondents from Velhe block, Pune city was accessible as nearest city, which was mostly preferred for getting hysterectomies done.

8.4.2 Mode of Transport

To understand the issues related to physical access to health care facilities, villages which were closer to town/ state highway as well as farther from the highway/ town were covered. In this area, all weather roads are connecting most of the villages. Mahabaleshwar is the tourist place in Wai block and hence this block has seen better development of infrastructure in recent period. Similarly some of the villages covered in Purandar block were on the state highway connecting Jejuri to Baramati. Jejuri is a famous pilgrimage in Maharashtra and hence has better road transport facilities. Baramati is one of the developed blocks as the political leadership of Baramati is very influential at state level as well as at the national level. Velhe block is closer to Pune city which is one of the major cities in the state. Hence all these areas have good infrastructure facilities in terms of all weather roads as well as state transport facilities. Similarly there is proliferation of private transport facilities such as jeeps and shared auto-rickshaws in these villages. In addition, several people owned motor bikes. Hitch-hiking is a common practice in this area. Given this abundance of options for travelling, physical access to health facilities was not articulated as a problem by
any of the respondents. Average time required to reach the facilities was less than one hour.

8.5 Communication with the Health Care Providers

Effective doctor-patient communication is one of the basic tenets of the good quality health care. Thus, medicine is not just considered as a science but it is also regarded as an art where the crux is the doctor-patient relationship. It is essential that the doctor has the skills to extract information from the patient, to counsel patient and facilitate informed decision making process. (Fong Ha, 2010)

In the international symposium organised to deliberate upon ‘Equitable Access to Health Care and Infectious Disease Control’, it was discussed that information is critical for expanding individual/communal choice sets. Information has been identified as a demand-side factor of access whereas communication was defined as information exchange and considered as a prerequisite for social interaction. Lack of opportunity to participate in communication process was seen as an indicator of one’s social position. (United Nations Research Institute for Social Development 2006)

In the present study, the respondents were asked to narrate their experiences about communication with the doctor. The objective for gathering this information was to see if the decision to undergo hysterectomy was taken with adequate information.

The details of the doctor-patient communication was sought on following aspects-

- What was the diagnosis given by the doctor for which hysterectomy was suggested?
- What different treatment options were suggested along with hysterectomy?
- What information related to surgery was given to respondents to enable them to take the decision regarding hysterectomy?
- What information was given regarding post-operative care to be taken?

Following section provides details about these aspects of interactions with the health care providers.
8.5.1 Information about the Diagnosis

Most of the respondents were not told about the exact nature of disease they were suffering from. In some cases the doctor said that there is problem with your uterus (mostly referred to as bag) for which you will need surgery. Fibroids in uterus are referred as gath (tumour) in local language and Pelvic Inflammatory Disease is often referred as suj (i.e. swelling). Many women were told that they have cervical erosion which is called as pishavila jakham hone (wound) in colloquial terms. Women with prolapsed uterus were told that pishavi satkliye i.e. the uterus has moved from its place.

8.5.2 Nature of Communication with the Health Care Provider

Respondents were asked about the details of the communication with the health care provider. From the narratives of the respondents, following patterns of the communications by the health care providers emerged.

Cryptic Communication. In some cases it was seen that doctors were not lucid in their communication.

Neeta’s doctor told her, ‘we have done our job of telling you that there is a fibroid in the uterus, anything can happen in this fibroid, if anything happens to you, don’t blame us. It may lead to cancer but I can’t say that definitely, we can’t tell you anything that’s inside, we can tell only about outer things. If you want to delay surgery, do it at your own risk.’ (40 years old respondent from Wai block who was operated at the age of 35 years)

Listening to such threatening communication, Neeta immediately decided to undergo surgery.

Doctors often only told that there is fault in your bag. Many a times, doctors gave inconclusive responses like the current health problem can turn into any other problem where by any other problem they often meant ‘cancer’. Sonali (44 years old respondent from Velhe block operated at the age of 39 years) said that the doctors don’t tell you what is wrong with you, they just ask you what is your problem and note it down. Though doctors did not give adequate information about the exact nature of illness, the respondents had no complaints about it. In fact, one of the respondents said that if the doctor talks about the severity of problem, which makes the patient
anxious then sometimes the patient may also die of shock, so the doctors don’t tell complete truth to save the patient from unnecessary shock. The respondent said that even if you were in the position of doctor, you wouldn’t have told the patient how severe her disease is.

**Giving Erroneous Information.** It’s a medically well established fact that uterine fibroids rarely turn cancerous, however, in most of the cases where respondents had fibroids; they were told that this can lead to cancer. In the community, any tumour is associated with cancer. Hence, the respondents with fibroids were apprehensive about the fibroids turning into cancer and hence decided to undergo surgery earliest.

**Use of Intimidating Expressions.** Nasreen narrated the communication with her health care provider, which was as follows-

‘...after doing USG and checking blood and urine, the doctor said that there is fault in your bag, there is a fibroid, you will have to remove the bag soon otherwise it can go on anything. Do you want money or person?....so I got operated in 15 days....’(34 years old respondent from Khatav block operated at the age of 31 years)

Such intimidating conversations often led to uncritical acceptance of the surgical treatment.

**Dismissing the Importance of Uterus.** In several cases, it was seen that the doctors dismissed the importance of uterus once desired family size is achieved. Sunita said, ‘seeing my hesitation for surgery, the doctor said to me that now since you have completed your family, why do you need it (uterus)?’ (40 years old respondent from Wai block operated at the age of 33 years)

Another respondent was told that as it is one day you will stop getting menses then what is the use of avoiding surgery now. As seen in the previous chapter that most of the respondents had no knowledge about the anatomy and physiology of the reproductive health system. Culturally also it is seen that the attitude towards women’s reproductive organs is instrumental and hence once it has accomplished its role of producing children, menses and associated problems are found more bothersome, hence women are ready to undergo surgery. It is expected that the health care provider will give scientific information and demystify the misconceptions.
However in reality they were found to be reinforcing the negative attitudes towards women’s body parts especially the reproductive organs.

To probe further, respondents were asked whether doctor had spoken about the consequences of not getting operated.

Almost half of the respondents (20) said that the doctor did not say anything about the consequences if the surgery is not done. Narrations of other respondents confirm that the communication by the doctors was often vague, inconclusive and fear mongering.

1. Doctors very often said that the disease may lead to cancer if surgery is not done promptly. In the community, any tumour is associated with cancer. Hence, the respondents with fibroids were apprehensive about the fibroids (gath) turning into cancer and hence decided to undergo surgery earliest. More details about how doctors inculcated the fear about cancer have been given in the subsequent section.

2. Doctors often said that they will not be able to take the responsibility of the consequences if their advice for surgery is not followed. Sometimes the doctors just said that it would be risky to delay the surgery without saying what the risk would be.

‘The doctor said that if you want to delay surgery, do it at your own risk, we have done our job of telling you, anything can happen in this fibroid (ya gathiche kaye) if anything happens to you, don’t hold us responsible, , we can’t tell you anything that’s inside, we can tell about things which are outside....’(Neeta, 40 years old respondent from Wai block operated at the age of 35 years)

3. Doctors were also seen to give unscientific information like in one case, the doctor said that if surgery is not done then there could be holes in the uterus, it may get rotten (bil padtyat, sadati) or saying that the fibroids will grow in size, they will get infected and may burst ( gaathi vadhtil, piktil, futatil) (Maya, 35 years old respondent from Purandar block operated at the age of 29 years)

8.5.3 Information Provided By the Health Care Provider to Enable the Respondents to Take Informed Decision of Undergoing Hysterectomy

Historically decision-making about health care issues reflects the paternalism in the medical system where the health care providers take the decisions on behalf of the care seekers. (Holmes 2002 cited in Wittmann-Price, 2004) However, recently
A paradigm shift has been noticed in the decision making related to health care where shared decision-making is being aimed at. (Bunn et al. 1997 cited in Wittmann-Price, 2004). Evidence regarding decision making reveals that better health outcomes and greater patient satisfaction ensue from active involvement of patient in medical care decision making. Besides, the patient has greater sense of personal control and lower levels of concern about disease. (Guillermo et al., 2006)

It is worth noting that the process of informed consent is an ethical as well as legal compulsion for the doctor. When a patient enters doctor’s clinic and speaks about her health problems, it is considered as implicit consent for routine examination, however for internal examination, invasive tests and risky procedures, specific expressed consent is required. (Rao, 2008)

Process of seeking informed consent is the indication of ethical practice. It acknowledges the autonomy of patients and respects their dignity and the right to self-determination. It is necessary that the patients’ right to decide about treatment options considering their concept of own good life and their freedom to act on their decisions are respected. Informed consent should be seen as a process, not onetime event. It should be a continued dialogue throughout the treatment process which should begin at the time of preoperative examination and continue through surgery and postoperative treatment. (Bernat and Lynn 2006)

To ensure that the medical care decision is an informed decision, it is mandatory that the informed consent form is signed by the patient and her relative. Informed consent is defined as the process by which the treating health care provider discloses appropriate information to a competent patient so that the patient may make a voluntary choice to accept or refuse treatment. (Appelbaum, 2007)

For the decision to be called informed decision, the patient should have adequate information about following aspects-

- The nature of the decision/procedure
- Reasonable alternatives to the proposed intervention
- The relevant risks, benefits, and uncertainties related to each alternative
- Assessment of patient understanding
• The acceptance of the intervention by the patient

In India, the doctor patient relationship is mostly of paternalistic nature where the doctor seldom involves patients in the decision making process. Similarly, patient also believes that since the doctor is the expert, he/she is in the best position to take decisions. This is especially true for the rural communities who have limited access to information about the disease or the different treatment options available.

The following section gives details about the decision making process that happened in case of 44 respondents who were interviewed in this study. The details would be given about what information women had prior to surgery, how much time they were given to take the decision about the surgery and such. Aspects related to intra-household decision making processes such as the discussions at the household level and the reasons for which women accepted hysterectomy as ‘the’ treatment for the surgery have been covered in the previous chapter.

Relationship between a patient and their health professional is one of the most complex interpersonal relationships. It involves the interaction between people in unequal positions, often non-voluntary, often addressing vitally important issues, emotionally laden, and requiring close co-operation (Ong et al., 1995).

**Information about the Nature of the Procedure.** It was seen that respondents had nominal information about surgery. Most of the times the doctor had only spoken about the route of surgery i.e. whether it will be done vaginally or abdominally. In case of vaginal surgery, the respondents were told that there would not be stitches from outside. In some cases, the respondents had asked if the surgery can be done through vaginal route, however the doctor had said that it is possible only if the uterus has already come down. In most of the cases, the method of anaesthesia was also told by the doctor. Doctors had spoken about the method of anaesthesia, as some of them knew that they will be given injection in the back. During the interviews, it was evident that none of the respondents were told whether the ovaries were removed or retained.
Information about Reasonable Alternatives to the Proposed Intervention. Medical literature discusses several alternatives to hysterectomy and clearly enunciates that hysterectomy should not be offered as first line treatment except in cases of cancer. All the respondents in the present study had undergone hysterectomy for non-cancerous conditions and hence it was expected that the doctors should have advised hysterectomy after exploring other options adequately.

Hence the respondents were asked details of the other treatments offered by their health care provider. In the study, some of the respondents told that they were directly asked to undergo surgery without suggesting any other treatment, not even medicines. In case of four respondents, the doctor had suggested alternative treatment but the respondent had refused. In case of one respondent, first surgery to repair the prolapsed uterus was advised. However, later the doctor said that it’s better to remove uterus.

Dhanashree’s (40 year old respondent from Wai block, who was operated at the age of 31 years) narration about alternative treatment and how it is perceived was quite revealing. Dhanashree told that when she started getting frequent menses, she consulted a doctor who advised that instead of hysterectomy, she can go for endometrial thermal ablation\(^1\). But the respondent was doubtful of success of this treatment. She also thought that if there are any side effects of thermal ablation, then those side effects will also have to be treated; hence instead of doing all this rigmarole, it’s better to get hysterectomy done. So, she changed the health care provider and consulted a doctor who advised her to go for hysterectomy. Her husband was also more agreeable to hysterectomy than any other treatment. The second healthcare provider dissuaded from going for alternative treatment saying that since there is a fibroid, it is better to remove it directly. Just before that Dhanashree’s father in law had died of cancer. So the family was worried about cancer and they did not want to take chance. Hence without going for any other alternative treatment, they opted for surgery. In this case, it was seen that though if doctors suggest

\(^1\) Endometrial ablation is a procedure to permanently remove a thin tissue layer of the lining of the uterus which is called endometrium to stop or reduce excessive or abnormal bleeding in women for whom childbearing is complete. ([http://www.hopkinsmedicine.org/healthlibrary/test_procedures/gynecology/endometrial_ablation_92,P07774/ accessed on 29th January 2015])
alternative treatments to hysterectomy which are rational, the acceptance for treatments other than hysterectomy is low. Hysterectomy is often seen as permanent solutions as none of the respondents had raised any doubts about success of hysterectomy.

Some of the respondents had tried taking medical treatment before undergoing surgery, but considering that the relief from medicines is temporary and there are side effects of medicines as well, surgery was accepted subsequently.

‘they gave me medicines and said that you will get relief, but there was no relief, so I again went to the hospital and said that I want to remove bag, because I had recurrent problem, I had to take injections all the time, and spend money on that, how much money do we have in rural area, I have to go to field for labour (majuri) so I said that I want to remove bag, they were saying let us do biopsy....’(Nilima, 43 years old respondent from Velhe block, operated at the age of 36 years)

Sometimes it was seen that the respondents wanted to avoid surgery and asked for alternatives to it. However, the health care providers declined such requests. One of the respondents said that she had asked the doctor if only fibroid can be removed keeping uterus. However, doctor declined saying that the surgery will not be possible in his hospital.

Similarly in case of prolapsed uterus, instead of surgeries to repair the prolapsed uterus, direct removal of uterus was advised. In these cases, there was no pathology in the uterus or any problem with menstruation, yet the healthy organ was removed. Given the negative attitude towards reproductive organs and menses, neither the doctor nor the respondent was keen to save uterus and hence options other than hysterectomy were not considered earnestly.

The stigma around the body and reproductive health issues within the family and community has been identified as one of the reasons why women do not access information related to their own bodies. At the same time, the health system is also oblivious to women’s need for information about their health needs. (Mathur, 2008)

Edozien L. (2005) identifies two reasons for insufficient information being provided to women undergoing hysterectomy about the reason for any treatment offered, the risks and benefits of the treatment, and the alternative options. First reason is that there is dearth of evidence on which to base counselling and secondly, due to the
limitations in training of the gynaecologists, they don’t offer choice of treatment options. Edozien mentions that most of the indications for which hysterectomy is performed such as uterine fibroid or dysfunctional uterine bleeding are amenable to medical treatments such as levonorgestrel releasing intrauterine system or other procedures such as endometrial ablation and embolisation of fibroids which preserve the uterus.

Use of alternative treatments such as levonorgestrel releasing intrauterine system or other procedures such as endometrial ablation have been successfully used in England and has led to reduction in the rate of hysterectomy. The treatments are being used since early nineties. For e.g. data from NHS in England has recorded a reduction of 64% in the number of hysterectomies between 1989-90 and 2002-03. (Reid P., Mukri F. 2005)

**The Relevant Risks, Benefits, and Uncertainties Related To Each Alternative.** It was seen that the alternative treatments were often posed as if they are deemed to fail. Sunita informed that her doctor said that *even if you do the surgery of pulling the uterus up, that is also one type of surgery. Why do you want to torture yourself twice?* (40 years old respondent from Wai block operated at the age of 33 years) Such communications created the impression that alternative treatments are not successful and hysterectomy is the ultimate treatment which will permanently resolve the health problems and hence the respondents decided for surgery.

**Information Regarding Post-Surgery Care.** None of the respondents were given information about the possible hormonal problems they might face after surgery. Doctors mostly talked about the duration for which rest is essential after surgery. Some of the doctors spoke about dietary restrictions such as avoid eating potato or eggplant. The biomedical science does not talk about any such restriction on food items; however, culturally it is believed that these food items delay the healing process by causing pus formation. Another dietary restriction was not to eat spicy or sour things as it may cause cough and coughing increases abdominal pressure which can result in wound dehiscence.

Seven respondents said that the doctor did not talk about any restrictions that need to be followed after surgery. Before surgery, twenty-six respondents were told that they
should not carry heavy loads for a certain period of time ranging from one to six
months and should not do household chores such as washing clothes or carrying pots
of water, which will increase abdominal pressure. However, in the rural setting, for
most of the women it was difficult to follow these restrictions for longer duration.
One of the respondents told that she was asked to refrain from sexual intercourse for
six months after the surgery. In one of the cases, doctor had talked about the exercises
to be done after surgery.

Most of the respondents were told that they should not do any work which requires
sitting in squatting position as it may affect the healing after surgery. However, most
of the household chores such as washing clothes or cleaning utensils are done by
sitting in squatting position. Hence, despite doctors’ advice, the respondents could not
follow it for a very long time.

In majority of the cases, rest after surgery was advised for six months. In the widely
used Indian medical textbook of gynaecology, it is mentioned that after six weeks of
hysterectomy, the woman can move out of home. The text book lacks mention about
various activities that are undertaken by a woman in the rural area and what kind of
care is required in rural context, hence may be the doctors do not have any standard
recommendation regarding what care is required after surgery.

In India, overall very few studies have investigated the ethical aspects of health care.
One such study conducted by Shubha Kumar et al (2012) which had looked into the
perceptions about informed consent was conducted in a private hospital in Tamil
Nadu. This study had shown that patients were not familiar with the information
provided in the consent process. Some of them had expressed that the information
was inadequate to take the decision. Power to decide about surgery was with the
doctor. Doctors articulated poor literacy in patients as a barrier to effective
communication. The study indicated the need to develop consent forms and audio-
visual aids in local language so that patients can proactively participate in the
decision making. In the study, patients had articulated the need to know more about
the surgical procedure as well as the post operative care. The study mentions that in
India, faith and respect for doctors is a cultural norm and also there is fear that asking
questions would be construed as rude behaviour and hence patients are reluctant to
discuss openly about the treatment options with the doctor. (Shubha Kumar, Mohanraj R., Rose A., Paul M, J 2012)

Overall one can conclude that the decision to undergo surgery was not an informed decision, it was more like a knee-jerk reaction where hysterectomy was performed mainly due to the fear of cancer and other reasons which have been discussed above

8.6 Route of Surgery

Out of these 44 women, 32 hysterectomies were performed by abdominal route and 12 were performed by vaginal route. Though vaginal hysterectomy has been proved to be the preferable route of surgery, (Roy K, et al. 2010; Johnson, N. et.al 2005; ) even in the absence of uterine prolapse (Ray et al. 2011) as the operative time and blood loss is less in this method and this route has less post-operative morbidities, requires less number of hospitalisation and has better patient satisfaction, however in the present study vaginal hysterectomy was offered to only those patients who had problem of prolapsed uterus.

8.7 Respondents’ Perceptions about the Quality of Care Received

Overall it was seen that most of the respondents were happy about the quality of care they had received during and after surgery. Most of them said that the doctor gave them adequate time and explained well before surgery. Some of them said that the doctor visited twice a day and considered that the doctor took good car after surgery. Respondents expressed positive opinion about the doctors when they received some concession in the bill. Even when the doctors spoke for ten minutes or asked obstetric history (which is a basic necessity for diagnosis), the respondents perceived it to be good quality care. Most of the respondents were familiar with the doctor as sometimes the doctor had also conducted their deliveries. Hence, they already shared a cordial relationship. In Indian context, the hierarchy between the doctor and the patient is well accepted and the patients don’t even think of challenging this hierarchy. In fact, little attention from the doctor is considered as good quality care.

Out of 44 respondents, only two respondents said that the doctor did not give enough time as he was seeing many patients. In case of Sandhya, pre-surgery check up was
done by one doctor and the surgery was conducted by another doctor, however, the doctor who conducted surgery directly posted her for surgery without even examining the patient. The respondent was very upset with this experience. She said, ‘....the sister examined me, the doctor did not talk to me before surgery, doctor does not even stand by you for five minutes, doctor just comes, examines and talks to sister in their (medical) language...’ (43 years old respondent from Purandar block operated at the age of 41 years)

One of the respondents, Shilpa was seen to be assertive as she had asked lot of information about surgery. She said, ‘we asked him lot of information, and told him that the surgery should be done properly, some doctors hurry unnecessarily, we told him that you can do it properly than only do it, otherwise we will go to some other doctor, later there should not be any problem with the bag....’(37 years old respondent from Khatav block operated at the age of 31 years)

8.8 Financial access to Hysterectomies

Out of 44 respondents, three respondents were operated in Trust hospital, two respondents in public hospital and remaining 39 were operated in private hospital. One of the respondents who was operated in Trust hospital reported that the surgery was done completely free of cost and no expenses were incurred for stay or medicines. Wide variation was observed in the expenses of surgery across the blocks. Those respondents who went to public hospital or trust hospital also incurred considerable expenses mostly on purchase of medicines.

The analysis of the expenses incurred by those respondents who were operated in private hospitals reveals following pattern-

<table>
<thead>
<tr>
<th>Name of the block</th>
<th>Number of respondents</th>
<th>Minimum expenses incurred on the surgery (in Rs.)</th>
<th>Maximum expenses incurred on the surgery (in Rs.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Velhe</td>
<td>8</td>
<td>3000</td>
<td>40000</td>
</tr>
<tr>
<td>Purandar</td>
<td>9</td>
<td>5000</td>
<td>18000</td>
</tr>
<tr>
<td>Wai</td>
<td>14</td>
<td>6500</td>
<td>25000</td>
</tr>
<tr>
<td>Khatav</td>
<td>8</td>
<td>7000</td>
<td>20000</td>
</tr>
<tr>
<td>Total</td>
<td>39</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Calculated from field data
Median expenditure of surgery for those respondents who were operated in private hospitals was Rs. 20000/-. Out of 12, four respondents in Velhe block reported that they spent 40000 rupees for the surgery. All these respondents were operated in hospitals in Pune city which could be the reason for the high expenses. Even same hospital was seen to charge differently for different patients. Since these respondents have undergone surgery in different time periods, analysis was done to see how expenses have increased over time period. This analysis includes only those cases where surgery was done in private hospitals.

### Table 8.2 Time Period Wise Variations in the Expenses on Hysterectomy

<table>
<thead>
<tr>
<th>Time period of surgery</th>
<th>Number of respondents</th>
<th>Minimum expenses incurred on the surgery</th>
<th>Maximum expenses incurred on the surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgeries conducted in last one year</td>
<td>7</td>
<td>6500</td>
<td>40000</td>
</tr>
<tr>
<td>Surgeries conducted in more than one year and less than five years period</td>
<td>18</td>
<td>5000</td>
<td>40000</td>
</tr>
<tr>
<td>Surgeries conducted more than five years ago</td>
<td>14</td>
<td>3000</td>
<td>30000</td>
</tr>
</tbody>
</table>

Source: Calculated from field data

The respondent who was operated fifteen years back had spent 10000 rupees for the surgery, whereas respondent who was operated 8 days back spent rupees 17600 for surgery.

#### 8.8.1 Management of Expenses for Surgery

Out of the 43 respondents who had to spend money for surgery, 21 respondents borrowed money from the relatives, eight managed from their own funds and 10 had to take loan or sell / mortgage assets. The rate of interest for loan from self help group was 2%. One of them also got partial reimbursement from husband’s office as he worked in State Transport services. In some of the cases though doctors had charged less, the cost of medicines was high.

Mukta (35 years old respondent from Wai block operated at the age of 35 years) described that the hospital was posh (bhari) and so it was expensive. Doctor visiting several times was considered as an indicator of good quality services. In case of Ragini (39 years old respondent from Khatav block operated at the age of 37 years),
the doctor had initially given estimate of rupees 4500 however later he charged 10000. The doctor kept her in a special room and said that the charges for the special room are high. Shubhangi (42 years old respondent from Velhe block operated at the age of 40 years) had paid 40000 rupees for hysterectomy. She said that the cost of surgery went up because she was given 55 bottles of intravenous fluids.

During discussion about managing finances for the hysterectomy, very few respondents spoke of financial constraints in accessing hysterectomy. Managing finances was easier for most of the respondents.

Case story of Bharati depicts how lack of financial access leads to delay and subsequent worsening of health condition.

Bharati is a 45 years old respondent from Wai block. She belongs to Scheduled Caste. She studied upto 6th standard. Before Bharati attained menarche, she was engaged and subsequently married off as soon as she started periods. Her husband was educated till 3rd standard. She was working as landless labourer in the beginning, now she is does cleaning job in a bank. She has a daughter and a son. Bharati started facing the problem of prolapsed uterus when she was around 35 years of age. Given the arduous nature of her work as a labourer, the problem went on increasing. She had complete prolapse of uterus. Slowly she also started getting white discharge and back ache. Every time she went to urinate, she had to push the uterus in. She had consulted a doctor who had told her that hysterectomy is the only treatment for her problem. But Bharati did not have money for surgery so she kept enduring the problem. Before going for work, Bharati used to insert the uterus in and apply a sort of bandage from outside to prevent it from coming down. She endured this problem for almost 4 to 5 years. Subsequently, she developed ulcers on the prolapsed part of the uterus due to constant irritation of cloth, but since she didn’t have enough money to undergo surgery, hence she kept suffering. Meanwhile she had heard about ring pessary as one of the treatments for prolapse but Bharati could not spend money to go to the health facility and get this treatment. Her husband was alcoholic, he spent most of his earning on liquor, so Bharati could never manage to save enough for her treatment. Later on, when her son graduated and got a job, he managed to secure finances. Bharati had spoken to the wife of the nearby medical shop owner, who then told Bharati’s son about his mother’s illness and the urgency of treatment. Finally at the age of 40 years, Bharati underwent hysterectomy.

From Bharati’s case story, it becomes apparent that on one hand women like Maya (respondent from Purandar block) who underwent hysterectomy after one episode of pain in abdomen, there were also women like Bharati, who had to endure reproductive health problems due to lack of financial access.
The following section gives details of health care access for delivery for these respondents. The rationale for studying health care access for deliveries in the study related to acceptance of hysterectomies is that both these events are major events of women’s reproductive life. As the findings in the previous section have shown that given the belief about reproductive health problems leading to cancer, the family members agreed for prompt treatment for these illnesses. Hence, it was felt necessary to study if family accords similar importance to delivery related services as delivery is also a potential situation where death may happen.

8.9 Information about Access to Health Care for Delivery Related Services

Total 130 pregnancies were reported by the respondents in this study. Out of 44 respondents, two had no children, 22 respondents had two children each, 15 respondents had three children and five respondents had four children. Information regarding place of delivery, reasons of home delivery and delivery related complications was sought for 113 deliveries which includes 4 neonatal deaths. Remaining 27 include MTPs and miscarriages.

Out of 44 respondents, 23 respondents had given birth to their first child by the age of 18 years. The data regarding composition of children reveals that out of 42 respondents who had children, 22 respondents had two sons whereas 18 respondents had one son. 12 respondents had no daughters, 22 had one daughter, seven had two daughters, two had three daughters and one had four daughters. Number of women with no daughters was much more than number of women who had no sons. There were only two respondents who had opted for surgery despite having no sons. Out of the two respondents, who had only daughters at the time of surgery, Maya (35 years old respondent from Purandar block who was operated at the age of 29 years) reported seven pregnancies out of which four were live births which were all daughters. She said that it seems God’s will that we can’t have son and finally she went for sterilisation. Only Kirti (Khatav block), who was 31 years old and working as ASHA, had considered family to be complete with two daughters. This indicates that it is only when women have at least one son, they felt that the family is complete and then they took the decision of permanently loosing the ability to reproduce.
Out of 113 deliveries, 68 were institutional deliveries and 45 were home deliveries indicating the total proportion of home deliveries to be almost 40%. Out of 44 respondents, 26 respondents reported home delivery. Further analysis of these 26 respondents revealed that youngest respondent who had home delivery was 30 years old whereas the oldest respondent who had home delivery is 45 years old. The last delivery reported as home delivery was by Namrata who is a resident of Khatav block. Her delivery had taken place in the year 2005 and subsequently in the year 2011, she underwent hysterectomy for the problem of white discharge. When asked about the reason for home delivery, Namrata told that during her second delivery, when she was in labour, the doctor wasn’t there in the nearest public health facility. The ANM, who was on duty, promised the respondent to come to the respondent’s home for delivery. However, after the delivery the baby was found to be asphyxiated and was taken to the health facility.

**8.9.1 Understanding the Paradoxical Situation**

It is important to explicate the paradoxical situation which shows that women who do not go to hospital for deliveries go for hysterectomy few years down the line. Essentially what are the barriers that women face in accessing institutional delivery as a service and how these barriers are overcome at the time treatment of reproductive health illnesses?

Reasons articulated by the respondents for not going to the hospital were as follows-

1. Many of the respondents said that there was someone in the family or in the neighbourhood who was trained in conducting deliveries; hence they did not think it was necessary to go to the hospital.
2. Some of the respondents also reported that they wanted to go to the hospital for delivery; however, before they could arrange a vehicle, they delivered the baby at home. After the delivery, doctor was called and he checked and certified that everything was okay.
3. Delay in reporting about labour pains- Suman (38 years old respondent from Purandar) had normal delivery first time, so she did not think it was necessary to go to hospital, however during second time she had PPH for which she was hospitalised later.
4. Sonali (44 years old respondent from Velhe) said that in those days, elder women in the family used to convince us that there is no need to go to the hospital and you will deliver normally at home, and hence I did not think about going to the hospital.

5. Institutional delivered was unaffordable for Arti (paristhiti naheem nan davakhanyat nele nahi). She was working till the last day and delivered within half an hour of starting labour pains. (45 years old respondent from Wai)

6. Most of the respondents narrated that in those days, in-laws never cared for them and they could not decide if they wanted to deliver at home or in the facility. It was reported that now a days, when a woman starts getting even mild labour pains, she is taken to the hospital. Women referred to their in-laws being illiterate (adani) so did not take them to the hospital.

One of the important differences between delivery and treatment of reproductive illnesses is that the delivery is one time event whereas reproductive illnesses continue for long time. In the rural areas, women are expected to work throughout the pregnancy; hence, there is no effect of pregnancy on fulfilling their other roles and responsibilities, plus delivery as such gets over within 24 hours whereas reproductive illnesses impact women’s daily lives. It compromises their ability to contribute to the work expected from them. The family cannot afford to incur recurrent losses due to the inability of the woman to work either in the field or at the household level.

Second important difference is that deliveries are no longer associated with mortality whereas reproductive illnesses are strongly associated with the possibility of cancer and subsequent death. Hence the family members do not wish to take any chance of complications by delaying the treatment of reproductive illnesses.

Third difference between seeking health services for delivery and reproductive illnesses is that at the time of delivery, the woman’s mobility is restricted as she is in labour and hence she is completely dependent on others for arranging for transport and other facilities for taking her to the institution whereas in case of reproductive illnesses, her mobility is unrestricted and she can visit the health care provider with less restrictions. Given all these reasons, probably those women who cannot access the service of institutional deliveries are able to access treatment for their reproductive illnesses.
By the end of this section, most of the findings of this research which reveal how women overcome the household level and health systems level barriers have been present. The next section of the thesis provides the details of the acceptance of hysterectomy and the contribution of individual level, community level and health system level factors in creating this acceptance.