Gender based inequities in health care access have been documented through various studies undertaken so far. The issue of access to health care for women is multifaceted as there is no single category as ‘woman’. Women are further divided into groups based on their caste and class. Similarly, geographical location that is whether women are residing in rural areas or in urban areas is one of the important determinants of their access to health services where women in urban areas are more privileged than women in rural areas. Women’s sexual orientation is yet another important determinant of their access to health care. Age and marital status are two more factors which determine what services women would able to access. For example, Reproductive and Child Health programme offers very few services for elderly women. Similarly, services like abortion services or contraceptive services can be accessed with difficulty by young unmarried girls. Research conducted in past several decades has contributed to enhancing our understanding about the burden of morbidities among women and various barriers faced by women in accessing health services; however, lack of gender disaggregated data is one of the major challenges in understanding the gender differentials in disease patterns or differentials in various health outcomes.

Taking hysterectomy as an illustration, the present study attempts to understand the dimensions of women’s access to health care such as ways of overcoming barriers to reach health facilities or the intra-household decision making processes and such. Access has been defined in several ways and various frameworks have been used to delineate the concept of access. The subsequent chapter of this thesis describes these frameworks in details; however, it is important to mention that the present study uses the definition of access as given by Meera Chatterjee. As per this definition, access requires overcoming barriers starting with the individual and progressively involving her/his family, and ultimately the state/market in health care. (Chatterjee M. 1988, quoted in Iyer, 2005)
The literature reviewed for the purpose of this research is divided into two sections. The first section includes review of studies which highlight the different reproductive health needs of women as well as evidence regarding demand side and supply side factors which impede or facilitate access to health care for women. The second section includes the review of studies which have specifically looked into different aspects of hysterectomy including medical as well as social aspects. This section provides evidence regarding hysterectomies from international level to national as well as Maharashtra state level.

Section I- Review of Studies Regarding Access to Reproductive Health Services

2.1 Women’s Reproductive Health Care Needs and Access to Reproductive Health Services

As early as in 1989, the study conducted by Bang A. and Bang R. highlighted the issue of high prevalence of reproductive morbidity among tribal women in Maharashtra. (Bang R, 1989) In this study, where 650 women above the age of 13 years were examined, about 55% of women had one or more gynaecological symptoms. The study reported that ninety-two percent of the women suffered from one or more gynaecological or sexual diseases and the average number of these diseases per woman was 3.6.

In the last three, four decades, several hospital based as well as community based studies have been conducted which give different estimates about the prevalence of reproductive morbidities among women. Depending on the location of the study (hospital based or community based), whether probing was done or not, or whether the study is based on self reported symptoms or the symptoms are confirmed by clinical examination, huge variation is seen in the prevalence of various gynaecological morbidities in these studies. (Garimella, 2002)

Current prevalence about reproductive morbidities in the state of Maharashtra can be gauged from the District Level Household and Facility Survey (DLHS-4) data. This
survey reveals that in Maharashtra about 14% women (n=45,690 ever married women) had any symptom of RTI/STI, 4.5% women had reported vaginal discharge and 9.2% women had reported menstrual problems in the period of three months before the survey. In the same study, 30.9% women had reported complication during pregnancy, 19% women had reported complication during delivery and almost 12% women had reported post-delivery complications. (IIPS, 2013) Overall the DLH Survey highlights the burden of reproductive morbidities borne by the women in the state of Maharashtra.

In terms of health care access, the DLH Survey-4 shows that in Maharashtra, 67% women received antenatal check up in the first trimester of pregnancy and only 37.3% women received full antenatal care\(^1\). Ninety two percent deliveries were institutional deliveries and 60% women had stayed in the hospital for 48 hours after delivery. These statistics highlight the deficient health care access for basic health services such as ANC or institutional delivery.

The NFHS-3 survey gives class, caste based inequities in accessing reproductive health services. For e.g. among the women who have delivered a child in the last five years in Maharashtra, the proportion of women receiving care at the time of delivery was four times higher and the women receiving antenatal care was two times higher in the higher income quintiles compared to the lower income quintiles. The survey revealed that poorer women, those living in rural areas and Scheduled Tribe (ST) women and Dalit women had lower access to maternal health care as compared to women residing in urban areas or belonging to higher wealth quintiles or upper castes. (IIPS, 2007)

Other reproductive health services where there are significant gaps in access are the services related to safe abortion and contraceptive services. In India, only 13% of currently married women in the age group 15 to 19 years reported using any contraceptive method in the NFHS 3 survey. The survey shows that use of methods other than sterilisation increases with the increase in education of women. (IIPS, 2007)

\(^{1}\) At least three visits for antenatal check-up, one TT injection received and 100 IFA tablets or adequate amount of syrup consumed.
2.2 Household Level Factors Shaping Women’s Access to Health Care

Health care access for women is largely shaped by the household and health system characteristics. In Indian context, women’s participation in decision making, access to and control over resources, and mobility are quite limited. (Bloom S. et al, 2001; Jejeebhoy and Sathar, 2001) McCleary-Sills et al. (2012) highlight the link between woman’s level of empowerment in the domestic and social spheres and her ability to take reproductive decisions. On the basis of the extensive review of the literature regarding the studies conducted between 1990 and 2008, they argue that restrictions on mobility or barriers to accessing public spaces; non-availability of resources; limitations on decision-making authority and restricted communication with powerful family members; and active interference, threats, or violence are the manifestations of women’s disempowerment in the family and community. The interplay of these factors results in women’s ability to actively and effectively seek reproductive control options where reproductive control refers to women’s ability to effectively define their childbearing intentions and, subsequently utilize safe and effective contraception and abortion services in line with these intentions. The authors document that in South Asia, husband as well as mother-in-law are key decision makers for women’s access to health services or regarding her reproductive decisions. (McCleary-Sills, McGonagle and Malhotra 2012)

Studies looking into the causes of low access to health care have also found out that the feeling of shame for reproductive illnesses, the absence of knowledge about effective cures and the fear of termination of their fertility were some of the reasons for not seeking treatment though women were aware about the illness. (Bang R and Bang A., 1994; Unnithan-Kumar M., 1999) Bang et al note that even though women recognise their health problem, they do not disclose it due to the fear of adverse reaction from family or community. In the study conducted by Bang A. et al, only 7.8 % women have had a gynaecological examination even though 55% were aware of the symptoms and 92% actually had it. (Bang R and Bang A., 1994)

Report of WHO Commission on Social Determinants of Health (2007) identifies lack of awareness which is knowledge of women, their families and health care providers about the existence of a health problem and acknowledgement meaning recognition that something should and can be done about the health problem as important barriers
to women’s access to and use of health services. According to this report, access depends both on factors affecting the demand side (how families treat women who may be potential users and how women see themselves) and the supply side (including different aspects on the side of providers). Women face economic barriers in health care access differently than men. (Iyer, 2005) Lower health expenditures on women as seen in NSSO (2004) indicate that men are offered more expensive treatments as compared to women.

A critical review of studies regarding decision making process before seeking abortion care done by Ravindran T.K.S. (2002) highlighted that the decision of seeking abortion or continuing with the pregnancy is mostly taken by the woman with her husband, whereas, in the cases of sex selective abortions, in most of the cases families had asked the woman to terminate the pregnancy. Another study conducted by Bhatia and Cleland (1995b) looking into the effects of socio-economic, demographic and health-related variables on healthcare seeking behaviour during pregnancy, delivery and the postnatal period had revealed that among the predictors of antenatal care seeking, education and the index of personal hygiene were seen to be strong positive predictors.

2.3 Health Systems Related Factors Defining Women’s Access to Health Care

As mentioned in the above section, characteristics of health systems are also influential in shaping women’s health care access. In India, curative health care is largely provided by private health care providers\(^2\), which include formal as well as informal health providers. For 80% of the illnesses treated on OPD basis reported in NSSO 60\(^{th}\) round, the treatment was sought from the private sources. In case of illnesses, which required hospitalisations, 60% of the hospitalisations were in the private sector. (NSSO, 2004) Geographical location of health care facility has also been established as one of the important determinant of access to health care for women. (Kundu S., 2010)

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\(^2\) According to the NSSO definition, the ‘private’ sources include private doctors, nursing homes, private hospitals, charitable institutions, and such.
Manju Rani and Sekhar Bonu (2003) had analysed NFHS 2 data to investigate the level and correlates of care-seeking and choice of provider for gynaecological symptoms among currently married women in rural India. The analysis had revealed significant state level variations in care-seeking behaviour and type of providers consulted. Private providers were the preferred choice by socially disadvantaged as well as better off women. The authors pinpointed the problems of service quality such as restrictive opening hours, poor interpersonal treatment from staff, illegal fees, lack of drugs and equipment, lack of privacy and confidentiality in the public sector, and the increased availability of private services as some of the reasons for preference of private services.

In addition to the power relations within the family, McCleary-Sills et al. (2012) also underscore the power relationship between providers and women which is identified as an important barrier affecting women’s ability to exercise reproductive control. The authors argue that the providers perceive and treat women as minors who require permission from others for making reproductive choices. Very often women are asked to get husband’s consent for abortion which is not a legal requirement in India. Secondly, the providers’ use their personal judgment of women’s morality, especially in the sphere of sexuality while providing treatment options to women. (McCleary-Sills, McGonagle and Malhotra, 2012)

2.4 Emerging Issues Regarding Access to Health Services for Women

Most of the literature on women’s access to health care has brought out the facts related to lack of access to health care for women and the reasons for the same. The barriers faced by women in accessing health care such as cultural barriers, availability of health services, and lack of financial resources have been highlighted as some of the barriers which impede women’s access to health care. Yet, in the same milieu, there are certain situations such as doing ultra-sound tests for sex determination, assisted reproductive treatments such as IVF and deliveries by Caesarean Section (CS) where women do overcome these barriers and seek those services albeit their non-requirement in some instances. Hence it is essential to also study the factors which facilitate women’s access to health care in such situations.
National Family Health Survey- 3 revealed that one-fourth of all pregnancies in the five years preceding the survey underwent an ultrasound test. Significant differences in utilisation of ultrasound facility were found between urban and rural women as forty-four percent of pregnancies to urban women underwent an ultrasound test, as compared to 16 percent in rural areas. Women with at least 12 years of completed education were almost eight times as likely to have an ultrasound test as pregnancies to women with no education. (IIPS, 2007)

2.4.1 Increasing Number of Deliveries by Caesarean Sections (CS)

According to the WHO norms (1985), a rate of 10-15 per cent was considered appropriate rate of CS for the medical indications. However, the NFHS 3 survey reveals that in India, in urban areas around 17% of deliveries were by CS. Among women who had completed education above 12 or more years, almost 30% deliveries were by CS. Similarly, among the highest wealth index group 25.7% deliveries were by CS. These statistics clearly indicate that there are certain sections who are misusing technological advancements in medicine. (IIPS, 2007)

Pai (2000) has delineated the factors influencing CS rates, where besides medical indications for CS, availability of skilled neonatal intensive care, better anaesthesia, availability of blood transfusion services were associated with increasing CS rates in India. Pai notes that lack of round the clock patient monitoring facilities, lack of trained nurses and difficulty of obtaining immediate second opinion possibly force obstetricians to resort to elective C-sections even without a strong indication. Pai also draws attention to the obsession among Indians about the auspicious date and time for baby birth which is achieved through doing CS. In the hospitals affiliated to medical colleges, generally the rates of surgeries are high as the resident doctors need practice to gain expertise in surgical skills. Additionally, the paper notes that since Caesarean section fetches more money than vaginal delivery, the doctors are more interested in deliveries by CS than deliveries through vaginal route.
2.4.2 Use of Assisted Reproductive Technologies (ARTs)

Infertility is one of the important medical problems, which has immense social implications for women in India. According to the definition given by WHO in 2005, a couple is declared infertile if the woman did not conceive after one year of unprotected coitus. Before 1975, the definition considered the period as five years to declare the couple infertile. This decline in the period has been beneficial to the medical practitioners. Despite the low success rates, ARTs are being used for aiding women to conceive in large numbers. ART is also one of the illustrations where it is evident that when families are interested, women’s access to health care is facilitated. In this case, since the families are so deeply interested in heirs, women are taken to the hospital for this costly treatment. (Sama, 2010)

The review of literature presented in the first section is not exhaustive but only depicts key issues related to women’s access to health care. After the discussion related to the overall morbidities among women and the problems faced by them in accessing health care services, following section deals with the issue under consideration in this study i.e. hysterectomy. In the beginning, the evidence emerging from studies conducted in countries other than India has been provided.

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Section II- Review of Studies Focussing on Hysterectomies

The term hysterectomy originates from two Greek words: “hystero” which means uterus and “ectomy” which means resection/removal from the human body. (Papadopoulos, Tolikas & Miliaras, 2010)

Depending on the route of surgery and removal of other allied parts of the reproductive tract, it is categorized as follows-

i. Total Hysterectomy- where uterus along with cervix is removed

ii. Subtotal Hysterectomy- where uterus is removed but the cervix is retained
iii. Total hysterectomy with bilateral salpingo-oophorectomy is where the uterus, cervix with fallopian tubes, and both the ovaries are removed.

iv. Abdominal hysterectomy is removal of uterus through abdominal route

v. Vaginal hysterectomy is removal of uterus through vaginal route

vi. Laparoscopic hysterectomy is the hysterectomy done with the laparoscope

2.5 Hysterectomy: International Evidence

Though there are several articles on hysterectomy in medical literature, there is dearth of literature when it comes to the social aspects of hysterectomy. (Markovic, Manderson and Warren, 2008)

The following section gives gist of some of the studies, which have explored the non-medical aspects of hysterectomy. The studies conducted from non-medical aspects have been summarised in a way that they would provide answers to the following questions.

- What is the prevalence of hysterectomy in other countries?
- Who are the women who are most likely to undergo hysterectomy?
- How do women decide whether to undergo hysterectomy or not?
- What are the perceptions of women as well as men about hysterectomy and its impact on different domains of women’s lives?

2.5.1 Prevalence of Hysterectomy in Other Countries

A study conducted to look at biosocial determinants of hysterectomy in New Zealand revealed that one in four women in the age-group 50 to 54 had undergone hysterectomy. (Dharmalingam, Pool and Dickson, 2000)

Uterus as an organ was strongly associated with women’s emotions. Hippocrates claimed that the womb wandered around the body and was responsible for mood changes in women. Hence removal of uterus was thought to negatively affect women. (Marván, Trujillo and Karam, 2009) Hysterectomy is the second commonest surgery among women, Caesarean Section being the first one. In USA, in 2000, 633,000 hysterectomies were performed. By age of 60 years, approximately one third of
women in the US have had a hysterectomy. (Babalola et al., 2007) Of these, 75% surgeries were among the women between the ages of 20 and 49. In the United Kingdom, in 2001, 21% of women aged 55–59 were estimated to have had a hysterectomy whereas in Australia, 14% of women aged 18 years or above had had a hysterectomy. (Markovic, Manderson and Warren, 2008) According to the Canadian Institute of Health Information’s (CIHI) website, more than 55,000 new hysterectomies are performed in Canada each year. Canadian women’s rate of hysterectomy—22%—was rated high by international standards. (Abramson, nd)

A study conducted by Keshavarz et al. (2002) had reviewed the hysterectomies performed, between 1994 to 1999 in the USA. The study had shown statistically significant increase in hysterectomy rates which increased from 5.1/1,000 in 1994 to 5.8/1,000 in 1998. Another study claims that over 650,000 hysterectomies are performed annually in the US and similar numbers in Europe. In Europe and USA, almost 50% of women over the age of 45 have had hysterectomy. (Mettler, Sammur and Schollmeyer, 2010) From 2000 through 2004, an estimated 3.1 million U.S. women had a hysterectomy. The hysterectomy rate decreased slightly from 5.4 per 1,000 in 2000 to 5.1 per 1,000 in 2004. From 2000 through 2004, rates of hysterectomy differed by age. Overall rates were highest among women aged 40–44 years and lowest among women aged 15–24 years. Hysterectomy rates among women aged 50–54 years decreased significantly over the study period, from 8.9 per 1,000 in 2000 to 6.7 per 1,000 in 2004. (Whiteman et al., 2008)

A survey conducted in Sweden revealed that from 1987 to 1999, the annual overall hysterectomy rate increased from 178 to 232/100,000 person-years. Thereafter, the overall hysterectomy rate declined and phased out around 210/100,000 person-years in 2003, a decrease of 11%. Comprising only 4% of hysterectomies performed in 1987, vaginal hysterectomy increased to 31% in 2003. Rates of vaginal hysterectomy by prolapse indication increased by a five-fold, whereas rates of vaginal hysterectomy by other benign indications increased by a near 20-fold. During the same period, total and subtotal abdominal hysterectomy decreased from 63% and 32%, respectively, in 1987, to 48% and 18% in 2003. (Lundholm et al., 2009)
Studies have also tried to investigate the proportion of hysterectomy which is clinically justifiable. Finkel M. and Finkel D. (1990) mention the use of hysterectomy for noncancerous conditions as a continuing source of professional controversy. It was said that rather than gynaecological need, the combination of patient and physician characteristics explains the variations of hysterectomy in different places.

Another study conducted by Amin et al. (2013) in Pakistan had attempted to determine the justification for hysterectomies and the frequencies of histopathological lesions and complications in patients with hysterectomy. In the study, hysterectomies performed between 1\textsuperscript{st} January, 2010 and 1\textsuperscript{st} January 2012 in a teaching hospital in Peshawar were retrospectively analyzed for presenting complaints, surgical indication, histological findings, and postoperative complications. In cases where the preoperative diagnosis was verified by the pathology report or if there was any other significant alternate pathology, then the hysterectomy was labelled as justified. In this study, in more than 90% cases histological findings had reconfirmed the clinical diagnoses. Hysterectomies were mostly performed for menorrhagia due to fibroids, prolapse or dysfunctional uterine bleeding. However, the study does not mention whether standard treatment protocols were followed or directly surgeries were advised. The authors have also raised the issue of high prevalence of hysterectomy in Pakistan and have indicated the need for regular audit of surgical procedures.

A study conducted by Nishimura et al. (1995) had compared the variation in the hysterectomy in physicians from different countries. The study had revealed that the doctors in the USA performed twice as many hysterectomies per capita as do those in England. More than one third of Japanese doctors and almost one fourth of Taiwanese doctors who responded had not performed a single hysterectomy during the previous year. Significant geographical variation in the clinical practice of physicians was noted across the countries studied.

2.5.2 Socio-Demographic Profile of the Women Who Undergo Hysterectomy

Studies have indicated that women with lower educational levels and lower income are more likely to have hysterectomy. (Kjeruljf, Langenberg and Guzinsld, 1993; Dharmalingam, Pool and Dickson, 2000) Possible reasons for this education wise difference was given as women with higher education have better access hence
consult a doctor soon after there are symptoms related to gynaecological morbidity. However, this is not the case for women from lower socio-economic group, hence the gynaecological morbidities may be diagnosed at later stage sometimes precancerous conditions may have turned into cancer hence hysterectomies are required.

Socioeconomic differences in hysterectomy have also been confirmed by the study conducted by Marks and Shinberg (1997) in Wisconsin in the USA. In this study, out of the 3326 women interviewed, 31% reported to have had hysterectomy. Only one tenth of hysterectomies were for cancer. The study revealed that women with at least a bachelor's degree had significantly lower odds of having a hysterectomy than women with only a high school education. Women in the lowest quintile of occupational status had about 22% higher odds of undergoing hysterectomy than high-occupational-status women. Women who had never worked before age 35 or 36 were at the greatest risk, their odds were about 32% higher than those of working high-occupational-status women. The study indicated that higher-status employment was associated with more control, less stress, and more satisfaction than low-status employment or no employment. These psychosocial factors lead to better health, including reproductive organ health—thereby reducing the need for hysterectomy.

The study revealed that early detection of problems was possible in higher socioeconomic group as women in this group had better access to screening tests. Highly educated women were also offered alternative treatments more than hysterectomy, as it is difficult to pressurise these women for surgery. Cooper et al. (2008) confirmed similar relationship between educational status and possibility of hysterectomy in a study which had examined the associations between indicators of socioeconomic position (SEP) and hysterectomy in two Australian and two British cohorts.

Dharmalingam, Pool and Dickson (2000) examined the prevalence and biosocial correlates of hysterectomy. Data were from a 1995 national survey of women aged 20 to 59 years. In this study Maori women were found to have marginally lower rates than non-Maori women. However, the study doesn’t provide any explanation for this finding. Another study conducted by Bower et al. (2009) had demonstrated that black women, compared with White women, had almost four times higher odds of
hysterectomy. The study indicated that the nonclinical factors such as patient education about alternatives to hysterectomy, environmental attributes, cultural or religious beliefs, issues related to patient–provider communication, physician preference, or other psychosocial factors were likely important contributors to these differences.

2.5.3 Decision Making Processes before Hysterectomy

Wu et al. (2005) have attempted to build a decision making tree for women considering hysterectomy. The important research question of their study was to find out how do women decide if they should undergo hysterectomy or not? The study was conducted in two phases. In the Phase I, the model development phase, data from a qualitative study of 14 women was gathered to establish a tree model outlining their decision to proceed with hysterectomy. In the second phase, the model tree was then tested with 18 women who were deciding whether or not to undergo hysterectomy. The study was carried out in 1999–2001 in Taiwan. Key findings that emerged from this study were that the decision tree is a cyclical process where changes in physicians, changes in health push women again into the decision making process. The study found that women who wanted to preserve the uterus, who could overcome the fear of benign fibroids turning into malignant ones, decided against surgery. Whereas, women who faced irrational psychological obstacles, who were unable to bear the physical discomfort and in whom the fibroid size was increasing, opted for surgery. The study revealed that fear of fibroids turning malignant was the best predictor of the decision. These women also believed that uterus is merely an organ for producing children, hence thought it was useless after having children. The study also found that the physicians did not provide adequate information.

Cabness (2010) conducted an exploratory study in the USA using a Web-based questionnaire to examine women’s lived experiences of hysterectomy on the physical, affective, social, spiritual, and sexual domains of women’s lives. The findings of this exploratory study (n = 74) reveal that when the physician is female, patients were more involved in decision making. The study also indicated that women’s pre-surgery physical experiences seemed to be the most critical factor in their decision-making. Women reported that frequent bleeding episodes affected their social life and also made them irritable, moody, depressed, scared or fearful. Due to this physical as well
as emotional disturbance, they opted for surgery. In the same study, the participants were asked to provide their recommendations to other women who might be considering having a hysterectomy. The respondents recommended that before undergoing surgery a woman should investigate all options, should ask questions. To seek information, they can talk to other women or find alternatives using internet, second opinion should be sought if necessary and most important recommendation was to listen to body, give it time to heal. (Cabness, 2010)

Another study conducted in the USA by Askew (2009) had looked into women’s choice of surgery. The study had compared women who decided to undergo hysterectomy with women who opted for removal of fibroids called as myomectomy. The study revealed that the choice of surgery was influenced by several factors such as information, attitudes towards the reproductive organs, and attitudes toward doctors. It was seen that doctors viewed hysterectomy as a means to reduce the risk of cancer and sometimes financial incentives were driving force behind suggesting hysterectomy. (Tavris, 1992 cited in Askew, 2009) Utilitarian view of looking at uterus as only useful for reproduction was also cited as one of the reasons behind doctors advising hysterectomy. In the study conducted by Askew, women who had completed their families opted for hysterectomy whereas childless women preferred myomectomy. Few women also thought that uterus is necessary for reasons other than fertility. Women who opted for myomectomy had seen several doctors before taking final decision as they did not believe in doctors’ opinion of hysterectomy. The common thing in both the groups was that the treatment choices were influenced by opinions and experiences of close family, partners, and friends.

Another study conducted in the USA using FGD and individual interview as method for data collection revealed that decision-making was influenced by weighing the risks and benefits of the surgery on different domains of women’s lives such as biophysical, psychological, social and spiritual domain. (Williams and Clark, 2000) Women across the life span, both African American and Caucasian were included in the study. In this study, the biophysical aspect included the symptoms that women were facing such as pain, bleeding, fatigue, bladder symptoms and other infections as other problems. In most of the cases, these problems were of chronic nature. Women postponed surgery until the problems became very severe. The psychological domain
included severe mood swings, emotions such as depression, irritation which were sometimes due to the physical problems that women were facing. The dilemma regarding undergoing surgery and its possible complications also gave birth to anxiety. The social domain included gathering information and support from the relatives, friends and health care provider. Women spoke to other women who had undergone hysterectomy. The spiritual domain entailed resorting to prayers and meditation for mental peace.

2.5.4 Women’s Perceptions about Impact of Hysterectomy

Cabness (2010) also studied the psychosocial dimensions of hysterectomy where the study examined women’s perceptions of their inner spaces and their experiences related to physical, social, emotional, spiritual and sexual life after hysterectomy. In the study, women described their pre-surgery emotional experiences as “irritable,” “moody,” “depressed,” and “scared” or “fearful” and said that the physical conditions were alleviated after surgery. Women felt being more sociable after surgery and had much improved sexual relations post hysterectomy. There was improvement in the emotional domain as women expressed relief at not having concerns about pregnancy or birth control. The women in this study identified “friends” as the most important source of social support, followed by “significant others” as a secondary preferred source of support. “Family” emerged as the least important source of perceived support. Positive attitude, exercise, and the support of friends and family were cited as the factors contributing to healing.

Another study conducted by Galavotti and Richter (2000) looked into women’s experiences of and attitude towards menopause, hysterectomy, and hormone replacement therapy (HRT). In the study, in-depth qualitative interviews and focus groups were conducted at four sites, viz., Alabama, New Mexico, South Carolina, and Texas. Information was also gathered on women’s concerns and experiences they have had or expected to have with healthcare providers and their perceptions about their friends’, families’, and sexual partners’ attitudes towards hysterectomy. The study found that women definitely were relieved of the symptoms for which they underwent hysterectomy. Women relied on prayers and spiritual help to overcome their fear, anxiety and depressions before surgery. Women expressed need for more
information prior to surgery like different types of surgery or other options for treatment. In some cases, women sought support from their male partners and in some cases from other friends or relatives. Women did not receive adequate information about removal of ovaries and its implications such as need for hormonal treatment thereafter. There were cultural differences among women towards health care provider. African American women in Texas and Alabama and several of the white non-Hispanic women expressed mistrust of providers and their motives for recommending surgery. Both groups felt that financial interests might influence providers; the white group said this might be truer for male physicians than female. African women also indicated that there was a possibility of population control being the motive behind suggesting hysterectomy. Women were not satisfied about the interactions with the health care providers as they felt that the health care providers did not give adequate attention to their problems. Women from different cultural groups consulted different members such as friends/relatives or male partners before deciding about the surgery; however, they felt that the ultimate decision was theirs. In general, women thought that men had negative views of hysterectomy, believing that it would make a woman less desirable or less complete, but many women also said their male partner was supportive. Women also perceived that since men lack the knowledge about women’s body and internal organs, they were apprehensive about their wife’s surgery and its effect on their sexual life.

Jean Elson’s work delves into the importance of reproductive organs for women in creating her gender identity. (Elson, 2003) In this study, analysis of 44 in-depth interviews of women who underwent hysterectomy was done to determine the role of gendered body parts in the individual’s perception of gender identity. This study was conducted in an urban area in New England. The study revealed that women placed significant value on ovaries as the source of female normality. Women considered uterus as merely an organ important for producing children, but the ovaries were considered as organ responsible for producing female sex hormones. Women related removal of ovaries with losing their sense of femaleness. Removal of uterus was considered essential for relief from bleeding and pain; however, women felt grief and anger for removal of ovaries. This indicates their perceptions of the relative values of uteruses and ovaries to gender identity. Women in the study discussed femaleness with regard to hormonal balance and sex drive, and femininity in terms of the ability
to display appropriate sexual attractiveness. Elson (2002) also looked into whether premature termination of menstrual function negatively affects women’s subjective gender identities. In her study, women acknowledged that since the time of their menarche, women closely associated menstruation with their gender identity. Though they found hysterectomy as a relief from the pain and discomfort due to the reproductive illness, they also regretted losing the cyclic nature of menstruation which was a regulator of their daily lives. They found menstrual cycles as a feeling of connection to other menstruating women; and considered menstruation as important for their own emotional needs.

2.6 Hysterectomy: Evidence from India

2.6.1 Prevalence of Hysterectomy in India

Though there is no national level survey indicating the prevalence of hysterectomy in India. There are limited studies, which have looked into the prevalence of hysterectomy in community, further, most of these studies are restricted to a particular geographical area; hence, the prevalence rates cannot be generalized. Premature menopause, that is menopause before the age of 40 (Conway, 2000), has been identified as an emerging area of concern in the field of women’s health in India. Analysis of NFHS 2 data by Syamala and Sivakami (2005) found large variation in the incidence of menopause among Indian states. The proportion of women aged 30-49 who are in menopause was highest for Andhra Pradesh (31.4 per cent) whereas, Bihar (21.7 per cent) and Karnataka (20.2 per cent) ranked next in order in the proportion of women who are in menopause. According to NFHS 3, for 18% of women in the age group 30 to 49 years the last menstrual period occurred six or more months preceding the survey which included women who had undergone hysterectomy. (IIPS, 2007)

The study conducted by Singh, Arora in three villages of Panchkula district in Haryana had revealed seven per cent rate of hysterectomy among women above age of 15 years. (Singh and Arora, 2008) Another study by Desai, Sinha and Mahal (2011) done in Ahmedabad district of Gujarat revealed that the prevalence rate of hysterectomy among the members of SEWA health insurance programme was 9.8%
in rural areas and 5.3% in urban areas, whereas among the uninsured group of women the prevalence was 7.2% and 4.0% respectively.

Some of the news reports which have highlighted the spate of hysterectomies in different states are as follows-

In Andhra Pradesh, over 11,000 hysterectomies were performed between July 2008 and March 2010 under Aarogyasri health insurance scheme of the Government. (The Hindu, 22/03/2010) In Rajasthan, a RTI application filed by a NGO revealed that out of 385 surgeries in 3 private hospitals 226 were hysterectomies, all in a span of 6 months. (HRLN, 2013) Approximately 16000 hysterectomies were reported from Bihar. These hysterectomies were performed under Rashtriya Swasthya Beema Yojana. (Indian Express, 27/08/2012) Another news report had shown that the hysterectomy was performed on 14 years old girl. In Bihar, 16 hospitals had earned 170 million rupees at the rate of rupees 10000 per hysterectomy. These figures indicate the scale at which unnecessary surgeries are being performed. (Anirban Guha Roy, Hindustan Times, Patna, 08/08/2012) Times of India had reported that the audit conducted by an insurance company in Chennai had revealed several young women to have undergone hysterectomies for problems like small fibroids, non-cancerous, causing excessive bleeding as the reason for removal of the uterus or ovaries. Though fibroids is a common condition where treatment is essential in only few cases. The doctors opined that since even smaller fibroids can be picked up by scan, some doctors tend to over treat. (Times of India, 12/11/2009)

2.6.2 Different Perspectives about Hysterectomies among Young Women

Barring few studies, there is no research based evidence regarding the problem of hysterectomy among young women in India. Most of the discussions have been in electronic media as well through news items and articles in news papers. Besides higher prevalence, hysterectomies are being performed among young women is a major concern in India. In the study conducted by Kameswari and Vinjamuri (2007) average age at which surgeries were done was 28.5 years. Similarly in the study done by Desai et al. (2011), average age of women undergoing surgery was 36.6 years in rural women and 39.3 years in urban women. An article by Roli Srivastava in Times
of India had highlighted the plight of women from Lambada tribe. In this tribe, women in their teens had reported to have had hysterectomy. (Srivastava, 2010)

The study conducted by Kameswari and Vinjamuri (2007) also revealed that most of the surgeries were done for treating those gynaecological morbidities which could have been treated medically. In a national consultation which was organised on the topic of, ‘Understanding the Reasons for Rising Numbers of Hysterectomies in India’ (HRLN, 2013) the president of FOGSI, Dr. Hema Diwakar shared that taboos associated with menses, cancer scare, lack of options, ease of access, surgery being perceived as one-stop solution and insurance, these could be some of the reasons for high incidence of hysterectomies. It is worth noting that despite being a representative of medical professionals, most of the factors cited were demand side and not the supply side.

Most of the literature has articulated hysterectomies as the problem of medical overuse where unethical practices of doctors are mainly blamed for the high number of hysterectomies along with lack of awareness among women about its consequences.

An interesting dimension of looking at hysterectomies has been provided by Thippaiah Anitha and Gulrez Shah Azhar (2014). The authors analysed the construction of the “need” for hysterectomy within the framework of relational ethics, which focuses on roles in relation to others, and the critical feminist intersectionality theory. This theory views the individual as an intersection of privileges and oppressions that jointly influence life choices as they relate to the ethical principles of autonomy, malfeasance, beneficence, and justice. The authors articulate the difference between the biomedical constructions of risk to the uterus versus social notions of the risks of the uterus. Also they equate the post-hysterectomy status as close to maleness which is a sign of power. It is pointed out that further research is necessary within the framework of ethics as well.

Sapna Desai (2009) in her analysis of health insurance programme of SEWA revealed that 43% of the gynaecological claims were for hysterectomies. Further qualitative investigation indicated that women rarely sought second opinion once hysterectomy was advised. Insurance provided financial security to implement the decision of
hysterectomy. Limited access to gynaecologists in public health system led to seeking care only during emergencies. Need for monitoring these hysterectomies was clearly articulated by the author.

In the newspaper ‘The Hindu’, there was a series of articles where different perspectives about this issue were expressed. One of the positions regarding hysterectomies was the state sponsored schemes like Rashtriya Swasthya Beema Yojana (RSBY) Yeshasvini in Karnataka, Kalaignar in Tamil Nadu and Arogyasree in Andhra Pradesh are responsible for this spate of hysterectomies. (Jain and Kataria, 2012) The authors argued that in these schemes, the insured person can avail health services from the private sector as well. As the financial access is taken care by the Government, these schemes result in increased utilisation of health care services. In such schemes, the doctors generally emphasize on surgical interventions which yield more remuneration. Lack of regulation of private sector is identified as one of the reasons for this increase in number of hysterectomies. The authors argue that most of these schemes have not institutionalised the mechanisms to monitor the implementation of schemes and the standard treatment guidelines have also not been enforced. Lack of capacities of the government hospitals to perform these surgeries drives away patients to private nursing homes. One of the reasons identified is the illegal private practice of the faculty members in Government medical colleges, who are more interested in treating patients in private set up as compared to Government hospitals.

As a rejoinder to the points raised by Dr. Yogesh Jain and Dr. Raman Kataria, Sapna Desai raised the issue of gender bias which is leading to high hysterectomy numbers. (Desai, 2012) In her argument, Sapna Desai raised a very pertinent question that if facilitation of financial access and privatisation of health services are the drivers of high incidence of hysterectomies, then why is it that only women’s organs are excised and not men’s. Citing statistics from Gujarat, Sapna Desai enunciates that increased hysterectomies are an example of supply-induced demand. She argues that in a gender biased society, the overall value system dismisses the utility of uterus once its function of giving birth is accomplished. Another important reason cited for increasing hysterectomies is lack of treatment for gynaecological morbidities at primary level.
In the same series of arguments, Dr. K.R. Antony articulated the problem of unnecessary hysterectomies as an indication of unethical practices by the doctors. He said that irrespective of the Government’s policies or the socio-cultural biases, it is the duty of the doctor to provide rational ethical treatment. Dr. Antony points out the absence of system of peer review or reported overuse of medical procedures. The professional bodies like FOGSI (Federation of Obstetric and Gynaecological Societies of India) or IMA (Indian Medical Association) have abdicated their responsibility of ensuring ethical conduct of medical professionals. He said that though the issue of unnecessary hysterectomies is being discussed in context of RSBY or other such schemes, but in reality the phenomenon of unnecessary procedures is an old one. Private doctors often convince women by posing hysterectomies as permanent solution to all reproductive health problems. (Antony, 2012)

Mamidi and Venkat Pulla (2013) have articulated the issue of unwanted hysterectomies as violations of human rights. The authors argue that women often lack the freedom to choose and make informed decisions in matters impinging on their fertility and health, similarly they are denied access to appropriate healthcare services, all these constitute as violations of human rights. In order to respect a women’s right to health, the State parties should ensure unrestricted access to health services for women. The main argument of the authors is that hysterectomies without consent and full knowledge of the consequences as well as information of alternative relief measures are manipulating woman’s body against her will, thus constitute violations of reproductive rights.

Syamala and Sivakami (2005) define hysterectomy induced premature menopause as a public health problem. They argue that since a sizeable proportion of women in the reproductive ages are now moving into menopausal stage, catering to their health needs will pose a double burden of providing services for tackling the problem of both maternity and menopausal issues simultaneously. This premature induction of menopause in women has very grave consequences on women’s bodies as the hormones produced by ovaries play crucial role in maintaining women healthy.
Figure 2.1- Different Perspectives about Hysterectomies among Young Women

Source: Created by the researcher from the Literature Review on this topic

2.7 Studies Conducted On Hysterectomy in Maharashtra

There are very few studies conducted in Maharashtra which have specifically investigated hysterectomies. One study has been conducted by a NGO called ‘Tathapi’ which works on women’s health issues. This study was conducted in nine villages from Marathwada region. The study revealed that around three thousand women across nine villages were encouraged by private doctors to undergo hysterectomies for no apparent medical reason. Most of these women were in 30 to 35 year age group. Women were asked to undergo surgery for health problems like ‘white or red discharge’. The study reported that women also went in for surgeries out of peer pressure, as hysterectomies have become a common-place trend among the women. Surgeries caused severe financial implications for women as they had to sell off their land to pay for the surgeries. (Bushra Ahmed, 2013)

Before this study by Tathapi, mass hysterectomies of mentally retarded women in a state run institute in Pune district were widely discussed in media and also legally challenged by women’s health activists. (Imam Zaka, 1994) The underlying issue here was complicated because women who were being operated upon were not the ones who had given consent for the surgery. Women’s health activists had alleged that Government is shrugging its responsibility of protecting these women from sexual abuse, instead hysterectomies were being done under the garb that the women are not able to manage menstruation in hygienic way. These hysterectomies of mentally retarded women were also legally unacceptable as the State does not have authority to
take decisions on behalf of these women. In this case, women’s groups had argued that conducting hysterectomies in the name of hygiene reinforces that menstrual blood is dirty. If these women can manage bowel and bladder hygiene, they can certainly be trained to manage menstruation as well. In an article by Nagmani Rao and Sarita Pungaliya (1994) on this issue, they pointed out the utilitarian approach towards a woman's womb. The question was asked that can a womb which is not going to be used for procreation be deemed 'useless' and therefore be dispensed with? Another question was asked that whether this utilitarian approach can be stretched for other 'non-useful' parts of the individual and/or society?

Another article which highlighted the rampant occurrence of hysterectomies in Maharashtra was written by Gopinathan (2006). The article mentioned that a doctor in Maharashtra, had reported that certain areas in Maharashtra have now become womb-free zones indicating that in Maharashtra, hysterectomies are being routinely performed for past several years. Gopinathan brings to the notice the differential and discriminatory approach towards women’s and men’s body parts. She says that 10% of men who have enlarged prostate glands contain cancerous tissue, yet the surgery of removal of prostate glands is not suggested as a preventive measure; whereas the ovaries are removed citing the cause of possibility of ovarian cancer though its prevalence is low. Doctors often assume that after reproduction and as women age they automatically lose interest in sex, and if they do not they are made to feel terrible. Removal of ovaries is also associated with loss of libido.

2.8 Medical Literature Regarding Hysterectomy

In the study by Kameswari (HRLN, 2013), it was seen that 41% of women had values of Follicle Stimulating Hormone\(^3\) (FSH) in menopausal range confirming the premature menopause induced by hysterectomy as the incidence of natural premature menopause is 0.1%. The study states that given the poor nutritional status and poor immunity of rural women, the chances of oestrogen depletion and loss of ovarian function are very high. However, the evidence regarding impact of surgical

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\(^3\) Follicle-stimulating hormone (FSH) is a hormone found in humans and other animals. It is synthesized and secreted by gonadotrophs of the anterior pituitary gland. FSH regulates the development, growth, pubertal maturation and reproductive processes of the body. FSH and luteinizing hormone (LH) act synergistically in reproduction.
menopause on women in India is scanty. Considering the serious consequences associated with the premature menopause, the following section provides gist of the evidence from medical literature investigating hysterectomies.

Studies that appear in medical journals mostly focus on the surgical approaches as well as post- hysterectomy complications. The following section summarises the medical literature concerning hysterectomy to providing information about the short term as well as long-term effects of hysterectomy on health.

2.8.1 Immediate Post Operative Complications after Hysterectomy

Bleeding during surgery, injuries to organs such as bladder, ureters and bowel, post-operative bleeding, retention of urine, urinary infection, wound infection, fever were the reported complications after hysterectomy. (Brummer et al., 2011) A study examining the correlation between BMI and risk of complications after surgery revealed that obesity increases the risks of bleeding and infections after Abdominal Hysterectomy. Women with BMI less than 20 had elevated risk of infections after laparoscopic surgery. (Osler 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) Dorairajan et al. (2004) have also confirmed higher incidence of bladder injury during vaginal hysterectomy than abdominal hysterectomy. But the chances of injury are lower in cases where the vaginal hysterectomy is done for prolapsed uterus than vaginal hysterectomy done for other conditions. A study conducted among Chinese women has 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)

Bayram and Beji (2010) indicate that there is no consensus regarding whether the hysterectomy affects sexual function. Sexual problems after hysterectomy that have been reported include dyspareunia (painful sexual intercourse) related to vaginal shrinkage and decreased lubrication, low libido, and not experiencing orgasm. Decreased ovarian functions, changes in pelvic anatomy, the symbolic psychological meaning of loss of the uterus were identified as mechanisms that could explain why
hysterectomy affects the sexual functions. Whereas, increase in sexual desire after hysterectomy was attributed to relief of complaints, absence of fear of pregnancy and absence of pain related to the condition requiring hysterectomy. One of the reasons for the contrasting evidence regarding how sexual function is affected by hysterectomy is that the sexual function improves gradually after surgery, hence the response of the woman would depend on at what time after surgery she was interviewed. However Peterson et al. (2010) have shown contrasting evidence as in their study conducted to assess sexual dysfunction after surgery, women’s sexual problems such as pain and problems with orgasm were seen to become worse over time.

2.8.2 Long Term Effects of Hysterectomy on Health

Removal of ovaries at the time of hysterectomy has been one of the important issues of concern as ovaries perform important hormonal functions. Studies have shown that women with long-term oestrogen deficiency have a reduced risk of breast cancer and of thrombosis; however they face increased risk of osteoporosis and heart disease, stroke, hip fracture, depression and anxiety. Hence, to avoid these, women who have undergone oophorectomy\(^4\) are advised hormone replacement therapy. (Conway, 2000; Sharma, 2011) Cochrane review of hysterectomy versus hysterectomy plus oophorectomy for premenopausal women done by Orozco et al. (2008) also confirmed that oophorectomy also increases the risk of cardiovascular disease. The review indicates the need of good quality studies of the benefits or harms of removing the ovaries at the time of hysterectomy. Until such studies are conducted, the authors suggest that oophorectomy should be approached with caution.

Another Cochrane review by Nieboer et al. (2009) compared the three surgical approaches for conducting hysterectomy; these are abdominal hysterectomy, vaginal hysterectomy and laparoscopic hysterectomy. The review indicated vaginal hysterectomy as the best surgical approach as it meant quicker return to normal activities, fewer infections and episodes of raised temperature after surgery, and a shorter stay in hospital compared to abdominal hysterectomy. The review also indicates the need for more research regarding the long term effects of the surgery.

\(^4\) Oophorectomy is removal of ovaries.
This finding is also endorsed by Johnson et al. (2005) Currently the medical field is also exploring alternative treatments for conditions such as menorrhagia, fibroids which are common causes of hysterectomy. Treatments such as endometrial ablation\(^5\), shrinking of fibroids by tissue necrosis have proved to be effective in these conditions. (Papadopoulos, Tolikas and Miliaras, 2010)

Overall observations which emerge from the literature review on this topic are as follows-

1. Women have substantial load of reproductive morbidities, and also high numbers of untreated morbidities.
2. Though there has been increase in research on issues related to women’s access to health care, several areas still need more explorations such as increasing surgical interventions or the decision making processes before acceptance of such treatments.
3. As regards hysterectomy, the evidence from India is scanty and there is an urgent need for studies looking into various aspects of this issue such as the prevalence of hysterectomy in India.
4. There is significant dearth of literature about how hysterectomy impacts women’s lives in Indian context.
5. Situations such as caesarean sections or hysterectomies, where there is supply induced demand of health services, there is a need to research these areas to see how the health care system shapes women’s ‘choices’.

In this context, the present study specifically looks into various aspects of the decision making processes before acceptance of hysterectomy as a treatment and its implications on women’s lives. The subsequent chapter delineates the detailed conceptualization of the study undertaken as part of doctoral research.

\(^5\) 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.