

# Medical Ethics: A case study of Hysterectomy in Andhra Pradesh

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## CHAPTER I

# **INTRODUCTION**

### **THE ISSUE:**

Life-HRG is a not-for-profit organization that has been providing basic healthcare services to rural masses in the arid district of Medak, hundred kilometers from the state capital Hyderabad in the state of Andhra Pradesh. The NGO observed a number of young rural women undergoing hysterectomy operation (along with removal of ovaries) as a solution recommended by qualified and certified allopathic medical practitioners in the area they work in. The indiscriminate resort to the surgical treatment has far-reaching health implications to the women. Life-HRG had, as part of its work, registered a total of 171 women under 40 who had undergone unindicated hysterectomy in just one administrative block of Medak district. The women had gone to the doctor with complaints like abdominal pain and white discharge, abdominal pain, spotting, white discharge, white discharge with foul smell and itching and genital prolapse and were recommended to undergo hysterectomy. Reasons for this appeared to be a multidimensional – the socio, economic, cultural background of the women that resulted in lack of awareness/knowledge and power wielded by the medical practitioners to influence the decision.

This practice is not a standard recommended practice even in modern medicine and is often seen in medical texts as a solution of last resort. Many times, conditions for which doctors suggest hysterectomy can be successfully treated with alternatives to hysterectomy that include less invasive surgeries and pharmacological treatments. Even when the surgical treatment is compulsory, within the limitations, there exist 3 to 4 kinds of hysterectomies with varying degrees of post-operational effects. Hysterectomies involve removal of one or all of the following organs: cervix, uterus, and the fallopian tubes and both ovaries. The kind of hysterectomy to be done depends on the specific condition of the patient. But most of them result in hormonal imbalances, which required long term treatment. They also alter the biological and sexual clock of the women with long term adverse consequences. Women who have undergone hysterectomy have a greater risk of heart disease and osteoporosis, and are more likely to become depressed. Unfortunately, there is little follow up care for hysterectomised women.

Since hysterectomy has such long-term effects on a woman's health, longevity, it is important for them to understand all possible consequences. They should understand when hysterectomy is an option and when it is necessary to save one's life. Moreover traditional healthcare solutions have had a different outlook to a large extent for a number of gynecological problems. Going for a hysterectomy, therefore, is a serious decision, which should be an informed one, based on individual case history. Both the doctor and patient should work together to determine the right treatment option for the latter. The doctor should also be able to suggest alternative treatment, including from the Indian Systems of Medicine. Medical ethics should surely demand this from the medical practitioners as per the authors of this case study.

### ***The Current Study:***

This study sought to explore the relations between science and ethics through the examination of the practice of hysterectomy. This is a study among rural women of AP, who have been advised and have undergone hysterectomy operations. The case study explores current practice in the field and compares this with medical ethical guidelines of ICMR to see where these have been followed and where the shortcomings are. It is based on the experiences of a doctor-couple interested in public health who came across an unusually high incidence of surgical treatment that has become common practice in the region that they work.

The case study relates to the issue of science and ethics as it plays on women's health and explores:

- the medical ethical guidelines in practice (or absence of the same), including informed consent. Whether or not the condition of a woman warranted hysterectomy, was there an alternative available, if the alternative was available why hysterectomy was preferred by the practitioner, what other socio-cultural

factors were at play in the decision-making processes, the nature of violence perpetrated against the women and their bodies etc.

- few cases of gynecology problems, which were successfully addressed by the healthcare practices without hysterectomies. In doing so, the positing of the need for a new framework to democratize the relationship between different systems of knowledge on healthcare and for a different medical expert-patient relationship.

## ***Methodology***

This case study chose to explore what the ethical concerns raised by the unindicated and risky recourse to hysterectomy in the Medak district are and the absence of medical ethical guidelines in practice including the much-touted 'informed consent', the consequent financial and health burden on the women and the inability to look at alternate practices of medical knowledge by adopting the following methodology:

1. administering a questionnaire to 171 women under 40 years, registered with LIFE-HRG;
2. taking up a survey in 12 villages of Munipally block in Medak district in Andhra Pradesh administering a questionnaire to 265 women who had either undergone hysterectomy or not
3. an analysis of the evolving discourse on medical ethics as reflected in the Code of Ethics evolved by the Medical Council of India and as reflected in the content of Indian Journal of Medical Ethics and specifically on Informed Consent and Doctor-Patient relationship
4. collecting the case studies of a few women who were treated in Life-HRG and about the alternative approaches possible.

In the process, the case study also explores which population is vulnerable to the lack of ethics in this sphere.

### **More details on the methodologies adopted:**

The combination of Life-HRG documentation on the women they treat and the circulation of a structured questionnaire among Life-HRG's patients and in the 12 villages in Munipally Mandal was used to understand hysterectomy from the patient's side and yields important insight for understanding medical decision-making, and the (assumed) prevalence of radical and definitive solution, e.g. hysterectomy (voluntarily as well as involuntarily) sought by the women. The understanding of this pattern of compulsory hysterectomy from the women's perspective involves: investigation of the socio-economic background of the women, women's utilization of healthcare systems, family structure, reproductive behaviour and sexual behaviour to determine to what extent hysterectomy is determined by the social and gender dynamics of rural society, diffusion and state of health/medical knowledge among rural population and perception of medical authorities (figure, purpose, practice, interaction). The data collected by LIFE-HRG of its patients over the past several years further yielded a general understanding of the physical nature of the harm in the short as well as the long run done to the women hysterectomised. This aspect highlights the nature and extent of violence perpetrated against these women; extensive qualitative interviews with these women aimed at uncovering the social, psychological and economic aftermath of the surgeries.

Along with the investigation of the medical practice from the perspective of the practitioner, collecting the perspective and subjective experience of the patient's encounter/interactions with the medical system at large to reconstruct the intricate process from both sides (doctor & patient) provided a rich insight on the nature of the patient-doctor relationship and indicated patients' perception of the "doctor figure".

An attempt was made to analyse the existing 'ethical framework' (Indian Council for Medical Research or ICMR guidelines) and to analyse to some extent the recent debates on medical ethics in India as reflected in the Indian Journal of Medical Ethics, to understand the state of medical ethics in India.

This discourse analysis was taken up as a reflection of the on-going process of medical-community-based re-conceptualization of ethical obligation of the physician. In a context of authority crisis and growing community distrust in its regulatory bodies, the discourse analysis aims at uncovering the process of reconstruction of the

doctor's figure (authority, responsibility and ethical obligations), the profession's worldviews and practice (interrelation between medicine and society, understanding of health issues, nature of the practice) and a re-definition of the doctor-patient relationship, as a means to contextualize the ethical concerns raised by compulsory hysterectomy and the ethical challenges and alternatives explored and implemented by Life-HRG.

Further, this paper studied the medical approach of Life-HRG (Dr Prakash and Dr Kameswari) to the issue of unindicated hysterectomy through extended interviews as an alternative approach that is indeed possible, devoid of violence and establishing a new kind of practitioner-patient relationship laying down a new code of ethics in practice.

## CHAPTER II

# **HYSTERECTOMY – THE CLINICAL PICTURE**

### **BACKGROUND**

Hysterectomy is the surgical removal of the uterus. It is the most commonly performed gynecological procedure. Hysterectomy may be total – removing the uterine body and the cervix, or subtotal – removing the uterine body but keeping the cervical stump intact. Removal of uterus also removes the child bearing capability of a woman and changes her hormonal levels. According to text books, hysterectomy is to be done to save life, relieve suffering and to correct deformity. However, according to reports, over 600,000 hysterectomies were performed in the US alone in 2003, of which over 90% were for benign conditions<sup>1</sup>. This led to a major controversy that hysterectomies are being performed for unwarranted reasons. In India, surgical menopause is common in women over 22 and osteoporosis – a common byproduct of menopause – is the highest debilitator in both rural and urban women.

#### Subtotal and Total Hysterectomy:

Subtotal hysterectomy is when the uterus is removed but the cervix is left intact. This is done in dire obstetric emergencies such as uncontrollable post partum hemorrhage and ruptured uterus to save the life of the woman. It is generally agreed that subtotal hysterectomy should be reserved for extremely moribund conditions. There is the likelihood of more cancer incidence in the cervical stump. In the 1940s, around 95% of the hysterectomies conducted in the US were subtotal. But in later years with improvements in surgical technology and preventive measures for cervical cancer, total hysterectomy became the norm.

Total hysterectomy is the removal of uterus along with the cervix. This is recommended when the following indications are present – fibroids, endometriosis that is not cured by medicine, uterine prolapse, cancer of the uterus, cervix or ovaries, persistent vaginal bleeding and chronic pelvic pain. Other options should be explored and explained to the woman before total hysterectomy is opted for. Since there is surgical disruption of the blood supply to the ovaries, total hysterectomy affects the functioning of the ovaries which produce the precious estrogen that protects women's health.

Total hysterectomy with bilateral salpingo oophorectomy is where the uterus, cervix with tubes, and ovaries are removed. With this there is a sudden onset of menopause. This is generally recommended as preventive measure for ovarian cancer. However, ovarian cancer is quite rare and accounts for only 3% of the cancers and about 1% of deaths in women. Removal of ovaries is not recommended as it increases the woman's overall risk of death by 40%. Post menopausal ovaries produce androgens that can convert into estrogens to protect the bone and blood vessels.

### **EARLY HYSTERECTOMY – THE WORK OF *LIFE-HRG***

In response to the situation of large numbers of unindicated hysterectomies in women under 40 and the lack of follow-up care and support for these young women, *Life-HRG* has been exploring the impact of early hysterectomy on the health status of the women. To do this, *Life-HRG* (1) Registered women under 40yrs who had undergone hysterectomy; (2) Classified them based on preliminary investigations; (3) Followed up further with high risk category, with specific clinical investigations.

This was to get a picture of the extent of cases which warranted a hysterectomy and the risks that hysterectomised women face.

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<sup>1</sup> Wu, JM, Wechter, ME, Geller, EJ, et al. Hysterectomy rates in the United States, 2003. *Obstet Gynecol* 2007; 110:1091 ; "[Are Hysterectomies Too Common?](http://www.time.com/time/health/article/0,8599,1644050,00.html?cnn=yes)". *TIME Magazine*. 2006-07-01. <http://www.time.com/time/health/article/0,8599,1644050,00.html?cnn=yes>. Retrieved 2007-07-17.

## ***Clinical Study of Women with Early Hysterectomy***

Before presenting details of the clinical condition of the women who underwent (early) hysterectomies in this study, given below is the standard medical procedure for hysterectomy – the symptoms and recommended treatment.

Some of the common complaints for which women seek medical intervention are:

- Pain in the abdomen and white discharge
- Pain in the abdomen
- Spotting
- White discharge
- White discharge with foul smell and itching
- Genital prolapse

The root causes of the above symptoms and treatment protocol as suggested in the gynecology text books are presented below:

- Pelvic inflammatory disease (PID) is an infection of the upper female genital tract, i.e. infection of the uterus, cervix, fallopian tubes, and/or ovaries. Although a Sexually Transmitted Infection (STI) is often the cause, many other routes are possible, including post-partum, post-abortion etc. Fever, cervical motion tenderness, lower abdominal pain, new or different white discharge, painful intercourse or irregular menstrual bleeding are the symptoms. Treatment depends on the cause and generally involves use of antibiotic therapy. Treating partners for STIs is a very important part of treatment and prevention.
- Pelvic inflammatory disease is common in young women who are sexually and reproductively active. While increased promiscuity and multiple sexual partners are held to be the main reasons for PID in developed countries, in the developing countries, septic abortions and puerperal sepsis (severe infection following childbirth, caused by infection of the placental site) are the important causative factors.
- Chronic cervicitis is very common and is found in about 80% of women who have some gynecological complaint. Chronic cervicitis represents a form of focal sepsis, is brought about by introduction of infection during abortion or child birth due to lacerations of the cervix<sup>2</sup>. It can also be the outcome of STIs. Cervicitis in acute stage can be effectively treated with antibiotics. It is difficult to eradicate the chronic cervicitis completely with medicines because of the nature of the mucous membrane.
- The cervix, or neck of the uterus, covers the cervical canal, the normally tiny passage through which a newborn must pass on its way into the world. Located at the inner end of the vagina, the cervix is vulnerable to a variety of sexually transmitted diseases. The delicate covering of the outer cervix is also prey to injury, which can strip off the surface layer of cells, resulting in cervical erosion. The cells lining the cervix are sometimes subject to abnormal growth as well, starting as cervical “dysplasia” and possibly progressing to cancer.

Recommended treatment and clinical procedures for the above disorders are the following:

- Acute cervicitis can be effectively treated with antibiotics.
- Pap smear is to be done to detect the presence of abnormal cells or dysplastic cells on the surface of the cervix. It is a sensitive and reliable screening test for cervical cancer.

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<sup>2</sup> In the present study, barring 3 or 4 women, all had had home deliveries and no ANC or TT injections.

- Chronic cervicitis is a form of sepsis. Apart from antibiotics, other treatments are available, one of which is Cyrosurgery – a safe, painless procedure that involves the use of extremely cold nitrous oxide gas. The gas is used to freeze and kill abnormal cells on the wall of the cervix. It is less painful, less expensive and easier for the physician to control and monitor.

### **The case of the women in Muniपाल Mandal of Medak district**

*Life*-HRG registered a total of 171 hysterectomised women from fifteen villages of Muniपाल Mandal of Medak district in Andhra Pradesh. Initial awareness camps followed by weekly meetings with women and health workers from 5-7 villages led to the registration of 108 women who had early hysterectomy. Later, the word spread and the remaining women approached Life-HRG for registration. All 171 women were under the age of 40 at the time of the registration (October 2008 to June 2009). Most of the women were underweight and belong to the lower income group. Following is a detailed description of the women and their clinical condition. The socio-economic characteristics of the women are analysed in a subsequent section of the report.

**Table 1: Age<sup>3</sup> at Marriage** (Details available for 148 women – it was not possible to elicit age for 23 women):

<b>Details</b>	<b>Number (n=148)</b>	<b>Percentage</b>	<b>Remarks</b>
Women married before menarche	33	22%	Youngest married at 7
Women married after menarche but before 18 years	114	77%	Average age at marriage – 14 years
Women married after 18 years	1	1%	

### **Observations:**

- In India the minimum legal age for marriage for women is 18 years. 147 of the 148 in the sample were married as children.
- Compared to older women, younger women are more susceptible to sexually transmitted infections due to biological factors such as hormonal fluctuations and permeability of vaginal tissue.
- Predisposing risk factors for cervical cancer are coitus before the age of 18, delivery of the first child before age of 20 and poor personal hygiene (Source: Shaw text book of Gynecology, prescribed text book for undergraduate medical students)

**Table 2 - Age at First Child: (Details available for 141 women):**

<b>Age group of women</b>	<b>Number</b>	<b>Percentage</b>	<b>Remarks</b>
13 – 15	67	47%	Average age at first child – 16 years;
16 – 19	66	46%	
20 – 23	8	6%	

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3 It was not easy to elicit the age of women - only 5 women in the study group could clearly state their age. But they were able to link time of menarche with time of marriage and given that the average age for menarche is 13, the age of the women has been calculated accordingly.

### **Observations:<sup>4</sup>**

1) Mothers in the 15-19 years age group face a 20-200 percent greater chance of dying in pregnancy than those aged 20-24. Those under age 15 are 5 times as likely to die as women in their twenties. The main causes are hemorrhage, sepsis, pre-eclampsia/eclampsia and obstructed labor (birth canal and pelvis are not fully developed).

2) For every woman who dies in child birth, 30 more suffer injuries, infections & disabilities, which usually go untreated and some of which are lifelong. (Mild injuries and lacerations of the cervix during childbirth may present themselves as chronic cervicitis at a later date, for instance)

3) Part of this heavy toll has more to do with poor socio-economic status and lack of ante-natal and obstetric care than physical maturity alone. However physical immaturity is the key risk for those under 15.

4) If a mother is under 18, her baby's chance of dying in the first year of life is 60% higher than that of a baby born to a mother older than 19 years.

### **Table 3 - Age at Hysterectomy:**

The following table presents data both on present age as on December 2009 and age at the time of hysterectomy.

<b>Details</b>	<b>Age</b>			<b>Total</b>
	<b>&lt; 30</b>	<b>31 – 35</b>	<b>36 - 40</b>	
<b>Present age:</b>				
No of women	67	51	49	167
Average age	26.4	33.2	38.4	31.9
<b>Age at Hysterectomy:</b>				
No. of women	92	42	20	154
Average age	24.6	32.7	37.7	28.5
Percentage	60%	27%	13%	

### **Observations:**

- Average age at the time of the study – 31.9 years
- Average age at which surgeries were done – 28.5 years
- Only 13% had hysterectomies between 36 – 40 years
- 60% had hysterectomies before the age of 30
- For those under 30, the average age at which hysterectomy was done – 24.6 years

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4 Source: Early marriage Child Spouses UNICEF Innocenti digest # 7, March 2001.  
<http://www.unicef-irc.org/publications/pdf/digest7e.pdf>

- On a temporal scale, while the average age of hysterectomy for older women in the group was 37.7, for the younger women it is 24.6 years indicating that more and more, these surgeries are being performed on younger and younger women.

**Table 4 – Place of surgery:**

<b>Name of institution</b>	<b>No of surgeries</b>	<b>Percent</b>
<b>Government Institutions:</b>		
AP Vaidya Vidhana Parishad, Sangareddy, Medak district	2	
Gandhi Hospital, Secunderabad	2	
Government Hospital, Sangareddy	2	
Niloufer Hospital, Hyderabad	1	
Osmania General Hospital, Hyderabad	1	
<b>Total government</b>	<b>8</b>	<b>5%</b>
<b>Private Hospitals</b>	<b>163</b>	<b>95%</b>

**Observations:**

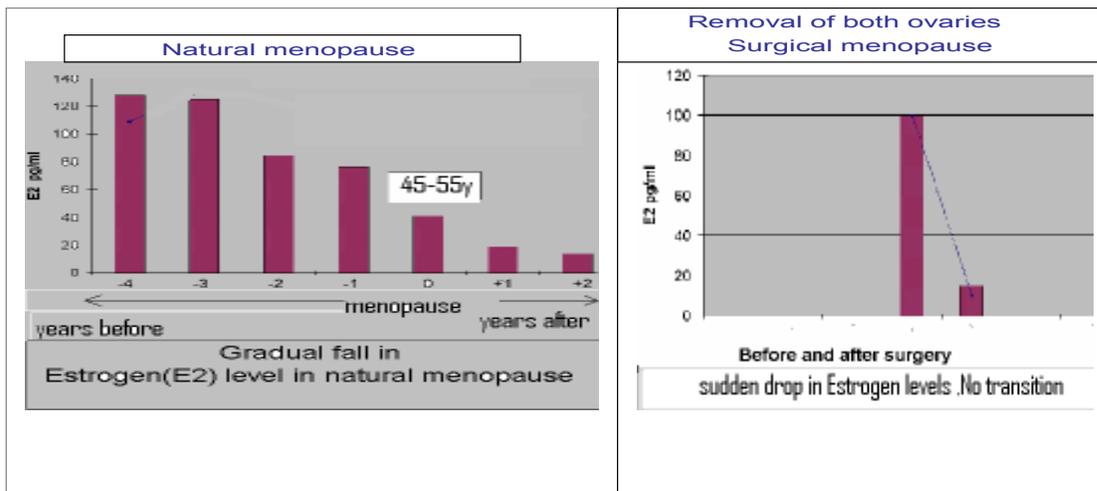
1. Those who were referred to government hospitals were those who had some hormonal or other symptoms. Private hospitals only treated those who were “healthy” with no history of other symptoms.
2. All surgeries done in Government teaching institutions had clear indication and good post operative notes.
3. However, at the district level, though post operative notes are available, the indication is not clinically justifiable.
4. For the 162 cases that were done in local private hospitals, the discharge summary is mostly blank with no information about procedure done or the follow up instructions.

**Table 5 – Surgery details (out of 165 done by abdominal route):**

Type of surgery <sup>5</sup>	Number	Percent
Total Abdominal Hysterectomy (TAH)	32	19%
TAH+Left Salpingo Oophorectomy/Right Salpingo Oophorectomy (LSO/RSO)	47	29%
TAH+Bilateral Salpingo Oophorectomy (BSO)	53	33%
Records not available	33	20%
<b>Total</b>	<b>165</b>	

**Observations:**

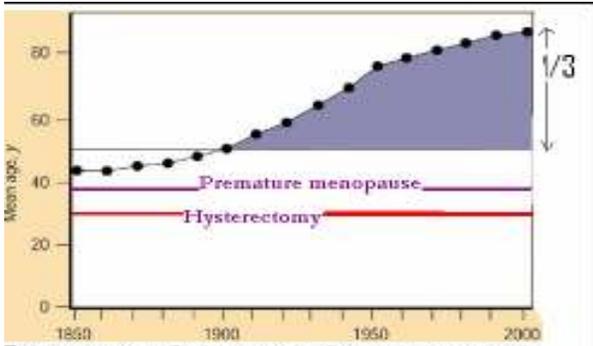
- High percentage of women were subjected to ovaries removal
- Removal of ovaries is the biological equivalent of castration and results in the immediate and sudden onset of menopause in contrast to natural menopause which is a gradual process. The figure below shows the impact of TAH+BSO on estrogen (E2) levels in natural menopause as opposed to the sudden drop in estrogen levels without any transition in this surgical menopause.



**UNDERSTANDING EARLY MENOPAUSE AND ITS IMPACT ON WOMEN'S HEALTH**

Menopause is defined as the time of cessation of ovarian function resulting in permanent stoppage of the menstrual cycles. Most women reach menopause between the ages of 45 and 55, with the average age around 50. However, about one percent of women experience menopause before the age of 40 years, which is known as premature menopause (the woman’s ovaries spontaneously stop producing eggs and the underlying cause may not be found). In some cases, early menopause is brought on by surgery to remove the ovaries or by medical treatments such as radiation therapy and chemotherapy.

5 TAH - Total Abdominal Hysterectomy; LSO - Left Salpingo Oophorectomy, RSO - Right Salpingo Oophorectomy, BSO - Bilateral Salpingo Oophorectomy. The removal of an ovary together with a fallopian tube is called salpingo-oophorectomy or bilateral salpingo oophorectomy if both ovaries and tubes are removed.



Today, most women live long enough to become postmenopausal.

In the developed world, the percentage of women over 50 years of age has tripled in the last 100 years.

During this period, women's life expectancy in the United States has increased from 50 to 81.7 years, meaning that more than one-third of life will be lived in post menopause.

The ovary is almond shaped, pearly grey in color & the surface is slightly corrugated. Before puberty the ovaries are small. After menopause they atrophy & become shrunken. During reproductive years the hormones produced in ovary are estrogen, progesterone, inhibin, and in small amounts testosterone and androstenedione (can get converted to weak estrogen in the fat tissue). The increased stromal cells (connective tissue cells) of the menopausal ovary continue to produce androstenedione which gets converted to oestrone. Though weaker than estrogen (10 times less potent than regular estrogen) oestrone is capable of exerting estrogenic effect on the target tissues.

After menopause, estrogen production falls. Although estrogen is a female sex hormone, it has many functions other than reproductive function and one such function is to

protect from degenerative loss. Estrogen is the hormone that helps prevent calcium loss and bone breakdown in women. Just before or during menopause, estrogen levels decrease and insufficient amounts of estrogen may lead to bone loss. Hence, due to a drop in estrogen level in the immediate five years of menopause a woman may lose up to 15-25% of bone mass, leading to mild to moderate or severe osteoporosis<sup>6</sup>. When the natural onset of menopause comes earlier than expected or when it is caused by the surgical removal of ovaries (in case of TAH, medical knowledge about post-hysterectomy ovarian function is limited), a woman's estrogen protection is reduced for a longer period of time span compared to natural menopausal situations and possibly heralds an onset of early complications.

**MEDICAL PROCEDURES CARRIED OUT FOR THE HYSTERECTOMISED WOMEN**

**Table 6: Recommended procedures and actual medical procedures carried out for the hysterectomised women**

Recommended Procedures	Observation – what was done
Pap smear is a simple and basic screening procedure that helps in the early detection of cervical cancer	Pap smear was done for <u>two</u> women only. This was in MNR and AP Vaidya Vidhana Parishad in Sangareddy in Medak district.
After surgery, Histo-Pathological Examination (HPE) is a required follow up procedure to assess impending malignancy	HPE was done in <u>one</u> case only.
The men also require medical interventions and need to be followed up with antibiotics to prevent onset of pelvic infections	Antibiotics were not given to the sexual partners or an inadequate dosage was given.
Cyrocautery is a simple, painless outpatient procedure that helps in healing cervicitis	Not a single woman had cyrocautery.

<sup>6</sup> A systemic skeletal disease characterized by low bone mass and micro-architectural deterioration of bone tissue with a resultant increase in fragility and risk of fracture

The above table clearly establishes that no recommended procedures were taken up or were taken up in a very inadequate fashion.

**IDENTIFICATION OF WOMEN IN THE HIGH RISK CATEGORY AND FURTHER INTERVENTIONS:**

Hysterectomy impacts the production of estrogen which is an important player in maintaining the health of the women. To find out more about the high risk category of hysterectomised women (extent falling under this category), 160 of the 171 registered women with Life-HRG were subjected to initial clinical investigations which were done at the village level in the Urdu Primary School, Peddachelmada, Medak District. The blood investigations were a) Serum Follicular Stimulating Hormone (FSH)<sup>7</sup>, b) Hemoglobin Percentage and c) Blood Grouping and Typing.

*Life*-HRG used the FSH values to classify the women into high risk categories for follow up treatment. As the women are not menstruating and the time of the cycle cannot be determined given that the post-menopausal rise of FSH level continues for the rest of a woman's life, the women were tested thrice during the last one year at four-monthly intervals to determine the consistent rise of FSH and identify the women who showed consistently high values as the high risk group. They are termed as the high risk group as they have entered artificial, premature menopause. While the incidence of natural menopause is 1% in the under-40 age group, *Life*-HRG found that 41.25% of the hysterectomised women have had early menopause and fall in the "high risk category".

**Table 7 - FSH Values in women with early hysterectomy:**

Details	FSH values			Total
	> 40	10 – 40	< 10	
Total number of women (n=160)	66	14	80	160
Percentage	41%	9%	50%	
Number of women below 30years	21			
Number of women between 30-40 years	45			

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7 Follicle-stimulating hormone (FSH) is a hormone synthesized and secreted by the pituitary gland. FSH regulates the development, growth, pubertal maturation, and reproductive processes of the human body. In both males and females, FSH stimulates the maturation of germ cells. FSH levels are normally low during childhood and high after menopause. This high FSH level continues for the rest of a woman's life. The monthly events that take place in the ovary are cyclical during reproductive years. During 1<sup>st</sup> week of the cycle FSH value is raised to stimulate the maturation of germ cells (follicles) in the ovary. (Upper level is 10 best measured during 3<sup>rd</sup> or 4<sup>th</sup> day of cycle) Of the several follicles, one follicle grows faster than the rest and produces more FSH receptors & estrogen. The rising estrogen level causes -ve feedback to pituitary gland leading to fall in FSH level by 7<sup>th</sup> day of cycle. After menopause, as the ovary shrinks and estrogen levels fall, the blood level of FSH rises gradually in response to the falling estrogen levels. Elevated FSH level (40 iu/ml) can be measured by testing the blood.

## CONCLUSION

From the interviews with the 171 women registered with Life-HRG and further clinical investigations, the following facts emerge clearly:

- Most of the women were married as children (average age was 14 years) and the average age at first delivery was just 16 years. The complications and risks associated with these phenomena are apparent.
- Further, the average age at which hysterectomies were performed on 154 women for whom data was collected was 28.5 years. 60% of the sample had hysterectomies before the age of 30 years and for these women, the average age at which the surgery was performed was just 24.6 years.
- On a temporal scale, while the average age at hysterectomy for older women in the group was 37.7, for the younger women it is 24.6 years indicating that more and more, these surgeries are being performed on younger and younger women.
- An overwhelming majority (around 95%) of the women got the surgeries done in private hospitals.
- From the hospital documentation available with the women, it is clear that private hospitals only treated those who were "healthy" with no history of other symptoms, while those who were referred to government hospitals were those who had some hormonal or other symptoms. The surgeries done in government teaching institutions had clear indication and good post-operative notes. The indication is not clinically justifiable in the case of a district level government hospital while the discharge summary from private hospitals is mostly blank, with no information about procedure done or on follow up instructions. It is clear from the interviews and these documents that the surgeries performed were unindicated in these cases.
- It is apparent that a high percentage of women were subjected to ovaries removal (33% and in fact, this is 40% of the women for whom information is available on the exact nature of the surgery). Removal of the ovaries is the biological equivalent of castration and results in the immediate and sudden onset of menopause in contrast to natural menopause which is a gradual process.
- Such "surgical menopause" leads to sudden drops in estrogen levels without any transition. Although estrogen is a female sex hormone, it has many functions other than reproductive function and one such function is to protect from degenerative loss.
- It is also apparent from the findings that post-surgical medical procedures whether that of a pap smear or HPE were either not taken up or done in a minuscule number of cases. This is a clear reflection of the lack of follow up procedures.
- Further clinical investigations by Life-HRG (on FSH values, for instance) show that many early-hysterectomised women fall in the high risk category.

It is also clear that there is a lot of research still required to understand the impact of hysterectomy on the health of women. There is very little knowledge regarding the function of ovaries beyond their reproductive function. According to standard Gynecology and Obstetrics textbooks ovarian function lasts for only 5 years. But that is not firmly established. A possible explanation for altered ovarian function after hysterectomy is reduced ovarian blood supply caused by the surgery, but the existence of a direct endocrine function of the uterus cannot be excluded. Women undergoing hysterectomy without oophorectomy in their premenopausal years would expect to benefit from continued secretion of estrogens to protect them from the conditions and symptoms associated with the climacteric and postmenopause. Most studies done have looked at postmenopausal women in the above-40 age group. There are no studies that examine women in the under-40 age group. There is need for a long term prospective study to fully understand the implication of subtotal or total hysterectomy on the women, and the ovarian function. Given the incidence of many apparently unindicated hysterectomies in the women studied by Life-HRG, it becomes important to understand the various factors that led to the surgery decision and what role did the medical experts have to play in the decision-making and whether they adhered to at least the laid-down ethical guidelines.

## CHAPTER III

# **HYSTERECTOMY – SOCIAL FACTORS AND CONSEQUENCES**

### **INTRODUCTION**

Most of the available studies on hysterectomy focus on the medical aspects which are related to either 'procedure' or 'time' of the surgery and rarely give details about the situations leading to hysterectomy (Leonard EL and Kreutner AK, 1971; Haynes and Martin, 1979; Atrash et.al., 1982; Loizzi P. et.al.; 1990; Scott et. al., 1997). A few other studies are focused on utero-vaginal prolapse leading to hysterectomy (Datta and Datta, 1994). Studies related to social determinants of hysterectomy are not many.

In recent times, social researchers attempted to work on a few of the related aspects such as menstrual health and gynaecological ill health. Some studies have exposed that menstrual disorders constitute major reproductive health problems (Patel, 1994; George, 1994; Bhatia and Cleland, 1995) and excessive bleeding is considered as a serious illness. Often it is associated with blind belief (Patel, 1994) or as a consequence of a contraceptive usage (George, 1994). Some other studies also have focused on menstrual problems as a consequence of surgical contraception (Puryastha, Bhattacharyya, 1992). Women perceived regular menstruation itself as an inconvenience for daily activities. Once the desired family size is achieved they wish not to have these cycles. A study by Joshi (1998) revealed that some women viewed hysterectomy as a long-term solution to the 'pain' and 'dependency' during the days of monthly menstruation.

A few other studies have highlighted how women do not recognize and neglect to take treatment for reproductive tract infections (RTIs) because these are asymptomatic (Wasserheit et al., 1989). Poor women also get increased risk of RTIs because of unhygienic management of menstruation. Untreated lower tract infections are likely to progress to pelvic inflammatory diseases. The community-based research on women's gynaecological health in India by Rani Bang (1991) showed that ninety two percent suffered from one or more gynaecological problems. This study not only brought out the magnitude of the gynaecological morbidity but also focused on the neglect associated with these problems. Christopher Elias (1991) in a study revealed that women had specific complaints such as genital sores, vaginal discharge and pelvic pain and these were actually related to sexually transmitted diseases (STIs). It is evident from various studies that the stigma associated with STIs discourages women to attend STI clinics. Barely a third of the patients in STI clinics are women (Jeyasigh et al, 1985; Mathai et al, 1991). On the other hand the primary health care programme in India does not have adequate facilities to attend to all sorts of reproductive care.

In Andhra Pradesh, as is the case with most parts of the developing countries, there is a deficiency of data pertaining to Hysterectomy. Nevertheless, there is indirect evidence that is available on the percent of women who have attained menopause before completing the reproductive period of life. This data suggests the probable role of Hysterectomy as the cause for early onset of menopause. According to second National Family Health Survey, 31.4 percent of the women in the reproductive age group have already attained menopause in Andhra Pradesh (IIPS, 1998-99). A further analysis by their age reveals that amongst the women who have had early menopause within the reproductive age group, nearly one-third of them (31 percent) are in the age group of 30-34 years, followed by the women in 35-39 years (29.5 percent), 40-45 years (25.1 percent) and 46-49 years (14.0 years). The data also suggests higher percentage of women with early menopause is associated with relatively younger ages. In addition, observations by a few medical experts reveal that in Andhra Pradesh there are more and more women of younger age group i.e. less than 30 years who are undergoing Hysterectomy. All these collated information suggests the possibility of decrease in the age at Hysterectomy in Andhra Pradesh.

While on one hand we have sporadic information suggesting the rise of cases of Hysterectomy as well as decrease in the age at the surgery; on the other hand, a number of studies on utilization of health services indicate women are poor utilizers of healthcare. For instance, the two national surveys by NCAER

(1992) and the NSSO (1992, 1998) examined both women's and men's utilization of health services. These surveys have indicated that there is a gender difference in favour of men in utilization of health services for in-patient as well as out-patient care. Variations in utilization across age groups and within each sex have revealed a higher rate of utilization for males than for females, and there were also variations across various age groups of females. Female children (0-11 years) had a greater proportion of illness episodes treated as compared to girls and women above this age (Madhiwala et al 2000).

A vast majority of specific studies that had information on women's utilization of health services and dealt with reproductive health services have focused on maternal health, i.e. especially pregnancy and delivery care and family planning. The overwhelming evidence in this regard relates to women's non-utilization of health facilities and indicated that women distrusted medical care or were reluctant to be in-patients at hospital. Studies examining the association of various socio-economic factors with utilization of services find that women using services were economically better-off than those not (Khandekar et al. 1993), had more years of education themselves as well as were married to men with more years of education (Khan et al. 1997), were non-working women and did not belong to the Scheduled Castes (Khandekar et al. 1993). In terms of choice of provider for reproductive healthcare, a preference for traditional means of care is indicated by many studies. The low cost of services appears to be an important consideration (Sahachowdhury 1998; Gantra et al. 1998b).

Regarding women's health-seeking behaviour in rural India, especially with respect to reproductive ill health, most of the women in both rural and urban areas have preferred to tolerate their ill health. Still many believe in non-disclosing the situation to maintain one's 'self-respect'. Even if they have decided to seek a treatment, often they prefer self-treatment or have been approaching unqualified health personnel. Such perceptions and beliefs constitute a "lay-health culture" which would intervene between the presence of morbidity condition and its necessary treatment (Sugathan and others, 2001).

Therefore characteristics of health care delivery system may not be the complete explanatory factors of utilization of health services. Other factors such as the social structure and characteristics of individual are also the determining factors of the utilization of health services. In trying to understand the determinants of utilization of health services by women, Chatterjee (1990) hypothesized the role of **need, permission, ability and availability**. She reasoned that when permission and ability interact with need, a demand for health services is generated. Actual utilization of health services occurs when this generated demand overlaps with availability. Within the Indian context, she says, the situation is further complicated by women's perceptions of illness, which are affected by women's cultural conditioning to tolerate suffering. This tolerance further varies with type of ailment and by region, which in turn results in low perception of need for health services when the actual need is great.

To further understand the factors that led to hysterectomies, an interview schedule was administered through a household level survey in twelve villages of Municipally mandal of Medak district in Andhra Pradesh. This helped in listing the symptoms and evolving a correlation between bio-medical conditions and self-reported symptoms. Further, focused group discussions were organized with a few women who underwent hysterectomy and those who did not. In-depth interviews were also held with local healthcare providers, i.e., RMPs (Registered Medical Practitioners). Consent forms were used to obtain informed consent from the women who were interviewed.

The data collection was carried out in twelve villages of Municipally mandal (block) of Medak district in Andhra Pradesh. The villages were: Peddachelmada, Antharam, Melasangam, Tatipalli, Mansanpalli, Kamkollu, Mogdhampalli, Pillodi, Chupalli, Garlapalli, Makthakrasaram, Bellur, Mallikarjunapalli, Allipur. The total number of women interviewed was 265 out of which 132 women had hysterectomy.

**Sampling for the study:** It was decided that at least one-third of the 32 villages in Municipally mandal would be covered in the study through random sampling and the 12 villages listed above were selected in the process. To explore the socio-cultural and economic conditions in which the women are placed and processes that led to the hysterectomies, it was considered essential to study all the women who had

hysterectomy in the reproductive age group (15-45 years). The researchers came across 133 such women who had hysterectomy in the reproductive age from the selected 12 villages. Due to incomplete information of one such subject, her information was not considered for further analysis, thereby leading to findings related to 132 hysterectomised women.

It was considered essential to explore why certain women opt for hysterectomy and others not – it was felt that a case-control approach within the same socio-geographical setup was necessary to understand the healthcare-seeking behavior of women. With the use of random sampling method, an equal number of women (133) in the reproductive age group of 15-49 years, who did not undergo hysterectomy in these villages were therefore selected as a control group.

The following are the main findings from the field level primary data.

## PROFILE OF THE SAMPLE

At the time of study, the average age of the women who had hysterectomy in the study villages is 33.4 and of the women who did not have hysterectomy is 28.5 years (Table 8).

**Table 8: PROFILE of the Women (expressed in %age)**

<b>Background</b>	<b>Hysterectomy women</b>	<b>Non Hysterectomy</b>
<b>Mean age</b>	33.4	28.5
<b>Education Status (Number of years of formal schooling completed)</b>		
Non-literate	84.8	63.9
1-5	6.8	7.5
6-8	5.3	11.3
9-10	3.0	12.8
11+	0.0	4.5
<b>Caste</b>		
Scheduled Caste	22.0	22.6
Backward Caste	52.3	48.1
General Caste	24.2	27.8
Scheduled Tribe	1.5	1.5
<b>Occupation</b>		
Cultivation	18.9	15.0
Ag labour	62.9	48.9
Household worker	13.6	30.1
Others	4.5	6.0
<b>Wealth index</b>		
Lowest	28.8	29.3
Low	37.9	34.6
Middle	28.0	24.8
High	5.3	11.3
<b>Total</b>	<b>132</b>	<b>133</b>

The socio-economic profile of the women who had hysterectomy in the study villages reveals that a majority of them are non-literate. Yet between the groups, more non-hysterectomy women had formal years of schooling and a few also studied beyond 10<sup>th</sup> class. Nearly half of them belong to *Backward* castes, one-quarter of them fall under *Scheduled* castes and tribes in both groups which could be a reflection of the population in the area. More hysterectomy women (82 percent) work outside home in some income-generating activities than non-hysterectomy women (64 percent). When households are categorized by Wealth index, nearly two-thirds of the women in both the groups fall into either low or lowest groups of wealth index.

#### **WOMEN'S HEALTH PRIOR TO MARRIAGE AND HEALTH CARE SEEKING BEHAVIOUR**

Menarche or marriage is the gateway to participate in reproductive behaviour for all the women in the study villages. It is assumed that the conditions leading to hysterectomy may not be always due to a particular health problem but it might have manifested over a period of time. Therefore the present study looks at reproductive behaviour and related health status of women ever since menarche to hysterectomy.

The mean age at menarche for the women in the villages is 12.8 years. Once attaining puberty, a majority of the women (94.7 percent) from both groups had menstruation at regular intervals. 11 percent of them mentioned that they have experienced illness during menstruation such as nausea, severe abdominal pain, weakness, vomiting and legs ache prior to marriage. All of them perceived length and volume of menstruation as a natural process and none of them felt the need for a treatment and opined that one has to bear with it. Women by and large are ignorant about causes leading to menstruation-related health problems. Prior to marriage around 10 percent of women in both the groups suffered from white discharge and urinary infection. Unlike ill health during menstruation, women realised the need to seek treatment for these problems. Around 3 percent of the women went for a treatment. The others were not permitted by their parents to seek treatment because of the fear of lessening the chances of marriage if one would come to know of her ill-health. Those who sought treatment preferred quacks as against qualified medical personnel.

#### **MARRIAGE, SEXUAL RELATIONSHIP AND GYNAECOLOGICAL HEALTH**

In the study sample, the age at marriage on an average was 12 years. Barely 6 percent women got married after reaching legal age at marriage - 18 years. Around 20 percent of hysterectomy women and 12 percent of non-hysterectomy women were married off even before attaining menarche. The median time gap between marriage and consummation of marriage is less than a month.

85 percent of the women were ignorant about coitus until marriage. More than half of them initially found it repulsive because of ignorance or fear. Twenty five percent of the women took a couple of months to develop a favourable attitude towards it. During early months of marriage the couple had regular coital relations and husbands never approached other women for sex during this phase. However when women were not able to actively participate in coitus, either during pregnancy or after childbirth, some of their husbands (25 percent) had extra marital coitus with commercial workers or other women. Few of the women were aware of the fact that husbands' sexual practices may impair their gynaecological health. Yet women continued to participate in coitus to preserve the marital relationship. Most of these women are not worried about their health. A few have realized the need to use condoms in the interest of their gynaecological health, yet have not been able to convince their husbands.

About 4 percent of women have agreed that after marriage, they had experienced burning sensation in vagina, pain in pelvis or abdomen during coitus and developed urinary problems. Nearly half of these women have at least once attempted to seek treatment. A majority of them consulted unqualified health personnel such as rural medical practitioners or elderly women of the village. Rarely did they go to primary health center or a qualified doctor. These women opine that unqualified health providers are kind

in their approach and it is easy to contact them. The other half of the women who did not seek treatment felt that it would bring disgrace on them if they disclosed their illness.

### FERTILITY AND HYSTERECTOMY

Higher number of children, early or later ages of pregnancy and frequent pregnancies are likely to have an impact on the uterus, which in turn may necessitate hysterectomy. Findings reveal that mean number of children ever born per woman who had hysterectomy in the sampled villages is 4 and the corresponding number of children for woman who did not undergo hysterectomy is 2.5. The average gap between two successive pregnancies is lesser for women who had hysterectomy than non-hysterectomy women. An analysis by parity of women reveals that percentage of women going for hysterectomy increases with increasing parity; particularly till third parity. Around 7 percent of women with a single child had hysterectomy; 28 percent with 2 children; 39 percent with 3 children. The remaining 25 percent had 4 or more children. One woman had hysterectomy even though she never had a child of her own.

Sex composition of the surviving children at the time of hysterectomy reveals that a higher percent of the women with two or more children and with a combination of at least a son and a daughter had hysterectomy than those who had children of same sex; relatively fewer women with no sons, i.e. who have only daughters had hysterectomy than those who had at least one son. Around 12 percent of women had Hysterectomy instead of tubectomy (a surgical procedure to make a woman sterile). About 3 percent were advised to undergo hysterectomy as they had a cesarean section and 2 percent were advised for hysterectomy when they had a still-birth.

### HEALTH CONDITION PRIOR TO HYSTERECTOMY

Women were asked to narrate their health status prior to undergoing hysterectomy so as to assess their health condition leading to the surgery. They were asked to recall and narrate what were the initial problems that they had experienced and the data is presented in Table 9.

**Table 9: Health Problems experienced by Women Prior to Hysterectomy**

Health problems prior to Hysterectomy	Women (n=132)	
	Percent	Number
Heavy white discharge	65.9	87
Itching or burning due to vaginal discharge	22.7	30
Bad odor in vaginal area due to discharge	15.9	21
Pain in lower abdomen other than the pain during menstrual	51.5	68
Pain or burning sensation while urinating, or having more	67.4	89
Pain in lower abdomen or vagina during intercourse	20.5	27
Blood after having sex, at times when not menstruating	11.4	15
Prolapsed uterus noticed	12.9	17
Abnormal growth in lower abdomen noticed	16.7	22
Swelling of lower abdomen noticed	19.7	26
Fullness in lower abdomen	31.8	42
Difficulty with excess urination	25.8	34

Most of the women suffered from more than one health problem. Two thirds of the women suffered from white discharge and difficult urination. Half of the women also mentioned of a pain in lower abdomen that is usually not present during menstruation. Nearly one-third of them have noticed fullness of lower abdomen; one-quarter to one-fifth of them complained of difficulty with excess urination, itching or burning due to vaginal discharge, and pain in lower abdomen or vagina during intercourse. Less than twenty percent of women had problems such as any other discharge along with white discharge, noticed swelling of lower abdomen, noticed abnormal growth in lower abdomen, bad odour in vaginal area during discharge, noticed a prolapsed uterus and bleeding after having sex.

Some of the reported symptoms have been grouped to classify them into bio-medically-defined morbidities.

- Prolapse - feeling of something (a mass or swelling) coming from the vagina, or leakage of urine when coughing or sneezing
- Urinary tract infection (UTI), abnormal frequency of urination, with burning sensation while passing urine
- Dyspareunia – pain during intercourse
- Lower reproductive tract infection (LRTI) – white or coloured discharge from the vagina with bad odour, itching or irritation;
- Acute pelvic inflammatory disease (APID) – lower abdominal pain or vaginal discharge with fever;
- Abnormal (dysfunctional) uterine bleeding (DUB) – irregular and unpredictable bleeding, lengthy or heavy menstrual periods;
- Uterine fibroids, as diagnosed by a doctor.

**Table 10: Morbidities prior to Hysterectomy by Bio-medical Categorization**

Biomedical categorization of morbidities	Women suffered	
	Number	Percent
Lower reproductive tract infection	87	65.9
Acute Pelvic Inflammatory Disease	71	53.8
Urinary Tract Infection	57	43.2
Uterine Fibroids	50	37.8
Dyspareunia	27	20.4
Prolapse	17	12.9
Dysfunctional uterine bleeding	15	11.4
<b>Total women</b>	<b>132</b>	<b>100</b>

The bio-medical categorization of morbidities reveals that more than two-thirds of the women were suffering from lower reproductive tract infection (Table 10). More than half of the women were suffering from acute pelvic inflammatory disease; about 43 percent of them suffered from urinary tract infection, 38 percent of the women had growth of uterine fibroids. One fifth of the women suffered from dyspareunia; around 12 percent each experienced prolapse and dysfunctional uterine bleeding.

## HEALTH CARE SEEKING BEHAVIOUR RELATED TO HYSTERECTOMY

Apart from understanding the health status of women prior to hysterectomy, information related to treatment is essential as it helps to identify the processes leading to the surgery. Decisions related to surgery are generally influenced by the advice of the healthcare provider with whom the morbid person interacts. Thus an analysis of details of treatment pattern of the women is carried out in the present study.

Women who realized their health problem were not initially comfortable to go to a doctor because most of these problems are related to *'personal health'*. The following comment reflects their typical attitude towards reproductive health.

*"How can we tell in the family the problem with which we are faced? Isn't it a shame to disclose these matters to others? It is better to bear it as far as possible rather than making ourselves shameless".*

When the problem becomes annoying, then they consult a doctor. Additional probing revealed that "going to a doctor" means going to "Rural Medical Practitioners" (RMP). All the RMPs in the study villages are unqualified medical practitioners. The RMPs in the villages have acquired some skills while assisting a doctor and later started treating people by themselves. Women preferred them because of various reasons. One usual comment related to this is:

*"Usually women are bound to have certain 'women's problems'. We tend to share about the same to our friends/ neighbours. We consult the same person as the other women are doing".*

In addition, the local RMP is easily accessible. In most of the villages a RMP is either a village member or from a neighbouring village. Even if an RMP is not a resident of the village, as he regularly visits the village, women find it convenient to go to him rather than traveling to a distance to reach a health facility.

In general, women are reluctant to visit the PHCs, as most felt that the concerned doctor did not visit the center regularly. Thus they either meet a paramedical person or return home without having a check-up. A few women also mentioned that the paramedical staff uses offensive language when women approach them with gynaecological problems. In contrast, the RMP appears to have better knowledge, skills and attitude than the government paramedical staff. Most importantly, the RMP is much more sensitive to them than the paramedical staff. The RMPs in turn, with or without initial treatment, refer the women to a qualified private practitioner. Only a few have consulted a public paramedical health personnel or a doctor at a primary health center for the illness.

On the contrary those women that did not undergo hysterectomy opine differently. They have primarily emphasized on hygiene and healthy eating habits for maintenance of women's health. Some of the relevant comments related to it are:

*"Women need to maintain hygiene, particularly during menstruation. The usual practice during menstruation is to use a cloth, which is reused after a wash. Even though women use detergents they wash the soiled cloth at night and dry them either on bushes or in dark corner of the house. This practice causes illnesses"*

*"One needs to eat fresh and warm food. The food habits have changed when compared to our previous generation. The food that we eat now has no nutrition as it is produced with lots of inorganic manure and pesticides. Hence we need to choose good food, eat at regular intervals and eat freshly cooked food. This keeps every one healthy"*

They are critical about the choosing of a healthcare provider. They opine that for minor ailments like cold, cough or fever the available RMP is acceptable. However for white discharge, they feel that one should

either go to a Government Area Hospital situated in the block headquarters or go in for alternative medicine. Some of the women in the FGDs have expressed faith in non-allopathic system of medicine and suggested an ayurvedic doctor in the block headquarters who had been administering alternative treatment that has been effective for many women.

#### **DECIDING FACTORS FOR HYSTERECTOMY**

Even though 54.6 percent of the couples mentioned that they have taken a combined decision to go in for a hysterectomy, it appears that they are actually led by the opinion of the social set-up in which they are placed. Often it is the first person on contact i.e. RMP, the medical practitioner whom they have approached and a friend/neighbour who had a hysterectomy.

In the study villages, 78.8 percent of the women consulted a doctor for their ill health. The doctor/surgeon whom the women contacted did not discuss with/explain to the women about their health condition. In 13.7 percent of cases, the qualified private medical practitioner insisted that the woman go in for an immediate surgery. In 65.1 percent of cases, the doctor emphasized that hysterectomy is the solution to their ill health. The health personnel often convinced the women that they are making the right decision for the improvement of their health by opting for the surgery. The remaining women (21.2 percent) were themselves convinced in favour of a surgery and hence, did not go to a doctor for an advice. These women were totally influenced by the local RMP and/or a friend/neighbor. The study also reveals that the women too do not expect the doctor to explain their situation nor felt the need to know about the causative factors.

Around one-third of the women (30.7 percent) did not seek any treatment, rather had the surgery directly. The other women (69.3 percent) took treatment some period prior to the surgery; majority (57.7 percent) took treatment from a private doctor. A few (6.8 percent) preferred to go to public health institutions. Some took treatment from RMP (4.8 percent). Of these 68.3 percent of women some tried more than one source of treatment. Nearly one-quarter of the women (26 percent) have prolonged the treatment for a longer period with the hope that surgery could be averted. Ultimately the women were convinced that hysterectomy is the only bring a solution to their ill health. None of the women have made an attempt to know alternate methods of treatment.

<b>Particulars related to Health prior to hysterectomy and after surgery</b>	<b>Percent of Women</b>
Consulted any healthcare provider for the health problems experienced by the woman prior to Hysterectomy	78.8
Whom did the women consult first for health complications	
▪ PHC Doctor	10.6
▪ Private Doctor	24.8
▪ RMP	64.6
Did the Health care provider explain the reasons for illness	
▪ No	100
What did the health care provider advice	
▪ Threat to life if Hysterectomy is not performed	13.7
▪ All health problems will subside by Hysterectomy	65.1
Took treatment prior to Hysterectomy	
▪ Yes	68.3
▪ No	31.7

Whom did the women approach for treatment	
<u>First time</u>	
▪ PHC Doctor/ Govt. hospital	6.8
▪ Private Doctor	57.7
▪ RMP	4.8
<u>Second time</u>	
▪ PHC Doctor/ Govt. hospital	1.0
▪ Private Doctor	23.1
▪ RMP	1.9
Persons who motivated the women to go in for Hysterectomy	
▪ Husband	26.5
▪ Self	10.3
▪ Both	60.6
▪ Mother/ Mother-in-law	06.1
▪ Government Doctor	02.4
▪ Private Doctor	65.3
▪ RMP	83.8
Prior to Surgery did the health care provider brief the women about benefits/consequences of surgery?	
▪ Yes	54.5
▪ No	45.5
What did the health care provider brief you about benefits/consequences of surgery	
▪ If surgery not performed immediately it would be threat to life	13.7
▪ Would be cured from health problems after Hysterectomy	40.8

In a setting where utilization of health services by women is dependent on **need, permission, ability and availability** (in the present situation, the cognizance of **need** is accompanied by **availability** of services while **permission** to seek care is driven by a network of **availability** and **motivational** factors), the exogenous **motivational** factors dominated the **ability**. Here, the motivation in favour of surgery is from the network of health service providers - Private Doctor (65.3 percent) and RMP (83.8 percent).

One of the pre requisites prior to a surgery is to inform the patient and her family members about the need and benefits of the surgery and the likely health consequences associated with it. In the present study population for nearly 46 percent of women no such discussion or briefing was given to the women or her family members prior to the surgery. For the women (55 percent) who have admitted to having had a briefing, it was mainly a reiteration that the surgery would solve all the persisting health problems (40.8 percent) and a sort of assurance given that the surgery would save the woman's life (13.7 percent).

## THE FINANCIAL IMPLICATIONS

Despite a total conviction that surgery would bring miraculous change in their health status, 61 percent of women preferred to undergo medication for few months prior to the surgery, as they were not financially equipped for an immediate surgery. The average annual income of the families engaged in labour is Rs. 12000/-. Hence most of the families had to find alternate financial sources, where they often end up taking a loan from village money-lenders. This in turn puts them into a debt trap on an average for a period of 5 to 10 years. Hence some of the families prefer to go for a non-surgical treatment for some

period. Even this treatment is no less expensive given their financial position. The median amount of money spent by women towards treatment prior to the surgery is around Rs.3000/-.

A majority of these women had hysterectomy at a private hospital (84.8 percent). However, comparatively speaking, women with higher age and parity and those who belong to scheduled and backward castes opted for a government hospital. In a majority of the cases where women had hysterectomy at a private hospital, though the woman's husband/head of the household decided the hospital, it was actually influenced by non-family members. A few women opted for a particular hospital after being referred to them by their neighbour/friend who in turn had such a surgery. In a majority of cases, the healthcare provider whom women had first contacted had a greater influence on selection of the hospital. Since many of these women have consulted a RMP, they preferred the hospital referred by him. Women and her family members believe that the personal relationship between the RMP and the doctor will ensure better care for them. Similarly RMPs believe that they are doing a favour to women by referring them to a familiar hospital. Though the RMPs did admit that they are paid an honorarium for referring a patient to a hospital, they insist that their referral is well intentioned. The average cost incurred for the surgery is Rs. 20,220/- in the study sample.

### POST-OPERATION EXPERIENCE

Subsequent to the hysterectomy, women stayed in the hospital for 11 days on an average. Around 23 percent of the women stated that along with hysterectomy, ovaries were also removed. Other women were ignorant about it.

Any surgery carried out on a person is to improve her health from the prior morbid state. Fifty three percent of women agreed that there is a relief from prior health problems. Even though many have agreed that their prior health problems have been addressed after the surgery, almost 47 percent of them have admitted that they are suffering from other complications. Further, 25% percent of the women are still suffering from abdominal pain, the problem that the surgery is supposed to have addressed. 5 percent of women are suffering from gynaecological problems such as white discharge and coloured discharge. Fifteen percent reported that they are suffering from non-gynecological problems such as weakness, body ache, backache, stomachache, indigestion etc. Given their present health status, nearly 40 percent of the women categorically stated that they would never advise any other woman to go for hysterectomy.

### DISCUSSION AND SUMMARY

To understand the conditions leading to hysterectomy, it is necessary to analyse from a bio-medical point of view. Medically speaking, the specified morbidities as per primary data gathered do not suggest a need for hysterectomy as the necessary solution for all women.

At the Patient's level: Medically, there is no correlation between fertility and hysterectomy and unlike sterilization hysterectomy is not a surgery by choice. However, examining the association between hysterectomy vis-à-vis the sex composition of the living children, the findings raise suspicion on the decision leading to the surgery. Perceptions of men and women as disclosed during focus group discussions revealed that a majority of women as well as men and the local RMPs opine that the role of reproductive organ diminishes once the desired fertility is attained. Most of these women and men also confess that there is no necessity to retain the reproductive organ if desired number and sex of children are born. Some of the women do not differentiate between tubectomy and hysterectomy.

The statistical findings have shown that there is a strong association between *women's attitude to oblige husbands' sexual desires* and various morbidities. Medically speaking once again, there is no association between women's obliging attitude and hysterectomy. The likely possibility is that the gendered conditioning of a 'perfect wife' plays a role in her coitus freedom/behaviour and this is likely to lead to certain infections. If it is not treated in a timely fashion, it may further lead to 'acute pelvic inflammatory disease' or 'dyspareunia' and 'urinary tract infections'.

In addition, low bargaining position to protect their own sexual health by some of the women when they are very much aware that their husbands have more than one sexual partner has a bearing on their gynaecological ill-health. Fear of violence and divorce weakened these women's bargaining position. In the presence of illness, women also viewed hysterectomy could be a solution to maintain better marital relationship with husbands by gaining the ability to participate in coitus. Women anticipated that 'obliging' the husband's sexual desires may decrease violence between the couple, which in turn may improve husband-wife relations. Men on the other hand are insensitive towards women's health. They opine that women are susceptible to ill health of one kind or the other, thus it is better to opt for 'permanent' solution.

The statistical findings have revealed that literacy levels have shown a significant negative association to 'Acute inflammatory diseases'. In other words more illiterate women suffered from gynaecological ill-health than literate women in the villages. Findings of focus group discussions revealed that illiterate women follow poor menstrual hygiene compared to the literates, which in turn may lead to lower reproductive tract infection. Untreated lower reproductive tract infection may lead to acute pelvic inflammatory infection.

Studies have shown that utilization of health services is affected by multitude of factors including availability, distance, cost and quality of services, socioeconomic factors and personal health beliefs. In the context of women, Chatterjee (1990) posited the role of need, permission, ability and availability. In the Indian context, the situation is further complicated by women's perception of illness, which is affected by women's cultural conditioning to tolerate suffering. In the present study as well, women did not disclose and seek timely care during initial stages of gynaecological ill health. Low perceptions for the need for treatment and women's gendered conditioning to tolerate suffering, whether it be of urinary infection or reproductive tract infection, has delayed in seeking timely care, which in turn might have amplified the gynaecological illness. Prior to marriage women were required to take permission from their parents to seek care. Some of the parents did not like to acknowledge the existing reproductive health disorders of a daughter prior to marriage, as it might have an adverse effect on the prospects of her marriage. This is especially in a society where marriage is considered important and having an unmarried daughter after certain age brings disrespect to parents, especially the fathers. With already existing social pressures of dowry, fathers prefer to marry off their daughters with out an acknowledgement of any ill health. After marriage women themselves delayed in seeking treatment as perceived need was low.

At the healthcare facility and with the RMPs: Even when women had come forward to utilize reproductive health services at a public health center, non-availability of a lady doctor, gender-insensitive approach of health staff towards patient's privacy and rude behaviour of health staff has de-motivated women to seek health care from the public health centers. Women assessed quality of care largely in terms of behaviour of health personnel rather than the actual treatment. This is particularly if they are suffering from reproductive health problems. Thus the women preferred to consult some one 'humane' and easier to access rather than for the health provider's qualification. Consequently the first person that women approached for a treatment was RMP. On the other hand a majority of the RMPs seem to be insensitive towards women's health in a real sense.

Again the 'interest' taken by RMPs in suggesting a surgeon/hospital needs to be understood with prudence. Though the RMPs have mentioned that they are helping the women by referring to an efficient surgeon/hospital, the justification of RMPs vis-à-vis the remuneration they receive for referring each case needs a detailed analysis in this aspect. However such an analysis cannot be carried out for the present study for want of more data.

At the private hospitals: The study reveals that a majority of women had the surgery at private hospitals. The findings show that the private practitioners insisted upon and emphasized the need for a surgery. Again the surgeons and other healthcare providers are not interested in briefing either the patients or the family members about the consequences of the surgery or look at alternatives. It reflects the careless attitude of the healthcare providers.

While the women and their families go with a pre-conceived conviction about hysterectomies, the reiteration of the surgeon with or without prior diagnostic tests raised no doubts among the women regarding the need for surgery. It is also apparent that the patients were not told about the exact nature of treatment – for instance, that ovaries were also being removed.

Analysis also reveals that no follow up procedures were adopted. The costs incurred by poor families in these unindicated hysterectomies are also the earnings of the private practitioner.

## CHAPTER IV

# **HYSTERECTOMY – ETHICAL CONSIDERATIONS**

### **INTRODUCTION**

The health care system is rapidly changing in India today. The speedy penetration of market-based approaches and the establishment of neo-liberal mindset as the dominant framework in policy-making resulted in unprecedented waves of privatization of the Indian economy from the early 1990s.

There is a rapid and unregulated development of corporate hospitals combined with the progressive decline of public hospitals. Moreover, the poor implementation and the absence of correlative reform of the regulatory frames left the sector without much control over the practitioner and the medical practice itself. Scandals of corruption, sanitary crisis and human rights violation frequently break out in national newspapers.

Increasingly discredited and distrusted by the Indian society, the medical community is facing a costly crisis of authority, which in exceptional instances even led to practitioners' murder by their own dissatisfied patients. The medical community struggles to address the harsh public criticism of the exploding cases of ethical misconduct riddling medical practice in India and in fact, remains rather apathetic. Indeed, while neither the central nor the state government promoted regulation of healthcare, the medical community which has its own regulatory bodies, timidly hit back. The Medical Council of India, the highest authority in charge of promulgating and implementing/enforcing legal and ethical guidelines, issued a new code of ethical regulation in 2002, as a revision of the earlier one, formulated 40 years ago.

The credibility of the new guidelines is however compromised by the successive scandals of corruptions that involved some of the members of MCI. Extensively debated by Indian media at large, it appears to be also critiqued by a section of the medical community itself. The MCI understanding, conception and articulation of ethical guidelines and the practitioner's responsibility toward patients as well as to society at large have been intensively questioned for the last 10 years. Doctors seem to distance themselves from the narrow, vague and somehow obsolete ethical framework established by medical councils. It appears that the physician's community is engaged in a dissenting re-conceptualization and re-actualization from below of the nature, aim and thrust of medical ethics. They question the doctor's medical responsibility as being too narrow and rather voice the need for a broader socially-concerned "responsibilization". Clearly, this differentiation has progressively set apart the medical community and its representative and regulatory bodies, leaving two sets of medical ethics and social responsibility, one unofficial competing for mainstreaming and improving the existing (official) one/framework. Thus understanding the ethics, or rather the lack of ethics, in the medical practice in rural areas should encompass the formal as well as the informal, yet seemingly pervasive, ethical guidelines operating side by side within the healthcare system in India. Along with the analysis of the existing official guidelines, the understanding of the ongoing processes of re-conceptualization of medical ethics will thus, allow to generate a more intricate contextual understanding of the ethical soundness of the set of discourse and practices surrounding hysterectomy as a recurrent practice in Medak to treat basic gynecological problems.

In the West, the medical community has been engaged in the slow and difficult exercise of self-reflection for the last 20 to 30 years. The profusion of public scandals of mistreatment of patient, harmful and cruel medical procedure, torture (especially in geriatrics and psychiatry) throughout the 1960s and 1970s discredited the medical profession. The social discontent led to internal discussion about the working of a system which was erected as a model for human welfare through the post-WWII era. Indeed, the knowledge frontier was constantly outperformed by massive breakthroughs in biomedical science and the generalization of groundbreaking therapies.

In the 1980s the internal debates took a heated turn with the members of the medical profession themselves publishing alarming accounts/research depicting the dehumanizing face of the medical practice. "*The Silent World of Doctor and Patient*", written by a Yale doctor and ethicist Jay Katz came out in 1984 severely criticizing the traditional pattern of medical decision making. Following this, new avenues for reflections on medical practice opened up – reflections on the nature of the medical practice, the doctor's figure and authority. This led to a process of reconstruction of medical discourse, practices and institutions as well as public self representation. Ethical obligations are also revisited and reformulated in this process.

In line with these western trends, doctors in India too engaged in similar introspection. Internal debates have emerged in the last decade about questions regarding the relationship between medicine and society, doctor's purpose, the nature of the medical practice, the knowledge ground on which the latter is constructed, the relationship with the patient and the patient himself/herself. Interestingly, practice and ethics tend to be interwoven and interdependently understood. The medical practice turns out to favor ethical practice and allow the doctor to sort out otherwise inextricable ethical dilemmas.

Alongside the attempt to endorse ethically sound, non violent practices within the discipline (of modern medicine), attempts are also made to explore alternative ethical and medical systems. Though relatively limited, this intellectual exercise is nonetheless significant and bears signs of promising developments in the recent past. Such an exercise has resulted in mainstreaming alternative systems such as Ayurveda in the Indian medical scenario, with some physicians adopting a multidisciplinary approach to medicine.

#### **ETHICAL OBLIGATION AND SOCIAL RESPONSIBILITY**

Ethical systems are normative systems establishing the do's and don'ts of a professional practice. As W. F. May puts it "ethics supplies a type of lens. Ethics supplies a type of corrective lens. Ethics relies heavily on the distinction between what is and what ought to be". Not neutral, unlike what was until recently commonly believed by practitioners and lay people, modern medical ethics, as much as the medical practice, is historically and socially shaped by specific cultural and social arrangements. It reflects certain perceptions and conceptions of the world. As a mode of understanding, modern medicine became naturalized by its very actors and institutions and thus established as the only "scientific" truth about health and only tool for human welfare. As for other by-products of western modernity (i.e. Science and Technology and the sub-disciplines therein), the conventional medical ethical framework reflects an unconditional commitment to progress through exact, rational understanding, expertise and domination of nature.

The Hippocratic oath continues to be the pillar of medical ethics; it structured and still structures ethics, albeit less significantly as it has been substituted or complemented by new ethical guidelines. It establishes the supremacy of the doctor. However, the ubiquity of the doctor and the silence of the patient, as we have seen, turned to be problematic. It provoked in the West as well as in the non-West new reflections about the nature of the ethical obligation of the medical professional. It is a process that as we will see in the case of India, elicited the recognition of the patient as an active participant in the medical encounter. And, with new challenges and new dilemmas (sex selection, HIV/AIDS treatment), the need for a new framework of ethics became imperative.

#### **ETHICAL STANDARDS**

The Medical Council of India/ICMR issued new ethical guidelines in 2002 to replace the former framework established as far as 40 years back. Elaborated by the MCI, it prevails throughout India and structures the practice of all medical personnel involved in healthcare. As regulating the practice, the code defines the doctors' dos and don'ts.

The code reasserts the specific commitment of the practitioner to "render service to humanity" unconditionally to which personal gain is a subordinate consideration. The physician can refuse to treat patients; however s/he has the obligation to attend cases of emergency. The respect for life and the

dedication to the patient's beneficence is thus one of the central ethical obligations of the doctors towards the patient and society.

The code also intends to reflect upon new concerns. Ethical issues, for instance, related to sex determination tests and the practice of referral received particular attention from the MCI in this new code. Some highlights:

- Following a decade-long public scandal, the MCI through Section 7.6 officially denounces the unethical misuse of pre-natal technologies. "On no account shall sex determination tests be undertaken with the intent to terminate the life of a female foetus developing in her mother's womb [...]".
- The same is noticeable regarding the regulation of referral: referring patient to other doctors or from generalist to a specialist as well as advising a colleague for second opinion have been since the 1990s sites of malpractice and corruption ('referral commissions', 'cut'). The code intends to regulate this medically valuable practice by elaborating traceability mechanisms (systematic medical records; referral notes) thus delineating the practitioner's responsibility.
- In the same vein, some dimensions of the code testify to a certain mainstreaming of the comprehensive, holistic and patient-centred perspective on medicine intensively discussed and theorized by the community of authors. Thus, for instance, the patient emerged as an actor of medical decision-making having *rights such as medical decision (consent) or being provided with complete, honest and graspable information*. The section on human rights/torture, though limited, is also an acknowledgement of the profession's entrenchment in the social world and the societal thrust of its practice.

However, the code of ethics' regulation remains firmly grounded in a conventional perspective on medicine where the patient remains a passive recipient, as we can see when it comes to the issue of consent. Patient consent is acknowledged as a crucial issue of the medical practice with the obligation to obtain a written consent (section 7.18 + section 7.218). However it is rather limited, vague and seemingly easy to overrule. The code of ethics regulation states that the Patient's Consent (and correlative right to confidentiality) can be overridden by the "laws of the State" as a "duty to society" in cases of severe health/sanitary threat to the population. Moreover, the patient's 'privacy' is ill-defined and allows the doctor to systematically dismiss it as the code also states: "the doctor should ensure himself that the patient, his relatives or his responsible friends have such knowledge of the patient's condition as will serve the best interests of the patient and the family".

In this way, the code of ethics perpetuate an intrusive and invasive attitude of the medical experts, negating the patient's intimacy and reestablishes the patient as passive and silent in the medical process by negating her/his right to decide and to confidentiality.

#### **ETHICAL STANDARD – INFORMED CONSENT**

The ICMR guidelines acknowledge the patient's consent as a necessary prerequisite to the medical process. However, consent is not systematically required as it is formulated in the case of redesign of

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8            Though with the existing formulation, the achievement of the written consent is misleading and may ultimately allow the practitioner to override the patient's opinion: ""to obtain in writing the consent from the husband or wife, parent or guardian in the case of minor... + other condition and process" (7.21: no in fertilization, in vitro, insemination shall be undertaken without informed consent.).

treatment. Defined as a contract, consent is defined as the patient's written agreement with the terms of the medical process displayed by the physicians. Though innovative, as it acknowledges the patient's voice in the medical process, the way consent is conceptualized in the ICMR guidelines still entails a conventional top-down understanding of the doctor-patient relationship.

Consent is "not a 'one-off' event of signatures on paper" and not a submission of the patient to a particular treatment but rather a process of communication. Consent is not reachable *per se* and requires as a pre-requisite the construction of the patient competence, that is, her/his capacity to decide. The consent is then perceived as a proactive process empowering the patient to consciously decide on what s/he considers best. Thus, consent is "a process of communication requiring the fulfillment of certain established elements like competence, sufficient disclosure, understanding and volunteering".

Adopting a holistic, patient-centered approach on medical processes, authors in the Indian Journal of Medical Ethics (IJME) have revisited what constitutes an ethically acceptable consent. IJME conceptualizes consent as a process, a dialogue, as requiring translation, with definite terms and constructing autonomy.

- Consent is seen as process of communication.
- Consent means a two way dialogue between doctor and patient as often as needed and whenever possible, a respectful exchange of views and it must rest on a respectful and compassionate relationship with a fellow human being.
- Translation in consent means a process of communication requiring the fulfillment of certain established elements like competence, sufficient disclosure, understanding and volunteering
- The terms of consent refer to extending the domains explored in the construction of informed consent – financial resources, family dynamics etc. There is the need to display full information to the patient.

#### **OBSERVANCE OF ETHICS IN THE CASE OF UNINDICATED HYSTERECTOMY**

If we recall the data presented in chapters 2 and 3, we can see quite clearly that there has been little adherence to the ethical standards laid out above. The following facts bear this out.

- A significant percentage of women had been referred to the private hospitals by the RMPs who received a "honorarium" as payment for their referral services
- A significant percentage of women said that there had been limited dialogue regarding their illness and different options were not offered to them
- A significant percentage of women had hysterectomies done with no proper procedures and protocols
- A significant percentage of women had no written case histories which is required in the case of follow up
- There appears to be blatant commercialization of medicine in the case of hysterectomy given the amount that is required to be spent on the surgery and post operative care
- There was little consideration to the terms of consent given that the majority of women were from the lower income group and illiterate – there was no attempt to probe into the financial situation and make it easier. In fact the patients had to incur debts in order to meet the surgery expenses
- There appears to have been little consideration given to the beneficence factor, as clinical investigations of the hysterectomised women show a negative impact on their health.

However, that humane practice of medicine is possible is evident in the practice of Dr Kameshwari of *Life-HRG* who approaches patients holistically and redefines the practitioner-patient relationship. As the next chapter would show, *Life-HRG's* work takes into account the social, economic, and health conditions of the woman before prescribing appropriate treatment.

## CHAPTER V

### **Ethical Practice in Life-HRG**

*Life-Health Reinforcement Group (HRG)* is a Non-Governmental Organization established in the year 1999 by a group of social scientists and medical doctors. Since inception, the organization has been striving to address issues around inaccessibility to basic amenities such as food & health and how this can be realized as a right. Through its urban and rural clinics and participation in disaster relief work, the organization has gained valuable learnings and experiences. Social & medical experiments lead to grounding an approach which looks at food as medicine, as a viable alternative for enhancing health of all citizens.

The work of Life-HRG, even as it provides a contrast to the violence of medical practice freed of any ethical control mechanisms as the many cases of hysterectomy studied in this case study have illustrated, showcases the interface of indigenous medical knowledge system with modern medical knowledge as an alternative approach to promote non-violent medical solutions to the gynecology problems faced by women in rural areas.

It also shows that alternatives can be endorsed with the frame of modern medicine by practitioners by:

- Re-establishing a "humane practice";
- Reconstructing ethical standards and implementing efficient mechanisms and frameworks;
- Re-conceptualizing the medical practice, understanding of health, disease and illness, medical authority and responsibility of the practitioner and the relationship between medicine and society.

In the case of Life-HRG, the creation of an interface between modern medical expertise and indigenous medical knowledge(s) is enabled by a prior or correlative critical stand towards modern medicine. For instance, Dr. Prakash's and Dr. Kameswari's interest in food as medicine and indigenous knowledge about nutrition is correlative to a prior conscious dissociation from mainstream modern medicine, that is, the ruling worldviews, understanding, authority construction and practice. Indeed both are, for more than 10 years now, in a position of defiance against the institutionalized discourse of modern medicine and the corresponding dominant social arrangement in India. Both expressed and constructed a deep distrust in the institutions of medicine (from fellow practitioners to medical journals) leading them to shape a practice rather autonomous from the healthcare system (e.g. distrust in Indian medical journals, little if no affiliation to medical centers/associations, freelance surgical practice, (almost) complete independence of practice within Life-HRG (the latter being progressively constituted as an alternative medical space for ethical conduct and medical experiments).

Simultaneously, Dr. Kameswari is particularly critical of the core of her expertise (obstetrics and gynecology) aware of its limitations and the potential harm it can do to people. Kameswari's uncertainty about the acquired expertise in obstetrics and awareness of the vulnerability/fallibility of her practice seemed to be the major incentive to open up her western medical practitioner's mind to indigenous knowledge.

Dr Kameswari's personal critical engagement with modern obstetric knowledge, questioning its universality, infallible veracity and capacity to bring good to people is a pre-requisite to the exploration and internalization of indigenous knowledge practice (this is apparent in her internalization of looking at the 'system as a whole'; that is, not only using food as medicine but fostering the rehabilitation of beneficent and yet defeated sustainable agricultural practices). She is also careful to avoid idealization of the past in the process. Thus, understanding Kameswari's exploration of alternative health/food knowledge system as an alternative to hysterectomy cannot be fully understood if the correlative process of re-conceptualization of 'medicine as a whole' is not addressed.

The earlier chapters dealt with the incidence of unindicated hysterectomies in one block of Medak district in Andhra Pradesh and explored the social factors and the clinical practice around this phenomenon. Dr Kameshwari's approach differs radically from those practitioners described in Chapters 2 and 3.

As has been seen in those chapters, some common symptoms for which women seek medical help and are routinely advised hysterectomy are:

- Pain in the abdomen and white discharge
- Spotting/irregular menstruation/heavy flow
- Genital prolapse
- Uterine fibroids

Dr Kameshwari has dealt with each of the above complaints and obtained positive results through non-surgical treatment. A few such cases – how they were dealt with and the results – are presented below, to establish that an alternative, non-violent and ethical approach is indeed possible.

#### **A. Pain in the abdomen and white discharge:**

Patient - 30 year old woman belonging to the lower income group.

Symptoms – Tenderness in the lower abdomen, white discharge with foul smell, backache, abdominal pain aggravated during period. These are typical features of Pelvic Inflammatory Disease which in this particular patient's case was a result of malnourishment, poor hygiene, early coitus and STD.

Treatment – 14 days antibiotics for both wife and husband (doxycylin, metronidazole with an antacid). In addition a pap smear was done and cryocautery for cervical erosion. In addition to these medical procedures, counselling was given to husband and wife regarding the need for abstinence and personal hygiene. The patient was also advised to take iron calcium supplement. The patient was also told that there is likely to be white discharge due to the cryocautery but this is different from pathological discharge. The total cost of the treatment was Rs 600 and the patient is not likely to require any intervention for the next 3 -5 years, as experience with several other women shows.

The socioeconomic status of the patient is important as in the case of those in the higher socioeconomic group, with better education, personal hygiene and resources, the likelihood of recurrence of the illness is minimal.

#### **B. Spotting/irregular menstruation/red discharge/heavy flow:**

##### Case 1:

Patient: 28 year old urban woman with 2 children.

Complaint: Irregular periods over the last 5 years and at present, heavy periods with clots. Monthly menstrual periods lasted for 28 days. As a result, the woman is severely anemic. Other doctors had suggested hysterectomy and blood transfusion.

Treatment: Followed protocols. Ultrasound of abdomen and uterus. This showed endometrial thickness of 17mm and the ovaries as polycystic. Next, the smallest possible disposable suction canulas were used to do outpatient biopsy for endometrial sample to rule out endometrial cancers which can occur very early in polycystic ovarian syndrome. The histology exam report showed simple hyperplasia. Since the patient showed all markers of insulin resistance, medication was finalized in consultation with the endocrinologist. Diabetic medicine (pioglitazone – 15mg) and progesterone was prescribed to control the

bleeding. Given the severe anemia – iron supplements were prescribed both in tablet form and in the diet.

Response: The treatment began in December 2009 and the February 2010 menstrual cycle shows a return to normalcy. The patient is under observation for the next 9 months.

#### Case 2:

Patient – 48 year old urban woman.

Complaint – Severe bleeding, anemic. She had already had a blood transfusion and D&C prior to consulting Dr Kameshwari. Hysterectomy was advised by other doctors.

Treatment – As with the earlier case, this too was a case of simple hyperplasia which can be treated medically. A thyroid scan was done to rule hypothyroidism. Counselling – rest, iron tablets, iron rich diet. In addition, suggested diet restrictions and the patient was asked to avoid processed foods to avoid xenoestrogens. Exercises were suggested for the patient to lose abdominal fat to control extraglandular production of estrogen.

#### **C. Genital prolapse:**

Genital prolapse in women in the reproductive age group is different from that in older women. In older women, prolapse occurs because of loss of muscle tone because of decreased estrogen production. In younger women, prolapse is mainly because of early bearing down during delivery, which causes laxity of ligaments and pelvic floor. In younger women hysterectomy is not necessary; this can be built with Kiegel's exercises which build muscle tone. The vaginal walls can be repaired through these exercises without removing the uterus. Dr Kameshwari has prescribed this successfully to young women who came to her with genital prolapse. In one case, an instance of 2<sup>nd</sup> degree prolapse was changed to 1<sup>st</sup> degree prolapse.

#### **D. Uterine fibroids:**

Patient: 45 year old woman

Complaint: Feeling of lump in the lower abdomen. Found a 9x8cms subserol fibroid. The fibroid was however a sessile fibroid, therefore there was no danger of torsion, so no severe emergency pain.

Treatment: Since she is in peri-menopausal stage and has a family history of menopause at 45 – 48 years, she was advised to wait as fibroids can reduce in size in the postmenopausal years. In the meantime she was counselled for change in diet and taught to monitor for emergency signs.

The above case studies clearly illustrate how the same symptoms can be treated very differently and humanely taking the patient and the patient's family into confidence.

## CHAPTER VI

### **Conclusions**

The main objective of this case study was to explore the ethics of medical practice using instances of unindicated hysterectomy as a case in point. It was clear from the data collected and analysed for this paper that women were being actively pushed towards unneeded hysterectomies especially by private medical practitioners along with RMPs in the villages and the same was increasing potential risks for these young women. Ethical considerations which require alternative treatment options, clear consultations with the patients and informed consent to be obtained, follow up procedures taken up etc., were clearly missing in the case of these young women who got hysterectomised.

In exploring the reasons for the high prevalence of hysterectomy in Andhra Pradesh, the case study attempted to analyze the doctor-patient relationship before and after hysterectomy. There is a clear case for the need for a meaningful interaction between the patient (lay person) and the doctor (the expert) – this is crucial if the doctor is to engage in critical self-reflection and to actively seek to enhance his/her expertise through dialogue with other non-conventional experts. This paper points to the violence perpetrated by “experts” on the general public and demonstrates the need for a new social contract between science and society that will take into account the marginalized people who have not benefited and in fact suffered from this kind of practice of science and technology. A new social contract would take into account the well being of the women and engage in meaningful interaction with them to determine the right/most appropriate solution. In doing this, medical practitioners are compelled to look to other non conventional systems of expertise to deal with the symptoms and come up with sustainable solutions.

While analyzing the clinical and social data that was collected as part of this case study, certain questions have emerged. These questions are related to the way in which medicine is being currently practiced and the violation of ethics which is either deliberate or due to lack of knowledge. The study also throws up questions regarding the way in which women's health is viewed and questions the current health policies vis-a-vis women's health.

The case study brought to light the question of responsibility on the part of the ‘expert’. The medical practitioner has the responsibility to

- Use knowledge to further practice
- Gather knowledge in the process of practice
- Generate a knowledge base

Any practice involves the production of knowledge. In this production of knowledge within the medical practice, there is the need for confluence of both the social and medical aspects of the patient and the need to redefine the relationship between the doctor and patient. Any treatment without taking into account the social background of the patient could lead to violence. The modern conception of the human body as a machine and increasingly specialized knowledge of certain parts of the human body leads to the treatment of those parts with little or no understanding of the human body as a whole.

The present case study raises the following questions on the practice of medicine:

- Is the approach to patients becoming more mechanical and therefore less humane?
- Is the patient viewed solely as a machine or as a human being situated in a social milieu that contributes to her problems and well being?

- Are the female reproductive organs expendable once their reproductive function is served?
- Is the current body of knowledge vis-a-vis the human body and the role of each organ in the overall wellbeing of the human being adequate?
- If current day practitioners are to add to the body of knowledge what should they do differently? Should there be a shift in the relationship between doctor and patient to that of increased equality and dialogue vis-a-vis an expert-layman relationship? Should the doctor view the patient as an important contributor to the body of medical knowledge?

The clinical analysis of the hysterectomized patients shows that there appears to be a gap in the body of knowledge regarding the after-effects of hysterectomy on young women. It is clear from the examinations done that the young women do suffer from a host of problems that typically occur later in the women's life. Also, there appears to be little follow-up or appropriate life style advice given to the patients after the surgery, along with counseling for the family, particularly the partner. Dr Kameshwari's practice illustrates very clearly that it is essential to understand the factors that have led to the original complaints and to decide the appropriate treatment which includes both mainstream medical intervention and lifestyle changes such as food intake and exercises, rather than deciding that surgery is the best option. This leads to the questions

- Do medical practitioners ensure that the patient has full and accurate information regarding her condition before deciding on surgery?
- Do medical practitioners have full and accurate information regarding the consequences of hysterectomy and alternative treatments?
- Where is the gap – is it in knowledge or in practice? If in knowledge, then that to a certain extent absolves the doctor, but if in practice, then it is a matter of violation of the rights of the patient and disregard for medical ethics?
- Have technological advances and subsequent easy surgical procedures led to the overuse of technology to “fix” problems on a short term?
- Have government sponsored health schemes, such as the Arogyasri in Andhra Pradesh, made it easier for hospitals and doctors to offer the option of surgery more widely than before?

Health policies targeting women are largely focused on the reproductive function of women. They do not take into account the fact that the uterus requires care beyond child birth and has a function within the human body that is not limited to mere reproduction. Rather women's health policies appear to ride on population policies and there seems to be a direct link between population and women's health. If women's health is to be dealt with in an ethical manner, there needs to be a delink between population and reproductive health and reproductive health needs to be seen as one of the women's right to health. The social analysis of the hysterectomized women shows that women who had early hysterectomies were largely from the lower income group and several factors seem to have contributed to the gynecological complaints – factors such as early marriage, poor nutrition, spousal relations, etc. Women's health is therefore not solely a physical condition, but is also influenced by social factors – an understanding of which is essential if one is to ensure complete treatment. If early hysterectomies are to be prevented it is essential that medical practitioners are sensitive to the social milieu in which the woman is situated.

In exploring the plurality of expertise, this paper asks for exploration of alternatives within the medical system and appeals to the experts to not be swayed by technology. It asks for a return to an interactive system of medicine where treatment is based on a sound understanding of the patient as part of a social system that can only be obtained through interaction. The case study also asks for a system of medicine where both the doctor and patient, along with other experts, are jointly concerned and responsible for the sustainable well-being of the patient.

## References:

1. Atrash, Hani K, HB Peterson, Willard Cates, DA Grimes, 1982, 'The risk of death from combined abortion-sterilization procedures: Can hysterectomy or hysterectomy be justified?', *American Journal of Obstetrics and Gynecology*, 142,3:269-274.
2. Bang, RA and Bang AT, 1991, 'Why women hide them: Rural women's view point on reproductive tract infections', *Manushi*, 69:27-30.
3. Bhatia, JC, J Cleland, 1995, 'Self-reported Symptoms of Gynaecological Morbidity and their Treatment in South India', *Studies in family Planning*, 26,4: 203-216.
4. Chatterjee, Meera, 1990, *Indian Women - Their health and Productivity* World Bank Discussion Papers 109, Washington, DC.
5. Datta DK, Dutta B, 1994, 'Surgical management of genital prolapse in an industrial hospital' *Journal of Indian Medical Association*, 92,11:366-67.
6. Elias, C, 1991, *Sexually transmitted Diseases and Reproductive Health in Women in Developing Countries*, The Population Council, Working Papers No.5.
7. George, A, 1994, 'It happens to us: menstruation as perceived by poor women in Bombay' in *Listening to Women Talk About Their Health Issues and Evidences from India* ed. By Gittelsohn, J, ME Bentley, PJ Pelto, M Nag, S Pachauri, AD Harrison, LT Landman, Har-Anand Publications, pp. 168-183.
8. Haynes, Douglas M., Benjamin J. Martin, 1979, 'Cesarean hysterectomy: A twenty-five-year review', *American Journal of Obstetrics and Gynecology*, 134,4:393-398.
9. IIPS, 1998-99, *National Family Health Survey (NFHS-2)*, International Institute of Population Sciences, Mumbai.
10. Jeyasinghe, P, Ralilanaiah, TBBDU, and Fernandes, SD, 1985, 'Pattern of sexually transmitted diseases in Madurai, India', *GenitourinaryMedicine*, 61.
11. Joshi, Archana, E Kurien, M Mishta, M Rajeshwari and S Biswas, 1996, *Socio-cultural implications of Menstruation and Menstrual problems on Rural Women's Lives and Treatment Seeking behaviour*, Operations Research Group, Working Paper, Baroda.
12. Leonard EL and Kreutner AK, 1971, 'Vaginal hysterectomy: A modality for therapeutic abortion and sterilization' *American Journal of Obstetrics and Gynecology*, 10, 8: 1096-99.
13. Loizzi,P, C.Carriero, A.Di Gesu, P.Greco and R.Nappi, 1990, 'Removal or preservation of ovaries during hysterectomy:a six year review', *International Journal of Gynecology and Obstetrics*, 31: 2357-261.
14. Mathai, R, Prasad PVS, Jacob M, Babu Goerge PS, Jacob JT, 1991, 'HIV Seropositivity among patients with STDs in Vellore', *Indian Journal of Medical Research*, 91.

15. Patel, BC, S Barge, R, Kolhe, H. Sadhwani, 1994, 'Listening to Women Talk about their Reproductive Health Problems in the Urban Slums and Rural Areas of Baroda' in *Listening to Women Talk About Their Health Issues and Evidences from India* ed. By Gittelsohn, J, ME Bentley, PJ Pelto, M Nag, S Pachauri, AD Harrison, LT Landman, Har-Anand Publications, pp. 168-183.
16. Puryastha, S, PK Bhattacharyya, 1992, 'Aftermaths of surgical sterilizations with special reference to menstrual disturbances', *Journal of Indian medical Association*, 90,2: 29-30.
17. Scott, JR, et.al., 1997, 'Subtotal hysterectomy in modern gynecology: A decision analysis' *American Journal of Obstetric and Gynecology*, 176, 6:1186-92.
18. Wasserheit, JN, 1989, 'The significance and cope of reproductive tract infections among third world women', *International Journal of Gynaecology and Obstetrics*, Supplement 3:145-168.