Understanding the Reasons for

RISING NUMBERS OF HYSTERECTOMIES IN INDIA

National Consultation 12th August 2013









Understanding the Reasons for

RISING NUMBERS OF HYSTERECTOMIES IN INDIA

National Consultation 12th August 2013











डॉ. सईदा हमीद Dr. Syeda Hameed



सदस्य योजना आयोग योजना भवन नई दिल्ली—110 001 MEMBER PLANNING COMMISSION YOJANA BHAWAN NEW DELHI-110 001

Foreword

Highest attainable level of women's reproductive health and rights is one of the most important goals India has set for itself. A number of new initiatives both by the Central and State Governments have been initiated for this.

The rising number of hysterectomies especially among young women in many States of India in the last few years, as reported in the press, is a matter of concern. The available data from studies based on small samples shows that while the percentage of hysterectomies conducted in India are less in comparison to most parts of the world, but why these are being performed at younger age group in India needs detailed research and analysis. As of now, there is dearth of comprehensive data set and studies to document the magnitude and issues related to hysterectomies in India.

The national Consultation on *Understanding the Reasons for Rising Number of Hysterectomies in India* jointly organized by the UNFPA, Health Watch Trust, Prayas and HRLN on 11th August, 2013 in New Delhi deliberated on different dimensions relating to this issue and drafted several recommendations emerging from this consultation. It gives me great pleasure to know that the report of this consultation is being published.

I am sure that the report would be a good reference document for the concerned Government departments, researchers and civil society organisations working on women's health and overall well-being of women and men. In essence, it will have impact on society as a whole.

Dr. Syeda Hameed)

Telephone: 23096570 Fax: 23096571 e-mail: s.hameed@.nic.in

Acknowledgement

The National Consultation on Understanding the Reasons for Rising Number of Hysterectomies in India held on 11th August 2013 has thrown light on many areas for further investigation. The plan for this consultation was made in the backdrop of press reports from many states and research studies conducted in some locations. Recognizing this that more explorations are required to be done to understand the reasons for rising number of hysterectomies in young age, the Health Watch Trust approached UNFPA for support which was willingly granted. A technical resource group comprising of Dr. V. Pendse, Ms. Sapna Desai, Prof. Leela Visaria, Dr. Dinesh Agarwal, Dr. Sharad lyengar, Ms. Kerry Mcbroom was constituted to plan for the national consultation. I owe special thanks to the group for their extremely valuable contribution. Special thanks to Ms. Frederika Meijer, Country Representative and Mr. Venkatesh Srinivasan, Asst. Representative of UNFPA. I also thank Ms. Chhaya Pachauli of Prayas and Mr. Sanjai Sharma of the Human Rights Law Network to shoulder many tasks relating to the organization of the consultation. Diviya Pant for writing excellent notes and Kshitiz Sisodia for preparing report also deserve many thanks.

I am extremely grateful to Dr. Syeda Hameed, Member, Planning Commission of India for considering our request for chairing the valedictory session of the consultation. Last but not the least, I extend my sincere thanks to Mr. Keshav Desiraju, Union Health Secretary, MoHFW for seriously taking our suggestions into account and for including hysterectomy related questions in the fourth round of National Family Health Survey (NFHS).

Dr. Narendra Gupta Health Watch Trust Prayas



Contents

Foreword	ii
Acknowledgement	•
Introduction	0.
Background: Hysterectomy in Context	0.
Objectives of the Consultation	02
Brief Outline of the Consultation	02
Session-wise Report	03
Welcome and Background to Consultation	03
Reviewing the Problem from Various Aspects	0.5
Legal, Policy and Grassroots Advocacy on Hysterectomy: Experience and Potential Directions	08
Action Groups	1
Valedictory Session	14
Annexures	15
1. List of Participants	17
2. Consultation on Rising number of Hysterectomies in India	19
3. Abbreviations and Acronyms	2
4. Population Research on Hysterectomy: Brief Summary	23
5. Making a Difference: A Study on Unindicated Hysterectomies	27
6. Presentations of Speakers	29



Introduction

Background: Hysterectomy in Context

Hysterectomy is the most frequently performed major surgical procedure in many countries in the industrialised world. Facility-based data in the United States, United Kingdom and Germany, for example, largely find that hysterectomy is the leading reason for women's admission into inpatient facilities. Studies of the population prevalence and epidemiology of hysterectomy have primarily been conducted in Western countries, where the vast majority of women who undergo hysterectomies in developed countries do so after the age of 45, primarily for benign gynaecological conditions. By age 65, the lifetime risk of hysterectomy ranges from 1 in 5 to 1 in 3 women in the United States, United Kingdom and Germany.

In India, there have been few population-based studies to estimate hysterectomy prevalence. Most recently, a 2010 cross-sectional household survey of 2,214 rural and 1,641 urban, insured and uninsured women in low-income households in Ahmedabad city and district in Gujarat, India, was conducted to investigate why hysterectomy was a leading reason for use of health insurance by women insured by SEWA, a women's organisation that operates a community-based health insurance scheme. It was found that of insured women, 9.8% of rural women and 5.3% of urban women had had a hysterectomy, compared to 7.2% and 4.0%, respectively, of uninsured women. Approximately one-third of all hysterectomies were in women younger than 35 years of age. Rural women used the private sector more often for hysterectomy, while urban use was almost evenly split between the public and private sectors.

Despite a lower prevalence compared to industrialised countries, hysterectomy has been a subject of recent controversy in India. The young age of women undergoing the operation, as well as suspicion of unnecessary hysterectomies in several states, is cause for concern regarding women's health and rights. For example, in Rajasthan's Dausa district, a Right to Information (RTI) application revealed that between April and October 2010, out of a total of 385 operations reported by three private hospitals, 286 were hysterectomy operations. Many of these women were under the age of 30, with the youngest being 18 years old. Reports from Chhattisgarh and Bihar have highlighted a high number of hysterectomies being performed under the Rashtriya Swasthya Bima Yojna (RSBY) insurance scheme, raising suspicion of unnecessary or profit-motivated procedures being conducted. In 2010, the Andhra Pradesh government had banned hysterectomies in private hospitals under its state-sponsored insurance scheme, after surveys suggested that hospitals conducted the procedure to claim higher insurance amounts. Maharashtra followed a similar regulation under its Rajiv Gandhi Jeevandayee Arogya Scheme.

Without systematic data, it is difficult to determine the population prevalence, if these procedures were necessary, and drivers of hysterectomy amongst young women in India. Poor access to quality health care

services is a well-documented concern for women across India, particularly related to reproductive and sexual health. Untreated gynaecological morbidity, barriers to treatment and lack of options available at a primary level may contribute to unnecessary procedures. Further, predominance of private facilities may lead to profit-seeking behaviour, which may be further compounded by government-sponsored tertiary health insurance within a weak public health system.

Given growing concern around the rates and drivers of hysterectomy in India – and lack of in-depth information – Health Watch Trust initiated a consultation in August 2013 to review current knowledge and experience related to hysterectomy and identify areas for action.

Objectives of the Consultation

The consultation brought together women's health advocates, practitioners, researchers and policymakers to:

- Review existing research on epidemiology, medical indications and type of facilities used for hysterectomy
- Understand the role of the private sector and health insurance in the rising numbers of hysterectomies
- Explore women's own perceptions about the need for and consequences of hysterectomy
- Review the health impacts of pre-menopausal hysterectomy and different treatment options available to women for conditions that often otherwise lead to hysterectomy
- Identify areas of research, action and advocacy with a range of stakeholders

Brief Outline of the Consultation

The consultation was designed to address a wide range of issues and provide a forum for stakeholders to relate their experience related to hysterectomy in India.

Ms. Vimala Ramchandran began the consultation with an introductory session on Health Watch Trust, outlining its history, significant projects, studies and surveys and current status of affiliation with Dr. Narendra Gupta and Prayas.

The first session provided background on hysterectomy and objectives of the consultation. The second panel discussion reviewed research and experience amongst experts, including the effects of hysterectomy on women's health and quality of life and a discussion on medical ethics. An afternoon session explored legal, policy and grassroots advocacy on hysterectomy, followed by a break-out session with three groups who focussed on key issues. A concluding panel suggested ways forward for action related to research, programs and policy.



Session-wise Report

Welcome and Background to Consultation

Ms. Vimala Ramchandran
Health Watch Trust
"Opening the consultation"



The consultation began with Ms. Vimala Ramchandran who gave a brief introduction to the Health Watch Trust – its origins, history, significant projects, studies, and surveys and current status of affiliation with Dr. Narendra Gupta and Prayas. She also introduced hysterectomy and why it is a cause of concern.



Dr. Narendra GuptaHealth Watch Trust

"Background to Consultation"

Welcome note and background to the consultation was given by Dr. Narendra Gupta from Health Watch Trust and Prayas. He extended warm welcome to the speakers and participants and succinctly provided overview of the consultation. He thanked all the speakers and participants to attend and address the consultation on the behalf of Health Watch Trust and Prayas. Dr. Narendra Gupta also contextualized the day's consultation by providing a background to the questions surrounding the issue of rising hysterectomies and delineating the desired objectives of the meeting. He explained the need for the consultation by pointing out that there has been a rise in the number of hysterectomies reported in India, many of which could possibly be not required. Yet, there is a lack of definite studies to explain this phenomenon. He mentioned one such epidemiological study undertaken by Sapna Desai of London School of Hygiene and Tropical Medicine, which, though of a small sample size, is fairly indicative of trends.

Dr. Gupta also reviewed current knowledge on hysterectomy:

- In India, though the number of hysterectomies is lower than many developed countries (where data is available), the mean age of a woman undergoing hysterectomy is much lower. E.g. the mean age in US and UK is 55-65 years, whereas in India it is 30-40 years, and even lower in Andhra Pradesh (24 years)
- Medical audits undertaken in UK, US and Germany broadly indicated that:
 - a. Many hysterectomies are for benign conditions and are avoidable;
 - b. There is a significant rural-urban and socio-economic divide;
 - c. The number of hysterectomies is higher where there was an increased concentration of gynaecologists and surgeons;
 - d. When medical and clinical audits were done more often, number of hysterectomies fell.

Dr. Gupta raised the question of whether hysterectomies can be optional, in terms of different kinds of hysterectomies and alternatives to hysterectomies. He briefly summarised his case study of 28 women's testimonies from Dausa village, in which the women were often not given options and were subject to insufficient medical investigations. He also noted that as part of the Save Uterus Campaign of 2010 under FOGSI, gynaecologists discourage elective hysterectomies, indicating that there exists significant demand for the procedure. He also said that studies have indicated that hysterectomies have possible side effects including decreased life expectancy, lower cardio-vascular function, reduced bone density etc. In the light of these points, he underlined the need to deal with the issue, developing protocols and procedures to understand the factors at play.

Dr. Dinesh Baswal
Deputy Commissioner, Maternal Health,
Ministry of Health and Family Welfare
"Keynote Address"



The keynote address was delivered by Dr. Dinesh Baswal. He too noted the lack of studies in India, small sample sizes of existing studies, and delineated the problem: reducing mean age of hysterectomies is a cause of concern.

After noting the high incidence of hysterectomies in Andhra Pradesh, Bihar, Rajasthan, Chhattisgarh, especially those under the RSBY and Arogyasree, he said that the government had issued guidelines to avoid unnecessary procedures. The RSBY guidelines, he said, were too simply that "proper investigation was necessary" before a hysterectomy. But the Arogyasree guidelines are more specific in terms of conditions under which hysterectomies can be sanctioned (these include age, cervical malignancy etc.)

He stressed on the need to forge a way forward by the following means:

- Ethical medical practice needs to be re-affirmed
- Medical auditing should be made more regular
- Internal monitoring by professional organisations such as FOGSI should take place, with possible debarring of members engaged in unethical practices
- More surveys to gauge the extent of the problem. (It can be included in NFHS-4)

- Complications post-hysterectomies need to be recorded and followed up
- Government of India guidelines would soon be finalized; features like a citizen's report card could act as a diagnostic and/or accountability tools; a proper assessment of hidden costs etc.

Reviewing the Problem from Various Aspects

In Chair:
Dr. K. Srinath Reddy
President, PHFI, Delhi



Dr. K. Srinath Reddy noted that the challenge was not just to identify causes but also to find ways to counter the rising incidence. Private practice was driven by monetary motivations; often government practice also feeds into private practice. Dr. Reddy stressed the need for public education about health, partly to clarify procedures, partly to protect against medical malpractice. Medical audits run the danger of fudged or inadequate records. Therefore, there is a need to maintain medical records along with patient interviews. He also called for a higher level of ethical awareness in medical education itself.



Dr. Amar JesaniIndian Journal of Medical Ethics
"Medical Ethics"

Dr. Amar Jesani next spoke about medical ethics. He said that in the mid-1980s, when he started work on medical malpractice and to make the profession accountable, the focus was on negligence manifested through death or injury of patient. He found that the profession was so tightly knit that accountability became difficult. For instance, due to the tacit understanding that there is "co-operation and competition" among the fraternity, evidence of experts as testimony in court was not often forthcoming.

He said that the medical council needs to supplement ethics education with determined mechanisms such as disciplinary action; there's a need to reactivate state level medical councils. He fore grounded some of the contentious issues at hand:

- a. In case of elective procedures being brought under the ambit of negligence, is one interfering with patient's agency?
- b. If primary reproductive healthcare is unavailable, does this agency effectively apply? How does that affect the element of choice in hysterectomy?
- c. How should the balance between Regulation vs. Prohibition be assessed?

He also talked about the extent to which changes in the medical practice have affected its ethical practices. With the accumulation of capital, the medical profession is looking for increased profitability, resulting in a de-emphasis on primary healthcare. Also, the private sector is invading public health, and its approach is not preventive healthcare. Providing an example to illustrate how markets can shape ethical viewpoints, he pointed out that in the 1970s, abortion was the major money spinner followed by caesarean section and hysterectomy. Now, since doctors are more conscious of abortion ethics, the incidence of abortion has decreased. Other factors such as development of abortive pills and drugs have further eroded the market for surgical abortions, making C-sections and hysterectomies more lucrative procedures.

Assessing the rising demand for hysterectomies, he said that there is a great deal of internalization of the need for procedures such as C-sections or hysterectomies. This, he pointed out, is a "therapeutic misconception" of doctors and patients.

As social insurance spreads, there is an increase in the rate of services, as shown by the experience of developed countries. While earlier hysterectomies were more prevalent among the middle classes, now higher insurance coverage has resulted in a rise in the procedure among the lower classes. He said, the problem needs interventions on the level of ethics education and systemic changes in hospitals such as

- a. Good record-keeping
- b. Medical audits
- c. Medical councils and/or other such bodies that can, like tribunals, facilitate punitive action
- d. An authority accessible to patients

He also made a distinction between informed versus involved consent, favouring the latter. He pointed out, definition of consent too is complicated: what exactly is consent? How far is it voluntary and what amounts to coercion? There can be coercion by the system and circumstances which can go unrecognized. Lack of choice can also amount to coercion. Therefore, instead of having a knee-jerk response against rising hysterectomies and withdrawing insurance cover for it, we need to factor in coercion better to prevent the need of women from being unethically exploited and commercialized. Regulation, thus, needs to be backed up by primary reproductive healthcare.

Dr. S.V. Kameswari
Life-HRG
"Implications on Women's Health"



Dr. S.V. Kameswari presented her case study on unindicted hysterectomies in Medak district of Andhra Pradesh. Some of the findings of studies conducted on rural women who engaged in spinning were:

a. Rates: 92 per 1000 women in Andhra Pradesh under the age of 30, as compared to 5.4 per 1000 women between 40 and 44 years of age in the US;

- b. In a sample of 15 villages in Munipalle mandal, the surgical history of registered rural women showed that all had had hysterectomies, 95% in private hospitals;
- c. Most of these women were small farmers and agricultural labourers;
- d. 82.5% were BC/SC/ST/MM.

She noted that in several cases, hysterectomy was accompanied by appendectomy as well, which was a matter of concern. After describing the sample of the study and methodology, including how age of the women was assessed, she explained the research question: does hysterectomy affect ovarian function?

The study calculated ovarian function by FSH values. Results were: 59% women had normal FSH ranges, 41% had menopausal range. This is significant in the light of the fact that the incidence of natural premature menopause is 0.1%. Correct assessment is affected by the fact that consecutive samples of FSH values are difficult to get. Discharge summaries post hysterectomies are just outpatient slips, which either do not mention age or make an approximation, and have no status of ovarian function.

A problem of methodology, such as how to calculate bone density in young women, gives rise to many clinical dilemmas. She pointed out that after hysterectomy, one cannot assess ovarian function or gynaecological problems by menstrual symptoms, requiring a multi-disciplinary team to make even a simple gynaecological intervention. This has negative implications for rural primary healthcare which struggles with insufficient resources.

She noted further limitations such as:

- a. It cannot be clearly assessed how long ovaries will work after hysterectomies. In most Western countries, menopausal and post-hysterectomy changes can be clubbed. This is not so in India where the mean age is much lower;
- b. It is difficult to treat natural menopause issues in such situations;
- c. The paracrine function of uterus on ovarian function is difficult to assess;
- d. Physicians tend to see the uterus as only linked to childbirth; and
- e. The logic behind oophorectomy is to prevent cancer. However, ovarian cancer is rare (82 per 1 lakh women) when related with the incidence of hysterectomies (92 per 1000 women), creating an artificial clinical situation.

She discussed the need to research into how lost ovarian function can be replaced. Low weight, low abdominal fat and poor immunity of rural women makes them more vulnerable to oestrogen depletion and loss of ovarian function. She noted the possibility of using flaxseed as alternative to HRT and medication because of its cost effectiveness, highlighting the funding crunch that faces such initiatives. There was an urgent need to increase awareness, develop protocol, strengthen primary gynaecological care, develop alternative methods of hysterectomies, and conduct assessment of ovarian function at least once a year for at least 10 years in women post-hysterectomy.

She also noted other India-specific complications that render it difficult to generalise based on Western experience. For example:

- a. The links between tubectomies and hysterectomies. Laproscopic tubectomies usually done in camps are unsterile and increase the risk of future hysterectomies;
- b. Women marry and give birth at a very young age before menstruation is naturally regularized and are then tubectomised, putting them at higher risk of complications leading to unnecessary hysterectomies;

c. Huge gaps in gynaecological care also enhance the complications caused by STDs. In case of white discharges from STDs, partners are often neither treated nor regular gynaecological treatment provided.

Conclusion

Dr. Reddy summarized the discussion by suggesting some immediate measures:

- a. Writing to the ICMR asking for a larger study;
- b. Convening meetings to finalise appropriate research questions;
- c. Conducting studies on health insurance and their impact on women's reproductive health, funded by the Planning Commission.

Legal, Policy and Grassroots Advocacy on Hysterectomy: Experience and Potential Directions

In Chair:

Poonam Muttreja,

Executive Director, Population Foundation of India

Co-Chair:

Ms. Deepanag Chaudhary,
McArthur Foundation

Ms. Poonam Muttreja
Executive Director,
Population Foundation of India
"Opening Remarks"



Ms. Poonam Muttreja introduced PFI and acknowledged that increasing number of hysterectomy could be a problematic issue and it needs to be looked into deeper. Root causes needs to be identified for the issue and some policy changes are needed. But in the crisis of data advocacy for this issue may be difficult. So the database needs to be gathered and some hardcore evidences are needed that can indicate it to be a very serious issue.



President, FOGSI
"Legal, Policy and Grassroots
Advocacy on Hysterectomy"

Dr. Hema Diwakar introduced FOGSI and its initiatives, primarily the KEY programme (Keep Educating Yourself) – the FOGSI-Torrent-Sensa KEY programme of 2013 called "saving the uterus." She talked about the demand and supply issues such as diagnostic and surgical problems, use of HRT versus non-HRT treatments.

Exploring the demand side, she shared some possible reasons for the high incidence of hysterectomies:

- a. Taboo associated with menses;
- b. Cancer scare;
- c. Lack of options;
- d. Desire to avoid problems in older age;
- e. Ease of access;
- f. Convenience surgery becomes a one-stop solution;
- g. Insurance.

She shared an interim survey being conducted by FOGSI in tier 1, 2, and 3 cities in Karnataka which will try to assess why elective hysterectomies are on the rise. She then highlighted challenges and action plans needed:

- a. Need for a registry of hysterectomies;
- b. Audits by an external body;
- c. Surveys of various settings, public, private, camps etc.;
- d. Develop guidelines and protocols;
- e. Master health checkups;
- f. Online or SMS based alerts;
- g. Standardized discharge cards.

She pointed out some lacunae such as absence of benchmarks, incomplete and inconsistent record keeping, need to gauge links between hysterectomies and heart disease or osteoporosis and creation of a "consortium of co-morbidities."

Ms. Kerry McBroom
Human Rights Law Network
"Reproductive Rights Initiative and
Public Interest Litigation"



Ms. Kerry McBroom represented the HRLN's reproductive rights initiatives and talked about the PIL as a valuable tool. The PIL, she explained, is

- a. A way of holding governments and actors accountable;
- b. A means to solicit a definite reply;
- c. An advocacy as well as accountability tool since it bases the problem within a rights framework, pitches it as a fundamental rights violation, brings media attention to it, creates a record of proceedings, and offers a genuine chance of making changes through government mandate and possibly clear laws.

She then specifically discussed the PIL filed by Dr. Narendra Gupta as the chief petitioner and Rajasthan, Chhattisgarh and Bihar as the respondents. The PIL outlines facts from states and case studies. More broadly, it looks at general health and contraception issues as well since a rights-based approach makes it necessary to look at the public healthcare system as a whole, and it provides the picture that hysterectomy is one part of a wider reproductive health failure.

She outlined the legal violations linked to general failure of Article 20 (Right to Life, Health etc.), Article 14, 15 – equality before law and discrimination (to bring in gender discrimination), International Law (Article 12), failure to comply with general rights by JSY-NRHM. She brought up the issue of informed consent, in relation to the Supreme Court ruling on Sameera Kohli versus Union of India and others, in which the SC agreed that unless it is a lifesaving procedure doctors have to comply exactly with a consent form. Consent needs to be informed as well as involved with a clear sense of advantages, disadvantages and alternatives to the patient. The SC acknowledged that consent does not mean anything in India and called for the need to develop a rights-based consent framework. She talked about role of ethics regulations and how doctors cannot solicit patients, and briefly spoke about the Consumer Protection Act.

She gave an overview of the demands: (a) compensation for the women in the fact finding studies and removal of violating doctors; (b) M&I body to ensure accountability, an independent RSBY monitor; (c) findings published in online form accessible to all; (d) investigation into village level health problems; (e) education and awareness camps; (f) evaluation of RHP. She pointed out that the response of the Chhattisgarh government was just a page long letter to two large files of petitions.



Dr. Narendra Gupta
Health Watch Trust
"A study on Prevalence of
Hysterectomy, Determinants and
a Community Education Program"

Dr. Narendra Gupta then presented more details on Sapna Desai's study on prevalence of hysterectomies, determinants and a community education program (data provided in background section). The study, conducted between 2010 and 2012 in collaboration with SEWA, was a population study and a health education intervention on hysterectomy in Ahmadabad city and district. It utilised household surveys, interviews with women and providers and discussions with key informants.

Some findings:

- a. Prevalence was similar amongst insured and uninsured women, and higher in rural areas;
- b. Women's reasons for hysterectomy included fear of cancer, convenience, trust in provider and cost effectiveness;
- c. Insurance status played virtually no role in decision;
- d. 2/3 of rural women utilised private providers, while 1/2 urban women did. Government doctors also conducted hysterectomies amongst young women, raising issues behind simply a profit motive.

Chief areas of concern identified by the study: (a) young age; (b) untreated gynecological morbidity; (c) gendered view of women's bodies that leads to unnecessary intervention; (d) lack of primary care for gynaecological issues.

Dr. Gupta also presented an overview of the fact finding study in Dausa in which the following was found:

- a. Four clinics conducted most of the hysterectomies;
- b. These clinics were also recognized for JSY and so could be mined for information under the RTI Act;
- c. Women on the whole said that their original complaints did not disappear after hysterectomies;
- d. No prior treatment was given before removal;
- e. Private hospitals came recommended by relatives and friends;
- f. The sequence of events from diagnosis to surgery was very hasty, often it happened on the same day itself;
- g. Other causes of painful abdomen and bleeding in rural women could not be ruled out given their lifestyle conditions.

Action Groups

In Chair:

Dr. Narendra Saini,

Hony. Secretary General, IMA

The group dismantled into three small working groups, each of which presented their recommendations after a discussion.

i. Track 1: Evidence on incidence, indications, epidemiology, OOP expenditures

Moderator:
Dr. M. Prakasamma
ANSWERS



Track 1 summarized their points of discussion and recommendations as follows:

- a. Limited epidemiological knowledge available;
- b. Hospital data incomplete and unreliable, perhaps community-based data could be sourced through community surveys;
- c. The need to assess difference in provider-institute relationships, the role of insurance, increase in supply side;
- d. Can we map providers and the correlation with number of hysterectomies;

- e. Some of the questions were about the origin of indications of hysterectomies whether post-tubectomy, post-birth, or post-menopausal;
- f. How changes in dietary and life practices may have led to changes in hysterectomy immunity, e.g. effect of change from a millets to rice diet in Andhra Pradesh?;
- g. Relation of contraceptives and family planning to indications.

The group also made a distinction between Real, False, and Fear indicators and made the observations that symptoms were falsified to construct a disease. Anxiety and lack of information was used and there is a need for in-depth information and records, out-patient notes and admission records. There is a need for improved information of menstrual system and endocrinology, as well as widespread understanding of indications of hysterectomy.

ii. Track 2: Role of professional associations - FOGSI, IMA and ASI - STGs for management of common uterine disorders





The group highlighted the following:

- a. Need for protocols, independently and within medical associations;
- b. Need for monitoring and evaluation of adherence to protocols in the form of medical audits;
- c. Need to maintain records and discharge cards;
- d. Effective Continuing Medical Education;
- e. Certification and ethical protocols to be organizational and independent;
- f. Enhanced gynaecological care at the PHC level;
- g. The compulsory rural practice programme for post-graduate medical students should not be opposed by medical associations;
- h. Implications of hysterectomies should be made known;
- i. Gynaecologists could perhaps collaborate with other experts, such as bone doctors, to assess damage by hysterectomies;
- j. There is a need to look at drug pricing and the interest of pharmaceutical companies. How the stakes of big business such as calcium tablets could be linked, if at all;
- k. Clarity needed on what correlations exist;
- I. Need for an expert group consensus meeting that gives some interim guidelines instead of waiting for the WHO or other such official guidelines to come about;
- m. Medical audits should include clauses that can be employed such as whether admission procedure was followed, hygiene conditions, diagnostic processes between detection, diagnosis and surgery.

iii. Track 3: Demand side, alternative/independent sources of information on need for hysterectomies

Moderator: Dr. Sharad Iyenger ARTH



After acknowledging the asymmetry of information, the following recommendations were made regarding the content of information required:

- a. Basic information on anatomy and physiology to be provided to women and children;
- b. Source of information should not only be those who have stakes in doing the procedures;
- c. Information on non-invasive and other contraceptions necessary in tackling misinformation;
- d. Information about cancer, STIs etc. to counter paranoia about cancer as a possible inflator of demand;
- e. Awareness of patients' bill of rights to include informed consent, right to second opinion with all relevant reports and case papers, post-operative information, and optional measures;
- f. Gender sensitization in school health education curricula;
- g. Information about common ailments such as anemia;
- h. Healthcare providers, including ANMs and ASHAs, to have information on laws and regulations, patient rights etc.;
- i. Improving community information channels by targeting students and school curriculum, information help lines such as call centres and medical hotlines, production of video skits and community radio programmes;
- j. Co-ordination and dialogue between overlapping government schemes such as NRHM, Family Planning, ARSH etc.



Dr. Narendra Saini Hony. Secretary General, IMA "Conclusion"

Dr. Saini acknowledged that gynaecological level doctors are available only at tertiary level, and that distance of health facility and cost are the biggest factors which affects the health seeking behaviour. Cancer screening is not available at primary or secondary level government health facilities. He said that an investigation regarding this will be done to identify gaps in the system and malpractice by doctors.

Valedictory Session

In Chair:
Dr. Syeda Hameed
Member, Planning Commission of India



Dr. Syeda Hameed was briefed about the proceedings of the conference in the valedictory session. During a discussion with the participants and panellists, these significant points were brought up:

- a. We do not have the last word on insurance or commercial aspects of the problem;
- b. Given that the problem is often of morbidity not mortality, one of the significant consequences is the economic unproductivity of women, which could well become a food security issue. This can be seen from the example of Andhra Pradesh in which loss of ovarian function in women has had consequences for general health and productivity of women;
- c. It was pointed out that alternative treatments, such as IUDs, are not reimbursed by social insurance. However, the discussion stressed the need for solutions that would be commensurate with ground realities, e.g. focus on preventive PHC, creation of strong indicators which take into account regional, socio-economic and other contextual factors;
- d. Mr. Niranjan Pant pointed out the need for regulatory mechanisms which incorporated a layer of external regulation in the self-regulation of the medical profession;
- e. Dr. Narendra Saini of IMA suggested an investigation into practices of hysterectomy which is clearly malpractice such as those in Dausa.
- f. Need for reliable national level data, and therefore few questions of hysterectomy should be included in NFHS-4.

Dr. Syeda Hameed acknowledged the increasing number of hysterectomy to be a cause of concern. She regarded the issue as one of the most alarming in terms of reproductive health rights of women and emphasised on the need of more detailed research and analysis of the issue. She requested participants to list out and frame a list of crucial questions related to hysterectomy which can be included in NFHS-4 for gathering data related to its prevalence and causes. Dr. Hameed assured her support to deal with the issue.

Dr. Anchita Patil
UNFPA
"Conclusion"

Dr. Anchita Patil represented UNFPA and she said that the points made by all the speakers in the consultations are valid and increasing prevalence of hysterectomy is a matter to be concerned about indeed. Data on this need to

be collected in the NFHS-4 survey in order to eliminate the problem for lack of availability of data on it. She also said that UNFPA is looking forward to supporting this issue.



List of Participants

			I	
S.No.	Name	Organization	Contact No.	E-mail ID
1	Aarti Dhar	The Hindu	9810131802	dharaarti@gmail.com
2	Ajay Kumar Chawariya	Public Health Resource Network	9999043048	ajaykumar.chawariya@phrnindia.org
3	Amitava Guha	CITU & JSA	9013379037	amitava45@gmail.com
4	Audrey Fernandes	Tathapi	020-24431106	tathapi@gmail.com
5	Chhaya Pachauli	Prayas	9828416876	chhaya@prayaschittor.org
6	Deepak Xavier	Oxfam India	9910268102	deepak@oxfamindia.org
7	Deepanag Chaudhary	McArthur Foundation	9810586602	dragchoudhary@mcfound.org
8	Devika Biswas	Health Watch Forum Bihar	9430359870	devikabiswas@gmail.com
9	Dinesh C. Sharma	Freelance Lournalist	9891118575	dineshcsharma@gmail.com
10	Diviya Pant	Student		diviya.pant@gmail.com
11	Dr. Anchita Patil	UNFPA	9811100201	apatil@unfpa.org
12	Dr. Bharati Prabhakar	CHSJ	8800729114	bharti@chsj.org
13	Dr. Dinesh Baswal	Deputy Commissioner, Maternal Health, MoHFW	011-2306 2288	dinesh 126@hotmail.com
14	Dr. Hema Diwakar	FOGSI	0900154448	drhemadivakar@gmail.com
15	Dr. K. Srinath Reddy	Public Health Foundation of India	011-49566026	kshrinath.reddy@phfi.org
16	Dr. S.V. Kameswari	Life-HRG	09848669840	lifehrg@gmail.com
17	Dr. M. Prakasamma	ANSWERS	09440065707	answers.mytri@gmail.com
18	Dr. Narendra Gupta	Health Watch Trust	941411038	narendra@prayaschittor.org
19	Dr. Narendra Saini	Indian Medical Association	011-23370009	drsaini-ima@medclik.com drnsaini@yahoo.co.in
20	Dr. Prakash V.	Life-HRG	9849020242	lifehrg@gmail.com
21	Dr. Sharad lyenger	ARTH	0294-2451168	sdiyenger@gmail.com

contd...

S.No.	Name	Organization	Contact No.	E-mail ID
22	Dr. Syeda Hameed	Planning Commission of India	011- 2309 6570	hameed.syeda@gmail.com s.hameed@nic.in
23	Kalpana	Manan	9425056985	kalpanaindr@hotmail.com
24	Kerry McBroom	HRLN	9650316596	kerry.mcbroom@gmail.com
25	Kshitiz Sisodia	Prayas	9828416876	chhaya@prayaschittor.org
26	Nibedita phukan	CHSJ	9990201700	nibeditaphukan@chsj.org
27	Niranjan Pant	Dy. CAG of India (Retd.)	9650722224	narpat@gmail.com
28	Nupur Sonar	Tehelka magazine	8527047314	nupur@tehelka.com
29	Pious Ahuja	HRLN	9958672188	pious@gmail.com
30	Poonam Muttreja	PFI	011-26856805	pmuttreja@ population foundation of india.in
31	Pratibha	HRLN	9891910349	pratibha.dmello@gmail.com
32	Saadia Aveem	HRLN	8447202794	saadiaaveem@gmail.com
33	Shivani	Student	9811009742	shivamgupta 55@yahoo.com
34	Sunita Choudhary	Sama	9769642335	suni 18 ju@gmail.com
35	Susheela D. Singh	Sama	8800423965	sama.genderhealth@gmail.com
36	Swapna Majumdar	Journalist	9868108972	swapnamajumdar 25@yahoo.com



Consultation on Rising Number of Hysterectomies in India

(Indian Women's Press Corps, 5, Windsor Place, Ashoka Road, New Delhi 110 001) Monday, 12th August 2013

Programme

Time	Session
09:30 am – 09:45 am	Welcome and Introduction to Health Watch Trust, Ms. Vimala Ramachandran, Health Watch Trust
09:45 am – 10:00 am	Background and objectives of the consultation, Dr. Narendra Gupta, Health Watch Trust
10:00 am – 10:20 am	Key note address, Dr. Dinesh Baswal, Deputy Commissioner, Maternal Health, MoHFW (Gol)
10:20 am – 11:45 am	Panel Discussion: Problem Review In Chair: Dr. K. Srinath Reddy, President, Public Health Foundation of India (PHFI) Problem review in terms of: Implications on Women's Health, Dr. S. V. Kameswari, Life-HRG (20 mins) Medical Ethics, Dr. Amar Jesani, Indian Journal of Medical Ethics (20 mins) Open floor (15 mins)
11:45 am – 12 noon	Tea Break
12 noon – 01:30 pm	Legal, Policy and Grassroots Advocacy on Hysterectomy: Experience and Potential Directions In Chair: Ms. Poonam Muttreja, Executive Director, Population Foundation of India (PFI) Co-chair: Ms. Deepanag Chaudhary, McArthur Foundation Speakers: Ms. Kerry McBroom, Human Rights Law Network (HRLN) (20 mins) Dr. Narendra Gupta, Health Watch Trust (20 mins) Dr. Hema Diwakar, President, The Federation of Obstetric and Gynaecological Societies of India (FOGSI) (20 mins) Open floor (15 mins)
01:30 pm – 02:15 pm	Lunch

contd...

Time	Session			
02:15 pm – 03:30 pm	Action groups			
	Facilitator: Ms. Kerry McBroom, Human Rights Law Network (HRLN)			
	Track 1: Evidence on incidence, indications, epidemiology, OOP expenditures, Dr. M. Prakasamma, ANSWERS			
	Track 2: Role of professional associations - FOGSI, IMA and ASI - STGs for management of common uterine disorders, Ms. Audrey Fernandes, TATHAPI			
	Track 3: Demand side, alternative/independent sources of information on need for hysterectomies, Dr. Sharad lyenger, ARTH			
03:30 pm – 03:45 pm	Tea Break			
03:45 pm – 04:45 pm	In Chair: Dr. Narendra Saini, Hony. Secretary General, Indian Medical Association (IMA)			
	Presentation of group recommendations (15 mins each)			
	Dr. M. Prakasamma, ANSWERS			
	Ms. Audrey Fernandes, TATHAPI			
	Dr. Sharad Iyenger, ARTH			
	Open floor (15 mins)			
04:45 pm – 05:30 pm	Valedictory Session			
	In Chair: Dr. Syeda Hameed, Member, Planning Commission of India			
	Concluding Remarks:			
	Dr. Anchita Patil, UNFPA			
	Sh. Niranjan Pant, Dy. CAG of India (Retd.)			



Abbreviations and Acronyms

ANM Auxiliary Nurse and Midwife

ARSH Adolescent's Reproductive and Sexual Health

ASHA Accredited Social Health Activist

ASI Association of Survey of India

CHSJ Centre for Health and Social Justice

CITU Centre for Indian Trade Unions

FOGSI Federation of Obstetric and Gynaecological Societies of India

FSH Follicle Stimulating Hormone

HRLN Human Rights Law Network

HRT Hormone Replacement Therapy

ICMR Indian Council of Medical Research

IMA Indian Medical Association

IUD Intra-uterine Device

JSA Jan Swasthya Abhiyan

JSY Janani Suraksha Yojana

KEY Keep Educating Yourself

NFHS National Family Health Survey

NRHM National Rural Health Mission

OOP Out of Pocket Expenditure

PFI Public Foundation of India

PHC Primary Health Centre

Understanding the Reasons for Rising Numbers of Hysterectomies in India

PIL Public Interest Litigation

RSBY Rashtriya Swasthya Bima Yojana

RTI Right to Information

SC Supreme Court

SEWA Self Employed Women's Association

SMS Short Message Service

STD Sexually Transmitted Diseases

STG Standard Treatment Guidelines

UK United Kingdom

UNFPA United Nations Family Planning Association

USA United States of America

WHO World Health Organization



Population Research on Hysterectomy: Brief Summary

Aug 2013 **Sapna Desai**

Global Research, Excluding India

Hysterectomy is the most frequently performed major surgical procedure performed in many countries in the industrialised world. Facility-based data in the United States, United Kingdom and Germany, for example, largely find that hysterectomy is the leading reason for women's admission into inpatient facilities. Studies of the population prevalence and epidemiology of hysterectomy have primarily been conducted in Western countries, with the exception of an early study in South Africa. Research in developing country settings such as Nigeria, Thailand and Brazil have focused on obstetric hysterectomy or reviews of facility history, with no (English) published population data available.

Population Prevalence

Country	Year	Sample Size	Respondent Age Group (years)	Population Prevalence (%)	Notes
United Kingdom ¹	2010	All-population register	65-69	23.9	Projection based on previous studies
USA ²	2009	180,982	50.8 (mean)	26.4	
Germany ³	2000	3,000	40-60	16.0	40.2% women >65 have undergone hysterectomy
Australia⁴	1998	14,072	45-50	21.9	26% had both ovaries removed
Ireland⁵	1995	17,735	50-65	22.2	
Finland ⁶	1989	1,713	45-64	18.5	
South Africa ⁷	1988	22,000	n/a	17.5 (Whites) 3.1 (Indians)	Age not indicated

Epidemiology and Risk Factors

The vast majority of women who undergo hysterectomies in developed countries do so after the age of 45, primarily for benign gynaecological conditions. By age 65, the lifetime risk of hysterectomy ranges from 1 in 5 to 1 in 3 women in the United States, United Kingdom and Germany. Women with

lower education levels and lower socioeconomic status are more likely to undergo the procedure. More affluent women are thought to opt for less invasive techniques, which may be more expensive or easier to access for them. Private health insurance in Ireland and Australia was associated with hysterectomy, particularly for rural women in the latter. However, in Brazil, women with higher per capita household income, a history of medical consultation for menstrual problems or tubal ligation before age 30 are more likely to undergo hysterectomy.

Medical Necessity

The necessity of hysterectomies for benign conditions has been questioned in several industrialised countries, particularly after research uncovered larger patterns of such hysterectomies in areas with higher concentrations of gynaecologists, regional disparities, and inconsistency in medical reasons for the procedure. Women's demand and elective use of the procedure has been identified as an important factor as well. Clinical audits in facilities, qualitative research with women, awareness-raising and greater monitoring of hysterectomy has led to recent, though slow, decrease in incidence in some countries, particularly the United Kingdom and United States.

The use of medical audits has been found as a potential mechanism to reduce unnecessary hysterectomy, if performed regularly. Reviews conducted outside of the West have found varying degrees of medical appropriateness. In Taiwan, a chart review in 1998 found that 72% of hysterectomies were appropriate, while the remainder were unnecessary procedures in younger, premenopausal women. The latter were conducted for pelvic pain, abnormal uterine bleeding and endometriosis. Similarly, in Pakistan, a quality assurance process at Aga Khan University in 1989 analysed 376 cases of hysterectomy. Conditions for which women underwent hysterectomy were: recurrent uterine bleeding, fibroids, and other gynaecological disorders. Of these, 92.0% were found to be justified. In Calabar, Nigeria, 80% of hysterectomy cases between 2001-2005 were reported to be justified.

Side Effects

More recent research has investigated the association of hysterectomy, particularly in premenopausal women, with a range of longterm medical conditions such as cardiovascular disease, depression and urinary incontinence. Findings are mixed, although some observational studies indicate links with psychosocial/sexual health, fracture risk, cardiovascular disease, and potentially, all-cause mortality amongst premenopausal women who underwent hysterectomy and oophorectomy.¹¹⁻¹³

India

Until recently, research on hysterectomy in India has largely focused on clinical research and effectiveness of surgical methods. Findings from population-based studies are summarised below.

Population-based Studies

Location/Year	Sample Size	Prevalence	Age	Facility Type – Public/Private
Andhra Pradesh (2009?), rural ¹⁴	3,452	14.5%	24 yrs (median)	Predominantly private Study on 171 women in similar area found 5% government, 95% private
Gujarat (2010), rural and urban ¹⁵	3,655	Rural Insured: 9.8% Uninsured: 7.2%	36 yrs	34% government 66% private

Location/Year	Sample Size	Prevalence	Age	Facility Type – Public/Private
1/2 women insured by VimoSEWA		Urban Insured: 5.3% Uninsured: 4.0%	39 yrs	55% government 45% private
Haryana (2001), rural ¹⁶	1,000	7.0%	Highest (15%) in age group 45-54 yrs	47% government 53% private

Concerns

- Age, lack of options presented and quality of care not necessarily 'high' prevalence (yet)
- Medical necessity questionable/unclear
- Oophorectomy performed with hysterectomy
- Where facilities available, high use of government hospitals as well
- High level of gynaecological morbidity and lack of treatment options
- Link to tubectomy/sterilisation

Key Findings from Non-Population Based Studies

- Bihar and Chhattisgarh Fact Finding Missions 2013: Medical indications seem largely unnecessary, poor quality of care, and lack of treatment options presented to women.
- Rajasthan Prayas investigation: Of 385 operations in three private hospitals, 286 were hysterectomy operations.
- Gujarat qualitative research: Providers prescribe hysterectomy as first-option treatment, either due
 to lack of equipment or ease of option including for cervical cancer.
- AP: Research on 171 women who underwent procedure found most were poor, illiterate and some suffered health problems post-hysterectomy. Hysterectomy perceived as one-time 'cure' for a range of gynaecological issues, both by providers and women.

References

- 1. Redburn JC, Murphy MF. Hysterectomy prevalence and adjusted cervical and uterine cancer rates in England and Wales. *BJOG: An International Journal of Obstetrics and Gynaecology* 2001, 108(4):388-395.
- 2. Erekson EA, Weitzen S, Sung VW, Raker CA, Myers DL. Socioeconomic indicators and hysterectomy status in the United States, 2004. *The Journal of Reproductive Medicine* 2009, 54(9):553-558.
- 3. Senator fur Arbeit FGJuS. Frauengesundheitsbericht Bremen 2001. Bremen: Media Meter, 2001, as cited in Stang A. Impact of hysterectomy on the age-specific incidence of cervical and uterine cancer in Germany and other countries. *European Journal of Public Health* 2013, 23(5):879-883.
- 4. Byles JE, Mishra G, Schofield M. Factors associated with hysterectomy among women in Australia. *Health & Place* 2000, 6(4):301-308.
- 5. Ong S, Codd MB, Coughlan M, O'Herlihy C. Prevalence of hysterectomy in Ireland. *International Journal of Gynaecology and Obstetrics: The Official Organ of the International Federation of Gynaecology and Obstetrics* 2000, 69(3):243-247.
- 6. Luoto R, Raitanen J, Pukkala E, Anttila A. Effect of hysterectomy on incidence trends of endometrial and cervical cancer in Finland 1953-2010. *British Journal of Cancer* 2004, 90(9):1756-1759.

- 7. Rossouw JP, Mostert WP, du Plessis GE. Surgical sterilisation and hysterectomy in South Africa: 1988. *South African Journal of Demography* 1994, 4(1):29-39.
- 8. Chao YMY, Tseng TC, Su CH, Chien LY. Appropriateness of hysterectomy in Taiwan. *Journal of the Formosan Medical Association* 2005, 104(2):107-112.
- 9. Rizvi JH, Afzal W, Ah A, Khan KS. Was that hysterectomy really necessary? Audit of Operative Justification at the Aga Khan University Medical Centre, Karachi. *Australian and New Zealand Journal of Obstetrics and Gynaecology* 1991, 31(1):80-83.
- 10. Bassey IE, Gyuse AN, Odusholu PO, Ekanem IA, Omotoso AJ. Justification rate for non-obstetric hysterectomies: a study of cases in University of Calabar Teaching Hospital, Calabar. *Nigerian Journal of Medicine: Journal of the National Association of Resident Doctors of Nigeria* 2011, 20(1):71-74.
- 11. Stewart EA, Shuster LT, Rocca WA. Reassessing hysterectomy. Minnesota Medicine 2012, 95(3):36-39.
- 12. Phung TK, Waltoft BL, Laursen TM, Settnes A, Kessing LV, Mortensen PB, Waldemar G. Hysterectomy, oophorectomy and risk of dementia: a nationwide historical cohort study. *Dementia and Geriatric Cognitive Disorders* 2010, 30(1):43-50.
- 13. Fletcher HM, Bennett F, Simms-Stewart D, Reid M, Williams NP, Wharfe GH, Wilks RJ, Mitchell S, Scott P. Cardiovascular disease risk factors in menopausal Jamaican black women after hysterectomy and bilateral oophorectomy: an observational study. *The West Indian Medical Journal* 2010, 59(6):625-632.
- 14. Padma Y. Hysterectomy: A Neglected Public Health Issue (presentation). In Hyderabad: National Institute of Health and Family Welfare, 2009.
- 15. Desai S, Sinha T, Mahal A. Prevalence of hysterectomy among rural and urban women with and without health insurance in Gujarat, India. *Reproductive Health Matters* 2011, 19(37):42-51.
- 16. Singh A, Arora AK. Why hysterectomy rate are lower in India. Indian Journal of Community Medicine 2008, 33:3.



Annexure 5

Making a Difference: A Study on Unindicated Hysterectomies

By Dr. S.V. Kameswari, Dr. V. Prakash

Life-Health Reinforcement Group (Life-HRG), a Non Government Organization, has been providing basic healthcare services to rural masses in the arid district of Medak, 100 kilometers from the state capital, Hyderabad in Andhra Pradesh. We have observed that a large number of young rural women undergo hysterectomy (sometimes along with oophorectomy i.e. removal of the ovaries which is considered to be prophylactic against ovarian cancer) recommended by qualified allopathic and other rural practitioners as a solution to many Gynec problems. 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 conditions can be successfully treated with alternatives to hysterectomy that include minimally invasive surgeries and pharmacological treatments.

Life-HRG has campaigned against unindicated hysterectomy, and even presented this fact to The National Human Rights Commission in 2004. It was presented in various meetings of medical and non-medical gatherings as an urgent ethical issue which must be addressed. In the next phase Life-HRG undertook a clinico-socio-economic study to deal with the questions of early hysterectomy with/without bilateral salpingo-oopherectomy, in 15 villages of Munipalli mandal of Medak District of Andhra Pradesh from May 2008 - May 2011. 171 women between the age groups of 20-40 years, who had hysterectomies done between 1-14 years ago participated in the clinical study. Most of them had already been through tubal ligation as part of family planning program before the hysterectomy. The clinical study was partly supported by DBT (DBT Project Title: Development of support systems to rural women who underwent early hysterectomies).

Background of the Women: Eighty-two percent of the study group women belong to BC/SC/ST/MM. Average age at hysterectomy in the study group was found to be 29.2 years. The average age at marriage was 14 years and average age at first delivery was 16 years. *In 80% of cases indication for hysterectomy was white discharge.*

Early Menopause: Forty-one percent of the women showed consistently high blood levels of the hormone FSH >40 IU/ml i.e. these women were showing menopausal levels of FSH. Of these women, 31% were still under the age of 30 years (natural premature menopause incidence is 1% between 30-40 year age group, while for those below 30 years the incidence is less than 0.1%).

Early Age at Hysterectomy and Bone Thinning: Women who had Total Abdominal Hysterectomy (TAH) with Bilateral Salpingo-Opharectomy (BSO) before 30 years of age had 5% less BMC, 3% less BMD, 5.6% less spine BMC when compared to women who had TAH with BSO after 30 years of age. The decision to perform prophylactic ophorectomy at this young age should not be permitted because women are at

a low risk of developing ovarian cancer at this age. It is important to note that the incidence of cervical cancer is 0.08%, where as the actual hysterectomy incidence in AP is at 9.2% in reproductive age group women, and the highest being 16.0 - 18.0% in six districts of AP.

In addition women who are less than 30 years of age have not reached their peak bone mass, and bone loss due to Hysterectomy starts even before the bone has been mineralized.

Duration since Surgery: All DXA parameters in the women had consistently high FSH above 40 IU/ml, irrespective of the state of the ovary, showed statistical deterioration of bone parameters with increasing duration since the hysterectomy.

Preserving the Ovaries: The medical fraternity generally perceives sparing the ovaries as a wise choice. Our study shows that 21% of women with menopausal level of FSH, had TAH even with one or both ovaries conserved at the time of TAH and 33% of the TAH group with both ovaries conserved showed consistently high FSH values.

These results point to the need for an in depth prospective study to know the effects of hysterectomy on premenopausal women and on ovarian function in order to estimate the risk for earlier ovarian failure following hysterectomy. The issue has shifted from un-indicated gynecological intervention and questions of how to retain the uterus to an iatrogenic clinical situation that would need a multi disciplinary team that could assess post-operative changes and propose interventions.

Our study on hysterectomy had thrown up the gaps in medical practice pertaining to women's health care. "Surgery is the option" and "only remedy "is impressed upon the patient, even for minor gynecological complaint or for that matter, ironically any complaint/s in the body and also to prevent cervical cancer in due course of time. Thus an artificial, detrimental and unusual clinical situation is created while we are yet to find out required follow up interventions for natural menopausal woman.

The entire issue reflects the need for strengthening gynecological care at primary and secondary levels,

and also to integrate cervical cancer screening into regular government programs. There is also an immediate need for awareness campaigns on how to preserve uterus and prevent ill effects of early and unindicated hysterectomy. Given the large number of women who may suffer from premature menopause, there is an urgent need to do a follow up intervention study with plant oestrogens on premature surgical menopausal women-to know the benefits on bone.

Impact of this Study: The results of this study were shared with the medical fraternity and with NGOs in 2010. At one of this meetings the IAS officer in charge of Women and Child welfare Dr. Chaya Ratan intervened and held consultations with Life-HRG group over 30 sittings, and based on their findings recommended a ban on hysterectomies in the Arogyashri program on 18th Jan 2011. In fact a ban was imposed on all organ removal surgeries. (See GO letter). It was clear that "white discharge" could no longer be an indication for Hysterectomy.

2006 – *Arogyashri* is put in place, starts

July 17th 2008 – Arogyashri 2

allows Laparoscopy assisted Vaginal

Hysterectomy.

July 17th 2008 to Nov 30th 2010 – 26,712 Hysterectomies, with repair are done in AP under Arogyashri

November 2010 to March 2011 -

About 30 Meetings with IAS officers (Dr. Chaya Ratan Secretary Women and Child Welfare) and GO is issued to stop all organ removals under Arogyashree on 18 January 2011. These are

- Hysterectomy
- Appendectomy
- Gall Bladder removal (Cholecystectomy)



Annexure 6

Presentations of Speakers

1.	Women's Account of Their Hysterectomies in Dausa District Dr. Narendra Gupta Prayas	30
2.	Legal, Policy and Grassroots Advocacy on Hysterectomy: Experience and Potential Directions Dr. Hema Diwakar FOGSI	43
3.	Hysterectomy Prevalence, Determinants, and Education: Grassroots Research and Intervention Experience from Rural Gujarat Sapna Desai	54
4.	Case Study on Unindicated Hysterectomies in Andhra Pradesh Dr. S.V. Kameswari, Dr. V. Prakash Vinjamuri Life-Health Reinforcement group	61

Women's Account of Their Hysterectomies in Dausa District

By Dr. Narendra pta Prayas



- A hysterectomy is an operation to remove a woman's uterus. The uterus can be removed through a cut in the vagina (vaginal hysterectomy) or in the abdomen (abdominal hysterectomy), depending on the reason for the surgery.
- A woman may have a hysterectomy for reasons viz.
 - Uterine fibroids that cause pain, bleeding, or other problems
 - Uterine prolapse, which is a sliding of the uterus from its normal position into the vaginal canal
 - Cancer of the uterus, cervix, or ovaries
 - Endometriosis
 - · Abnormal vaginal bleeding
 - Chronic pelvic pain
 - Adenomyosis, or a thickening of the uterus

Women's Account of Their Hysterectomies in Dausa District

- In April 2011, some newspapers have reported that uterus of around 226 women belonging to Dausa district in Rajasthan were removed by some private homes/hospitals while seeking care for pain in abdomen and menstrual problems
- On knowing about these large number of hysterectomies in a short span of time, civil society groups conducted some enquiries



What was done?

- Civil society groups of Dausa obtained a list of women who were subjected to hysterectomies in April 2011 through RTI
- Members of civil society met the women and took their accounts of the hysterectomies - a total of 16 women could be contacted



Women's Accounts



Gulab w/o Ram Avtar, Resident of Village Khedla, Tehsil Sikrai, Dt. Dausa



- · Age: unknown
- Children: 3
 - Oldest: 15 yrs old son, delivered in Govt. SMS hospital, Jaipur
 - Second: 13 yrs old son, delivered in Private Vaijanti hospital, Alwar
 - Third: 11 yrs old daughter, delivered in the private Madhur Hospital, Bandikui
- Her tubes were ligated about 10 years back in a sterilization camp organized by the Govt.
- She has been experiencing pain abdomen and general body pain since past six years. She also had complain of body ache and heart burning.
- She sought treatment for this in Government SMS Hospital, Jaipur, private Vaijanti Hospital in Alwar and in the last showed in Madhur Hospital, Bandikui.



Gulab 1

- The doctor at Madhur Hospital advised sonography and did it in the hospital. After conducting sonography, he said that "Bachhedani ko nikalna padega, isme sujan aa gayee hai. Aage cancer hone ka khatra hai" (uterus has to be removed because it has swollen and there is danger of cancer happening later on).
- She was admitted in Madhur Hospital soon after the report and operated the same day in the evening. She remained in the hospital for seven days and charged Rs. 20,000/- She was discharged on 21st December 2010 from hospital.



Sunita w/o Ram Khiladi, Resident of Village Khedla, Tehsil Sikrai, Dt. Dausa



- Children: 3 (9 year old son, 7 years old daughter and about six years old son)
- Her tubal ligation was done soon after her last son was born in Manpur camp.
- She has been experiencing pain in abdomen and irregular menstrual cycle since then and seeking treatment from different places.
- About a year back Dr. Madan of private Madan Hospital, Bandikui during organizing a camp with
 free consultation in Sikrai, suggested sonography for which he took Sunita in his vehicle to his
 hospital in Bandikui. After sonography, Dr. Madan said "Bachhedani galane lag gayee hai, isko
 nikalana padega" (Uterus has been decaying and required to be removed).
- Sunita and her husband Ram Khiladi wanted to seek one more consultation but Dr. Madan
 insisted for immediate hospitalization and operation "Usne hamko sochane ke liye koi time hi
 nahi dia aur mujhe usi samay bharti kar liya" (He did not give us any time to think and
 immediately admitted).

Sunita 1

- They did not have enough money but Dr. Madan said "Whatever money you have, deposit it and get remaining money by evening".
- The sequence of events were that Sunita was consulted in morning, admitted in the afternoon and operated in the night same day.
- Discharged after 7 days and paid a total of Rs. 20,000/-.
- But even after the operation, there was no relief and I had to seek consultation every 10 to 15 days.
- Initially, she used to go Dr. Madan only and he has prescribe medicines which cost
 me around Rs. 1000 to 1500. But now she is taking medicines from my village
 doctor (quack). She still have pain in abdomen and weakness. Her bleeding
 problem is gone.

P.S. According to Ram Khiladi and Sunita, Dr. Madan is a very clever doctor and he keeps advertising about himself through organization of free consultation camps. Once anybody seeks any consultation from him in any of these camps, she and he are trapped by him.



Kamod w/o Ram Karan Singh r/o Brahman Mereda, Tehsil Sikrai, District Dausa



- Only one child of 5 years old (son).
- She has been having problem of pain abdomen and irregular menstruation since past two years and shown herself to doctors in Sunil Nursing Home in Alwar town. She was given medication but her problem continued.
- About 12 months back, she consulted Dr. Madan of Madan Nursing Home, Bandikui.
- Dr. Madan did sonography and said that her uterus has damaged and it requires to be removed. Kamod and her husband wanted to seek another consultation but Dr. Madan said that this is an emergency and any delay may cause cancer.
- He admitted Kamod at 10.00 AM in morning and the hysterectomy was performed between 2.30 and 3.00 PM
- Kamod was discharged after 7 days and total expenses were about Rs. 20,000/-. Kamod still suffers from pain abdomen and has to repeatedly take medicines for this. She has to spend about Rs. 1000 every month.



Chameli w/o Tulsi Ram Singh r/o Village Badwali, Post Biccpada, Tehsil Baswa, Dt. Dausa



- Chameli has four daughters and one son. The son is the youngest and aged about 5 years. Her eldest daughter is 13 years old and other daughters are aged 11, 9 and 7 years.
- She had complaint of excessive menstrual bleeding and for that showed herself to Dr. Rita Joshi of Monilek hospital in Jaipur who prescribed medicines for three days, but this did not treat her problem.
- About two and half years back, she consulted Sugam Hospital in Bandikui.
 Sonography was conducted on her and advised immediate removal of her uterus as it has become bad.
- Two days later, she was admitted at 9.00 AM and operated by 12.00 noon. She was discharged from the nursing home after nine days. Amount paid was Rs. 15000/-.



Chameli 1

- Chameli still has problem of pain abdomen and many times sought medical advice takes medicines prescribe by different persons regularly.
- Her family borrowed Rs. 1 lac at 24% annual rate of interest which her family has not been able to repay so far.

Kailash w/o Ram Singh r/o Lotwada, Baswa



- She has two daughters aged 10 and 8 years.
- She underwent tubal ligation six years back and hysterectomy 3 months at Dr. Madan's Hospital in Bandikui.
- She was having complaint of pain abdomen and excessive menstrual bleeding since past one year. For this, initially, she showed to a local doctor (unqualified) in her village and got some medicines. But this did not help and then on 5th December 2010 she went to Dr. Madan's Hospital. A sonography was done that itself and was advised hysterectomy.
- She was immediately admitted and operated the same day. Her family spent about Rs. 20,000/-.
- She still has the same complaints of pain abdomen. Problem of excessive menstruation is over. She still has to take medicines for her pain abdomen.



Anguri w/o Babu Lal r/o Chhoarwada, Tehsil Sikrai



- She has one daughter aged 12 years and two sons aged 10 and 8 years.
- She had tubal ligation in Government camp around 6-7 years back.
- She had problem of pain abdomen and excessive bleeding which started one year after tubectomy. She took medicines from different places for it but no relief. She went to Dr. Madan's Hospital on 26th December 2010.
- A sonography and x-ray were done and then advised hysterectomy by citing that her uterus is decaying and it may become cancerous.
- Dr. Madan scared them by saying that this is emergency and she should be immediately admitted. She was operated the same day in evening and discharged after seven days.
- Her family paid Rs. 9000/- for the operation and stay. She still has the problem of pain abdomen and has to get medication for it regularly.
- She carried her sonography report and discharge ticket of Dr. Madan's Hospital. The sonography report says no abnormality detected but the discharge ticket shows first degree uterine prolapsed.



Sita w/o Ram Gopal r/o Chhokarwada, Tehsil Sikrai



- Sita has three sons aged 4, 3 and one year old.
- Since past two months, she had complaints of pain abdomen and excessive menstrual bleeding.
- She went to Dr. Madan's Hospital in Bandikui. After sonography, she was advised hysterectomy citing bad patches in uterus and possibility of turning it into cancer later on.
- She was admitted the same day and operated the same day. She was admitted for seven days.
- Her stitches after operation got infected and pained a lot. She continued to vomit. Her family quarreled with Dr. Madan but not helped. Her family spent about Rs. 20,000 at the time of operation.
- Pain abdomen still continues. She at times felt very nauseated. Her family borrowed money to pay to Dr. Madan.



Lajo r/o Kedla



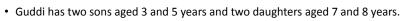
- Lajo has three sons aged 17, 15 and 11 years.
- After birth of her third son, she underwent tubal ligation the same year.
- Hysterectomy was done at Dr. Madan's hospital but her problem of pain abdomen continues.

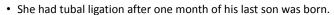
Kaushalya Meena

- She has two children aged five and three and half years.
- She visited Dr. Madan's Hospital in Bandikui for pain in abdomen and excessive menstruation.
- After sonography she was advised hysterectomy by mentioning its turning bad and may get cancerous after a while.
- She was admitted the same day and operated the same day. She was admitted for seventeen days.
- Her family paid Rs. 9000/- for the operation and stay. She complained that her problem of pain abdomen continues as it is.
- The sequence of events are that she went to show to the doctor at 3.00 PM. Her sonography report was available at 4.00 PM and by 6.00 PM she was admitted and operated at 8.00 PM.
- She did not have any documents. One of her stitch became infected took several weeks to heal.



Guddi w/o Mohan Lal, r/o Pamedi, Tehsil Baswa, Dt. Dausa





- About 18 months back she began to have complaints of pain in abdomen, excessive menstrual bleeding, extreme weakness not been able to do work and felt her entire body getting turtle.
- On advise in villages she went to Balaji Hospital in Bandikui some time in evening. At around 6.00 PM sonography was done and advised hysterectomy because there is danger to her life otherwise. "The Uterus has spoiled and may burst and it may also cause cancer".
- She was admitted at 7.00 PM and operated at 9.00 AM next day morning.
- She said "I was not given anaesthesia. Some 8-10 persons men & women caught me. I got unconscious. I remained admitted for 10 days. My wound was dressed every day. We spent out of our savings. But my pain still continues and I am still on medication. There is no relief and there is complaint of gas." Balaji Hospital run by Dr. Dhakar husband and wife couple.



Guddi w/o Devi Sahay, r/o Manpur, Daur Meena Pada, Tehsil Baswa, Dausa



- Guddi has a son aged 15 years, a daughter aged 13 years, another daughter aged 10 years and a son aged 6 years.
- Three months after the last son was born, she had tubal ligation in a camp organized by the Government.
- Her hysterectomy was done three years back at Katta Hospital, Bandikui. Prior to her visit to Katta Hospital, she had complaints of pain in legs, head ache and weakness.
- She was admitted the same day. She was operated after two days by giving anaesthesia. She was admitted for 11 days and paid Rs. 8,000/-. overall expenditure was nearly 20,000/-.
- But after discharge Guddi still has complaints of head ache, pain in feet for which she went to Manpur and have couple of drips. She paid up to Rs. 500 for two bottles of drip.



Kajori w/o Hazari, r/o Meena Pada, Tehsil Baswa



- Kajori is mother of six children four girls aged 12, 14, 16 and 17. Her two sons are aged 21 and 10 years.
- She had tubal ligation after 4 months of last delivery.
- Her uterus was removed about 5 years back at Katta Hospital, Bandikui when she went there to seek treatment for pain abdomen.
- She reached hospital at 8.00 AM, immediately sonography was done and advised removal of uterus by operation because uterus has become diseased. She was operated at 7.00 PM in evening the same day. She remained admitted for 8 days and paid Rs. 10,000/- to the hospital and cost of medicines was separate.
- Her pain abdomen is still the way as it was before the operation and sometimes there is swelling as well. She is still under treatment. She is still seeking treatment from Katta Hospital but there is no improvement.

Champa w/o Shambhu, r/o of Meena Pada, Tehsil Baswa, Dausa



- Champa is mother of four children 2 boys aged 12 years and 5 years and two girls aged 15 and 10 years.
- She had tubal ligation 5-6 months after last delivery. Her uterus was removed 3 years back in Katta Hospital, Bandikui citing prolapsed of uterus after sonography.
- She went to Katta Hospital to get treatment for her problem of pain abdomen. She was admitted the same day in morning when she went and operated after anaesthesia at around 9.00 PM the same day.
- She was discharged after 15 days. She said but there was no relief of pain abdomen even after the operation. But her prolapsed is over. She is still getting medicines for pain abdomen.



Phooli w/o Chhote Lal, r/o Meena Pada, Tehsil Baswa, Dausa



- Phooli gave birth to 4 children all sons who are aged 22, 19, 17 and 15 years old.
- After last delivery, she had tubal ligation. She had complains of pain in abdomen, gas, head ache and menstruation after every 15 days.
- About three years back, she went to Katta Hospital to get treatment. Doctor advised sonography which was done by him.
- The doctor said that she has some growth in the uterus and it is required to be removed. She was admitted and operated after 3 days. She was discharged after 9 days.

Lali w/o Lalu r/o Meena Pada, Tehsil Baswa, Dausa

- Lali has three sons and one daughter. Her sons are aged 18, 14 and 6 years.
- After six months of last deliver, she had tubal ligation.
- She began complaints of pain abdomen, body ache about three years back. She first went to Balaji Hospital in Sikandara and from there to Banikui.
- She was admitted the same day and after sonography next day, the doctor of Balaji Hospital advised uterus removal because of its diseased status. Her hysterectomy was done the same day. But her problem still continues.
- There is swelling around stitches and when she went to Balaji Hospital again, she was admitted for one day and night. During this period drips were given. But her problem reoccurred soon.



Discussion

- The cardinal principle is "Hysterectomy is usually considered only after all other treatment approaches have been tried without success". However, no prior treatment of any kind administered in case of the women whose uteruses were removed as the narrative of these women suggested.
- Testimonies reveal that most women went to private hospitals in Bandikui either on hearing from friends or relatives.
- The pattern of events which lead to hysterectomies in these private hospitals look quite similar for all women – they arrived in hospital in morning, a sonography of abdominal region with uterus advised, sonography done in the same hospital and doctor of the hospital after seeing the sonography report suggested removal of uterus immediately by citing emergency.

Conclusion

- Testimonies of the women and examination of case papers show that utmost haste was observed in performing hysterectomies while there were no emergent medical indications for doing so.
- The problem of pain abdomen, back ache and menstrual irregularities is common amongst women especially those living in villages, have given birth, suffer with anaemia & undernutrition and engaged in a lot physical work. Painful heavy bleeding also called dysmenorrhoea and menorrhea can happen to women for no particular reason or abnormal pathology. But in several instances, it can also occur owing to infections and other illnesses not necessarily of uterus.
- Therefore, ruling out of all the causes which may be responsible for pain abdomen and painful irregular menstruation through different tests before performing hysterectomy should have been done which according to the testimonies was not done.
- Diagnosing pre cancer stage based on sonography of the uterine area cannot be a conclusive reason for hysterectomy.



Way Forward

- Owing to limited time spent in interaction with women, it is difficult to ascertain the precise indications which led to hysterectomies in the private hospitals of Bandikui town.
- However, there is an urgent need for more detailed investigation both by getting case papers of the women who were subjected to hysterectomies if provided willingly or under the Right to Information Act.



LEGAL, POLICY AND GRASSROOTS ADVOCACY ON HYSTERECTOMY

EXPERIENCE AND POTENTIAL DIRECTIONS

Slide 1



KEY - Keep Educating Yourself: Each one Teach one (CMEs in every society)



FOGSI MSD KEY PROGRAMME - Cancer cervix – kill it before it kills you

FOGSI MSD KEY PROGRAMME – BUILDING CONTRACEPTIVE CHOICES

FOGSI HLL KEY PROGRAMME - Building contraceptive choices

FOGSI CIPLA KEY PROGRAMME – Building contraceptive choices

FOGSI BAYERS KEY PROGRAMME – Building contraceptive choices

FOGSI EMCURE KEY PROGRAMME - SAVE THE MOTHERS

FOGSI Uth Health KEY PROGRAMME – SINGLE STEP TO STOP GDM

FOGSITORRENT KEY PROGRAMME - SAVETHE UTERUS

FOGSI WELLESIA KEY PROGRAMME – PCOS UPDATE

FOGSI ACKUMENTIS KEY PROGRAMME –PROGESTERONE UPDATE

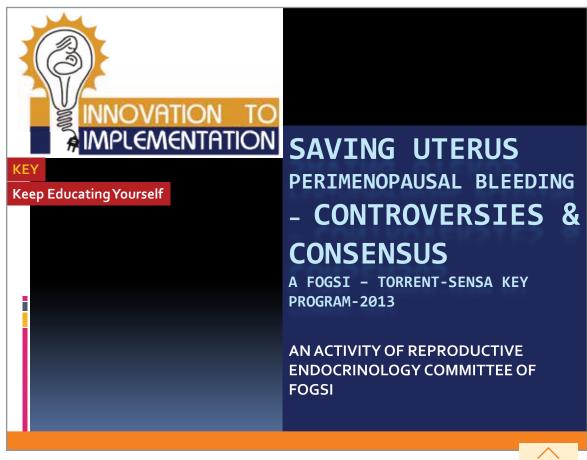
FOGSIGSK KEY PROGRAGMME - ADOLESCENCE - ACT NOW!

FOGSI WANBERY KEY PROGRAMME - 9 months 9 challenges!

AND MORE







UNNECESSARY HYSTERECTOMY THE CONTROVERSY THAT WILL NEVER DIE

Varanasi

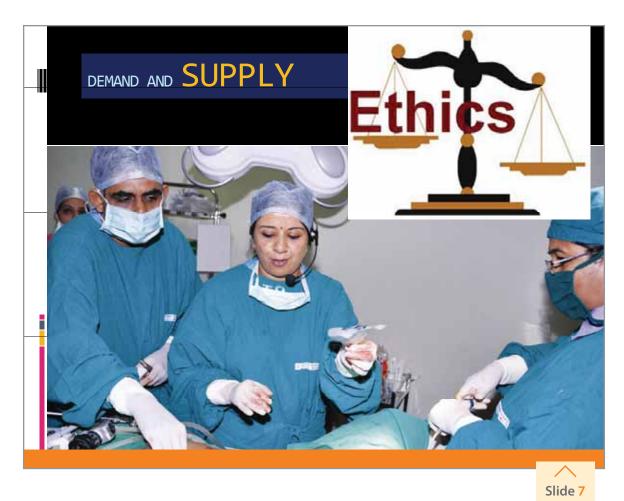
- Gurgaon
- Gwalior
- Rajkot
- Bengaluru
- Odisha
- Gadag
- Tumkur
- Islampur
- Aurangabad
- Cuttack
- MORE

Slide 5

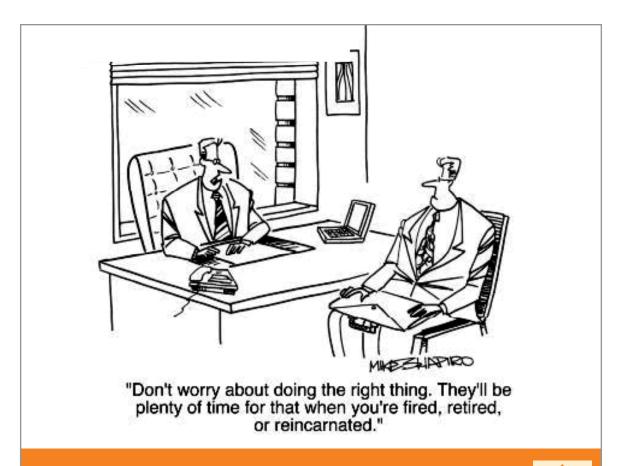
PROGRAMME

- Diagnostic Dilemmas
- Non-hormonal Treatment Need & limitations
- Hormonal Treatment Basis & Modalities
- Panel Discussion- Case based Situational Analysis
- Surgical Management (Video or talks)
- Minimally invasive procedures
- TCRE
- Endometrial ablation procedures



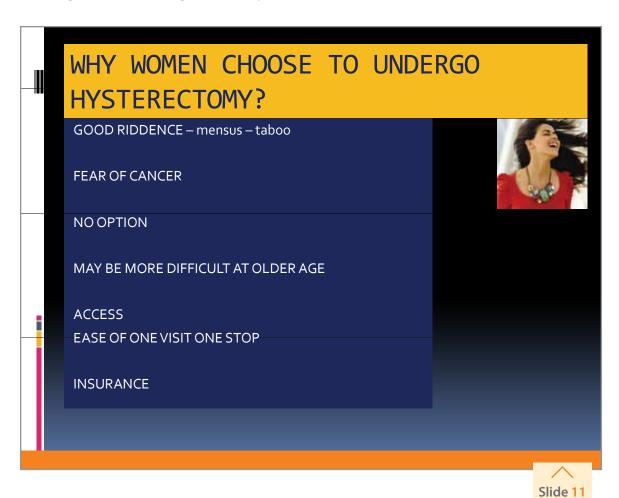


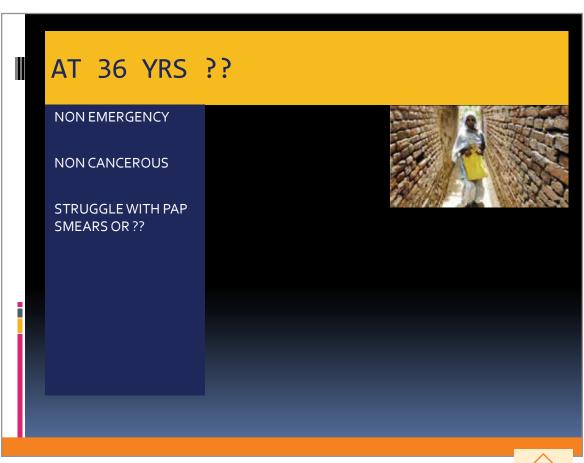


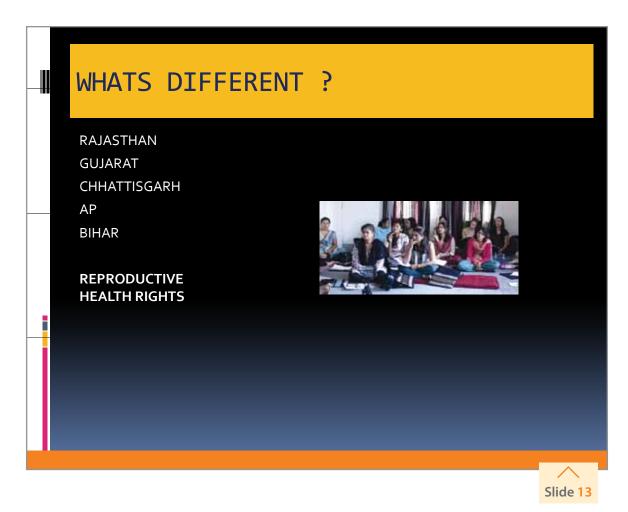












UK

- ONE LAKH per year
- 46 % DUB
- 75 % COULD BE AVOIDED
- SOUND REASON / GOOD DISCUSSION ON ALTERNATIVES DOES IT REALLY HAPPEN?
- MIS INFORMED CONSENT

Slide 14

In USA - Hysterectomy Epidemic

- 600,000 hysterectomies every year
- 2 % of these actually necessary
- 76% did not meet ACOG criteria
- 420000 could have avoided hysterectomy

Slide 15

Public Forum: "Coping with mid life crisis" Hindi/English
Feedback forms to be filled and sent at the end of the session

FOGSI THINGS TO DO

- REGISTRY
- AUDITS

- SURVEYS
- PRIVATE/PUBLIC/CAMPS/TEACHING SESSIONS
- ISSUES OF REMOVAL OF OVARIES

Slide 17

FOGSI THINGS TO DO

- Absence of a national or regional bench mark of what is considered appropriate for hysterectomy prevalence
- Clinical records not uniform /not complete
- Hysterectomy and heart disease/ osteoporosis
- Developing guidelines









Slide 21

Hysterectomy Prevalence, Determinants, and Education

Grassroots research and intervention experience from rural Gujarat

Sapna Desai



Background

- Hysterectomy leading reason for rural VimoSEWA members to be hospitalised
- Average age of claimants: 36 years
- Claims data cannot provide population data or insight into role of insurance
- VimoSEWA initiated a population study and health education intervention on hysterectomy (2010-2012)



Study Methods

- Population-based survey of 3,855 women (insured and uninsured) in Ahmedabad district and city
- In-depth qualitative interviews with 35 women who have had hysterectomy and 10 who have not
- Interviews with public and private providers, midwives, health workers and other key informants



Study Population

- Representative sample of uninsured women drawn from 50 villages and 12 urban pockets
- Insured women selected from VimoSEWA database who live in same areas as uninsured
- Demographic Profile:
 - Women workers in informal economy (agricultural labourers, home-based workers and service providers)
 - Approximately half have not attended school
 - 2/5 do not have toilet
 - 4/5 live in kuccha dwellings



Prevalence

	Rural women	
Ever hysterectomy	Insured (n=1,128)	Uninsured (n=1,086)
Prevalence (% with 95 %CI)	9.9	7.0
	(7.4-12.5)	(5.9-8.1)
Mean age	36.3	37.0

- Education/SES/Housing not associated with having undergone a hysterectomy
- Urban prevalence lower (5.4%/4.0% in insured, uninsured)
- Insurance status: VimoSEWA members slightly more likely to undergo hysterectomy as well as all hospitalisation (note: scheme covers up to Rs. 5,000)



Prevalence in Context

• Very limited (almost no) population studies in Asia, Africa and Latin America, outside of India

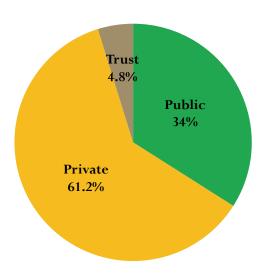
Rural Haryana: 7.0% (Singh and Arora 2001)
 Rural Andhra Pradesh: 14.5% (Padma YR presentation)

- Prevalence ranges from 26-36% of women in US, UK, Australia, Germany and South Africa by age 65
- Hysterectomy leading reason for hospitalisation globally
- While prevalence not 'high' in India, average age quite low: elsewhere above 45 years or post-menopausal



Hysterectomy Provider Choice

Type of hospital: rural women



- Considerable use of public sector as well
- Provider choice did not vary by insurance status
- Urban women:
 - 55% public
 - 45% private hospitals
- Average expenditure about double in private hospitals



Women's Experiences: In-depth Qualitative Interviews

Health

- All had been sterilised by mid-twenties
- High burden of gynaecological ailments: menstrual bleeding, pain, cysts/fibroids, prolapsed uterus, infections

Hysterectomy process

- Many sought advice of 2-3 providers; mix of public/private
- Provider choice depended on convenience, trust, and cost
- No other treatment options suggested in most cases
- Women did not delay procedure once advised; fear of cancer common
- Insurance played virtually no role in decision process for women



Women's Views, Cont.

Health systems issues

- Gynaecological care only available at tertiary level
- Distance and cost to women major barriers to seeking early care
- No cancer screening

Side effects

- Ailments related to early menopause
- Some also expressed relief at no menstruation, no pain and no risk of cancer/further ailments



Providers' Views

- Hysterectomy most "practical" solution, particularly for rural women who travel far
- Do not have skill/equipment to perform other, less invasive procedures that require follow-up
- Unaware and unconcerned with side effects
- Those who didn't conduct operations regularly: expressed personal choice and ethics as reason

Health Education Intervention

- SEWA conducted health education sessions on hysterectomy with women over 2 years, randomised by CHW clusters
- CHWs provided women with information on hysterectomy, using film, group education and community media





Intervention Results

- Improved levels of awareness on:
 - what hysterectomy procedure entails
 - alternatives/first-line procedures to explore
 - questions to ask of providers
- Did not decrease rate of hysterectomy amongst insured or uninsured in a 2 year period (not surprising)
- Health education critical but only one part of required systemic interventions

Summary: Issues of Concern

Women's health

- Young age at hysterectomy
- High burden of untreated gynaecological morbidity
- Gendered view of women's bodies: why is uterus dispensable post-childbirth, for both women and providers?

Health system

- Provider bias to perform operations
- · Lack of primary gynaecological care, both public and private
- Low availability and use of first-line procedures, particularly for rural/poor women
- No systematic method to gauge medical necessity of hysterectomies

Lack of data and research

- Lack of population-level data and trends
- Require qualitative experiences of women
- Medical case review



Key Advocacy and Research Needs

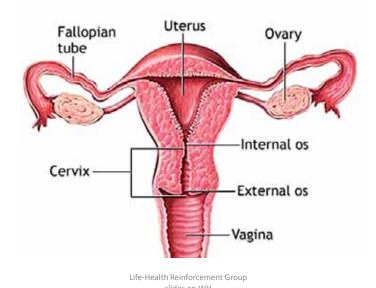
- Advocacy
 - Affordable, quality gynaecological care at primary level
 - Health education on hysterectomy
 - Provider regulation and tracking
- Research
 - Population-based studies
 - Facility tracking and clinical case review
 - Inclusion of hysterectomy in NFHS
 - Qualitative research with women and providers

Case Study on Unindicated Hysterectomies in Andhra Pradesh

By Dr. S.V. Kameswari
Dr. V. Prakash Vinjamuri
Life-Health Reinforcement Group

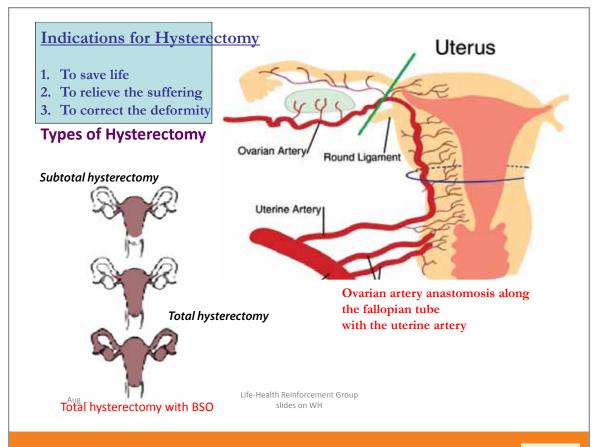


Understanding Women's Body



Aug-13



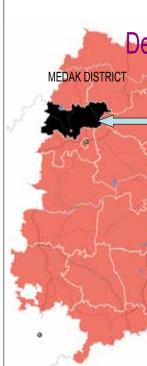




Few Facts about Hysterectomy

- All over the world Hysterectomy is the second most frequently performed major operation for women of reproductive age. 90% of all hysterectomies were done for benign reasons.
- Situation- International Vs Andhra Pradesh:
- Hysterectomy rate for the U.S was 5.4. Per 1,000 women.
- AP (DLHS-3- 2007- 92 PER 1000 of reproductive age group women in AP)
- *Lug-1Highest among women between ages 40-44 yrs old Vs 20-40y.





Aug-13

Details of the Study

- 120 km from Hyderabad
 - 15 villages in Munipalle Mandal of Medak district
- Registered -171 women
- All registered women are under 40years.
- Agricultural laborers/small farmers
- 82.5% belong to
- BC/SC/ST/MM

Life-Health Reinforcement Group slides on WH

- Average age at Marriage - 14yrs
- Average age at first delivery-16 yrs
- •Hysterectomies done before the age of **30yrs**.
- 95% surgeries are done in **private hospitals**
- High percentage of women were subjected to ovaries removal



Demographic Data

Variables	Number of Subjects considered	Minimum (years)	Maximum (years)	Mean	Standard Deviation
Age at the time of registration	167	22	42.25	32.95	5.43
Age at marriage	152	7	19	13.27	2.23
Age at 1st child	142 4 infertile	12	23	15.84	2.027
Age at Hysterectomy	159	18	40	29.15	5.60
Months since Hysterectomy	160	6 months	180 months	46.32	35.60
HB% ug-13	152	Jife-Health Reinf 2 0 slides	orcement Group on WH 12.8 %	10.74	1.27



FSH Values in Normal Situation

- Before puberty: 0 4.0 mIU/ml
- Reproductive age group—4 -33 mIU/ml
- Post menopause->40 mIU/ml

FSH Values in our Study group

- 59% had values -7-23miu/m
- 41%(66women) had ->40mIU/ml

Natural premature menopause incidence is 0.1%-1% between 20-40y age group

Aug-13

Life-Health Reinforcement Group slides on WH



Surgical Details

Ovary status	Number	Percentage
Ovary removal status not known	12	18.2%
One/both ovaries retained	15	22.7%
Bilateral Oophorectomy	39 Life-Health Reinforcement Group	59.1%

Aug-13

slides on WH



Symptoms of Menopause

Hot flush and night sweats
Atrophy of genitourinary tissue,
Vaginal dryness,
Mood changes,
Osteoporosis
Heart disease.

Aug-13

Life-Health Reinforcement Group slides on WH



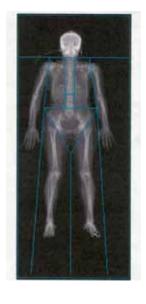
ABOUT DXA

- Dual-energy X-ray absorptiometry (DXA) is the gold standard for non-invasive measurement of bone mineral density (BMD) & assessing BMC.
- Using these values and subject demographics,
 DXA software calculates T-scores and Z-scores

Aug-13

Life-Health Reinforcement Group slides on WH





Region	BMC (g)	Fat (g)	Lean (g)	Total (g)	%Fat (%)
LArm	80.5	719.2	1247.0	2046.7	35.1
R Arm	89.5	863.8	1412.3	2365.6	36.5
Trunk	275.7	5807.7	12431.0	18514.5	31.4
L Leg	183.5	2489.6	3936.3	6609.3	37.7
R Leg	183.9	12753.7	23096.7	36663.4	34.8
Total	1135.7	13319.2	25282.9	39737.9	33.5

Total BMD: 0.798

DXA Picture is reproduced from Dr. Veena Satrughna's presentation with permission

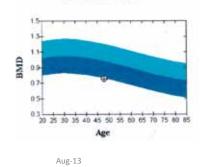
Aug-13

Life-Health Reinforcement Group slides on WH





Image no	t for	diagr	nostic	use
Total	ВМІ	DCV	1.0%	12



Region	BMC	BMD	T-Sco	ore
	(g)	(g/cm2)		
L1 5.00		0.602	-2.9	
L2 7.39)	0.715	-2.8	
L3 9.52		0.814	-2.5	
L4 10.9	2	0.8	827	-2.6
Total	32.82	0.	754	-2.7

DXA Picture is reproduced from Dr. Veena Satrughna's presentation with permission

Life-Health Reinforcement Group slides on WH



	1.6						1
	1.4						-
	13	_					
8	1.0	-	-				-
BMI	0.8					-	
	Ce		-0	-	_		
	0.4						-
	62		44				

Region		Area (cm2)	BMD (g/cm2)	T-Score	Z-Score
Neck	2.55	3.99	0.641	-2.5 72%	-1.7 79%
Troch	3.87	8.03	0.482	-2.7 67%	-2.3 70%
Inter	12.29	16.51	0.744	-2.9 65%	-2.5 68%
Total	18.71	28.52	0.656	-2.7 67%	-2.2 71%

DXA Picture is reproduced from Dr. Veena Satrughna's presentation with permission

Life-Health Reinforcement Group slides on WH

Aug-13

Slide 13

Bone Parameters

Variable	Post opera	tive Duration Mo	onths since	Sig
	surgery			
	<24	24-48	>48	
	Months	Months	Months	
	n=18	n-24	n-13	
Total body bmc	1610.8 ^a	1502.8ab	1374.7 ^ь	0.001
Total body BMD	0.99a	0.96 ^{ab}	0.91 ^b	0.021
Total body tsc	-1.3 ^a	-1.7 ^{ab}	-2.2 ^b	0.022
Lumbar	38.2ª	35.8ab	33.3 ^b	0.049
Spine bmc				0.004
Femur	3.1 ^a	2. 9 ^{ab}	2.6 ^b	0.001
Neck bmc				
Aug-13	Life	 Health Reinforcement Gro slides on WH 	oup	

slides on WH

Slide 14

Cases vs. Controls

Variable	Mean after controlling weight				
	Cases N=40	Controls N=43	SIG		
Total body bmc	1564.4	1675.8	0.030		
Total body BMD	0.96	1.05	0.000		
Lumbar Spine BMC	37.5	42.3	0.008		
Neck BMC	3.0	3.4	0.000		

Control data is reproduced from Dr. Veena Satrughna's study with permission



New latrogenic Situation

- Artificial menopause occurring prematurely in 42% of the study group, 8% showing fluctuating hormone levels,50% with normal values
- As natural premature menopause occurrence is only 1%.-before 40y
- Can no longer assess ovarian function based on menstruation.—needs serial investigations to know the ovarian function
- Simple gynecological intervention now needs multi disciplinary team

Aug-13

Life-Health Reinforcement Group



Limitations of Knowledge/Practice

- 1)?? how long Ovaries work after total hysterectomy
- 2)Surgical disruption of the blood supply to the ovaries
- 3) Paracrine function of an uterus on ovarian function
- 4) Most physicians are trained to see the uterus of little value other than for the purpose of childbirth
- 5) Routinely advising women undergoing hysterectomy to have their ovaries removed to prevent ovarian cancer -- ovarian cancer is quite rare

Thus creating a detrimental, artificial, unusual clinical situation wherein the fact is that this has happened/happening while we are yet to find out follow up required for natural menopausal woman.

Aug-13

Life-Health Reinforcement Group slides on WH



Impact of the Study

- Adopted as one of the case studies in SET Dev project titled >Medical Ethics – A case study of Hysterectomy in Andhra Pradesh >for details please log on to:
 - http://kicsforum.net/kics/setdev/hysterectomy-ethics-in-S-T-for-setdev-final-1.pdf
- Could establish links with local R&D Institutes like NIN
- Corrective steps were taken by Govt.Of A.P., to reduce the number of hysterectomies done under Rajiv Arogyasri.

Aug-13

Life-Health Reinforcement Group slides on WH



The Search is for...

- 1) How to replace the function of removed ovary/lost function
- 2) Is it possible to replace? If it is possible in what form we have to supplement? how long? estrogen /tailor made estrogens(SERMS)/plant estrogen
- 3) How to monitor the side effects of estrogen? How long?
- 4) What about SERMS/for each sign/symptom how many separate SERMS we need to give them?
- 5) OTHERWISE go for alternative -what about phyto-estrogens?
- 8) whether simple plant seeds/leaf can work as ovary
- 6) If at all to prove the effectiveness of plant estrogens –how to prove the efficacy & standardize dose.
- 7) "Whether these fluctuations have has any effect on bone & other parameters like Lipid profile & vaginal mucosa.
- 8)Is this fluctuations similar to menopausal transition
- 9)Needs serial serum FSH values yearly to know the ovarian activity in pre menopausal women as 33% of the women are showing high FSH values after TAH.

Aug-13

Life-Health Reinforcement Group slides on WH



What Has to be Done

- Need to build awareness on how to care of uterus
- Need to practice as per protocol
- STRENGTHEN GYNEC CARE
- Invent new & alternate methods to hysterectomy
- Assessment of ovarian function for at least 10 years by measuring ovarian function once in a year.
- If ovarian function is losing consider them as premature menopause group & follow them as one.

Aug-13

Life-Health Reinforcement Group





Slide 21

Thank You

Life-HRG,
10-16.Amar Premalayam,SBI Colony,Road No.2,
Kothapet,
Hyderabad -500 035,
Cell- 9849020242,
email -lifehrg@gmail.com.

Life-Health Reinforcement Group slides on WH

Aug-13



Prayas/Health Watch Trust 8, Vijay Colony Chittorgarh - 312 001 Rajasthan, India

Tel: +91.1472.243788 Fax: +91.1472.250044 E-mail: info@prayaschittor.org URL: www.prayaschittor.org