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REPORT

Consultation on
Hysterectomy: New Evidence
& Directions for Research, Advocacy and Programs

Indian Habitat Center, New Delhi

18th September 2018

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Introduction

Hysterectomy, the most common non-obstetric surgical procedure amongst women, has become an increasingly important public health issue in India. A limited number of community-based studies in India have suggested that hysterectomy is conducted amongst women at an exceptionally young age – ranging from 28 to 36 years –and largely amongst low-income women. Anecdotal evidence has also indicated a potential role of health insurance, as well as provider and patient moral hazard, in promoting the procedure as a first-line treatment for gynecological morbidity in the absence of appropriate and affordable treatment for rural women in particular.

In 2013, UNFPA supported a national consultation on "Understanding the Reasons for Rising Numbers of Hysterectomies in India." Organised by Health Watch Trust, Prayas and Human Rights Law Network, the consultation brought together over 30 researchers, practitioners and policymakers to examine the current state of evidence, experience and policy regarding hysterectomy and women's health. One of the key issues raised during this meeting was the lack of national estimates of prevalence and patterns of hysterectomy. As a direct result of the consultation, a small technical group wrote to the Ministry to propose the addition of a short module on hysterectomy into NFHS-4. Accordingly, questions on hysterectomy were included that allow for estimates of prevalence, median age, type of facility and reasons for the procedure.

Once the NFHS data were available in 2018, Prayas, Population Council and UNFPA organized a follow-up consultation on 18 September 2018 to examine emerging evidence and identify actions for research, advocacy and programs. Ms. Chhaya Pachauli commenced the consultation by welcoming all the delegates. Dr. Narendra Gupta subsequently briefed the participants about the meeting's objectives and the rationale for this follow-up consultation. Dr Gupta emphasized that Rashtriya Swasthya Bima Yojana 2013 data indicated that hysterectomy was found to be the second most frequent claim (after cataracts) made under the scheme and represented 3.7 percent of total procedures. Also, over 46 percent of all obstetric and gynecological procedures were hysterectomies. He welcomed the diverse background of participants as key to devising a meaningful way forward and introduced the main objectives of the consultation as to:

1. Examine the national evidence base on hysterectomy

2. Propose policy and program priorities

3. Identify areas for further action

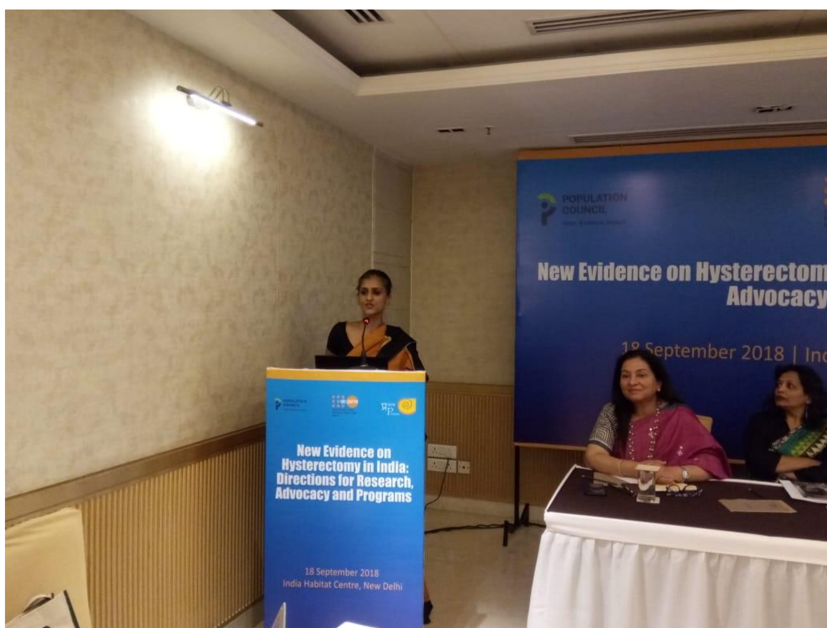
Session 1: State of the Evidence

Dr Kirti Iyengar, UNFPA, chaired the first session joined by Dr Sapna Desai, Population Council; Dr Nilangi Sardeshpande, Independent Researcher; and Dr Jaipdeep Malhotra, President, FOGSI. Directing the session, Dr Kirti Iyengar invited Dr Sapna Desai to share evidence from NFHS-4.

1.1. Dr Sapna Desai: Hysterectomy – A Summary of New Evidence

Dr Desai emphasized that it is essential to examine the epidemiology of hysterectomy to understand population level patterns. Setting the context, she explained that hysterectomy has been a matter of debate in developed countries as well, where population-based studies have provided evidence on trends and concerns. In India, before NFHS-4, the only available data were based on small-community based studies and localized investigations including the PIL with Hon. Supreme Court initiated by Dr Narendra Gupta. Most studies reported relatively low prevalence of hysterectomy, but most of them did not include age at the time of the procedure. She referred to the findings of the first incidence study on hysterectomy in India conducted by SEWA, Gujarat which indicated high incidence, a low median age (36) and about 2/3 of procedures in the private sector. The study also explored drivers of hysterectomy, which suggested a complex combination of individual, socio-economic and health system factors.

Dr Desai shared NFHS-4 findings, which estimated overall prevalence of hysterectomy as: 3.2 percent amongst women 15-49 (0.4 % for 15-29 age group, 3.6 % for 30-39 age group; 9.2 % for 40-49 age group). However, the alarming finding was the median age of 34 years in women who underwent hysterectomy. While the prevalence was low compared to estimates from settings such as the United States, Australia and Ireland (ranging from 22 to 26 percent of women), the median age in India is approximately 15 years younger than global patterns. However, she cautioned that it is difficult to compare prevalence across countries without age-specific or age-standardized prevalence estimates.



Amongst women in ages 40-49, NFHS data shows high prevalence of hysterectomy in four states: Andhra Pradesh (22.4), Telangana (20.1), Bihar (14.5) and Gujarat (12.6). NFHS 4 findings shows that 70 percent of the hysterectomies were conducted in rural areas as compared to 30 percent of those in urban areas. Also, the proportion of hysterectomies conducted in private sector (68 %) was higher than the public sector (32 %). She presented findings from a multivariate analysis of background factors associated with hysterectomy: education, caste, religion, socioeconomic status, parity and age, in which lower education and previous sterilization emerged as the strongest predictors. Dr Desai shared major reasons reported by women for hysterectomy: excessive menstrual bleeding /pain (55 %), fibroid/cyst (19.5 %) and uterine prolapse (13.4 %). Other reasons include cancer and severe post-partum hemorrhage. She concluded the presentation by identifying three types of research priorities: (i) epidemiologic research on long term effects; (ii) intervention research on non-invasive alternatives and (iii) health systems research on incentives and the role of insurance.

Dr Kirti thanked Dr Desai for providing insights on the evidence found in NFHS-4 and invited Dr Nilangi Sardeshpande to present findings from her research on women's perspectives on hysterectomy.

1.2. Dr Nilangi Sardeshpande: Women's perspectives on hysterectomy – Summarising community-based research

Dr Sardeshpande presented an overview of evidence on perspectives and circumstances of women who undergo hysterectomy. She highlighted that gynecological morbidities are a serious issue with rural women, particularly agricultural workers. For rural women, excessive bleeding (or even slightly abnormal menstruation) hampers their work in field, given restricted access to affordable menstrual hygiene products and lack of clean and safe toilets. Research has consistently found that women seek hysterectomy for freedom from pain and difficulty caused by gynecological problems. Dr Sardeshpande emphasized that a fear of cancer not addressed by service providers has contributed to demand for hysterectomy amongst women. The expense, time (including repeated visits) and pain associated with treatment of gynecological morbidities have instilled fears in women and families, rendering hysterectomy a pragmatic decision. Explaining the prevalence of hysterectomy in younger women, Dr Sardeshpande shared that young women are critical, productive family members for agricultural work and household responsibilities. Gynecological morbidities are associated with weakness and limits their productivity. Also, some women report preferring

hysterectomy as an escape from the menstrual cycle and associated taboos once they have desired number of children. She summarised the reasons for unnecessary hysterectomy in the pre-menopausal phase as: increase in insurance-based health services, gender biased view of women's bodies and health, lack of basic gynecological health care at the primary level and unethical practices by doctors. Therefore, despite hysterectomy being a major surgical procedure with considerable side effects/long term consequences, Dr Deshpande concluded by warning that it has become an accepted phenomenon at the community level amongst women, elders and broader society— a "convenient" solution to most gynecological problems. She emphasized the importance of addressing women's views and context when considering alternatives to hysterectomy.

1.3 Discussant: Dr Jaideep Malhotra

Dr Malhotra empathized with the situation of women, especially rural and poor urban women, related to hysterectomy. She acknowledged that most women are caught between household responsibilities and gynecological concerns, along with the financial and physical costs of medical treatment. She suggested that effective interventions to raise awareness on treatment, respecting one's body, sex education and menstrual taboos would help address unnecessary hysterectomy. Similarly, she recommended that counselors should be a part of service delivery to explain the long-term effects of hysterectomy, to ensure that women can make an informed decision. Dr Malhotra emphasized the need for robust clinical practice guidelines and protocols to avoid mistakes and unnecessary surgical procedures along with improved accountability. She shared her disapproval of media-led blaming and nabbing only doctors; instead, she called for analysis of the complexity of the matter and various factors that contribute to medical practices. She advocated the use of info-

graphic and user-friendly health education material, giving examples of programs like Fam Health on Tatasky channel and Save The Uterus by the Indian Menopause Society in order to improve knowledge of individual health and government entitlements. Referring to Dr Sardeshpande's finding that mostly doctors do not provide a definite answer to chances of cancer in gynecological morbidities, she recommended that universal cancer screening be implemented across India.

Discussion

Sterilization and Hysterectomy

Dr Malhotra opinioned that due to many complex reasons, the mind set of getting rid of hassles by just getting an operation drives women and families to seek sterilization as well as hysterectomy. Dr Rajib Acharya, Population Council responded that in the case of sterilization, the family planning program includes incentives for sterilization. Dr Iyengar supported the argument, noting that evidence suggests sterilization is the first choice (especially in the public sector) offered to women who want to adopt family planning. Dr Acharya suggested that the quality of sterilization operations may also contribute to morbidity that ultimately promotes hysterectomy in young women.

Dr Sylvia Karpagam strongly disagreed with the idea that the decision of sterilization and hysterectomy lays with women alone. She argued that doctors, as experts, should influence the decision and provide a patient with complete information. She called for robust medical checks and balances on both government and private doctors as well as the need to promote ethical medical practice.

Dr Reva Tripathi, Head of Gynecology, Hamdard Institute and Dr C. Nirmala, Govt MC, Kerala both noted that broader social and economic factors play an important role, along with women's attitudes, in hysterectomy becoming a permanent solution to health problems. Dr Nirmala emphasized the need to see the bigger picture, of which doctors and hospitals also play an important part. She gave the example of Kerala where fertility rate is lower than the replacement level, yet use of spacing methods (post-partum IUCD) is very low (around 2%) and women prefer sterilization.

Roli Srivastava, Correspondent, Thomas Reuters, shared that she did not observe a link between sterilization and hysterectomy in areas she has reported from (Telengana and Maharashtra). However, she found that women were seeking doctor's advice for the presence of swelling/cyst, for which hysterectomy was offered by doctors as the best solution. She also found that these women were quite young at the time of operation.

Dr Niranjan Saggurti, Population Council, suggested that NFHS should also have covered the other non-medical reasons behind hysterectomy, and that analysis should consider standards to estimate an excess rate of hysterectomy as well as the role of health insurance.

Dr Anant Bhan pointed out that the discussion was not intended to blame the doctors, but that doctors cannot absolve themselves from the issue; they must play a greater role. Explaining the example of the influential role played by doctors in addressing sex change operations, he explained that despite of being a societal issue, the doctors (psychiatrists) played an important role by helping individuals deal with sexual and gender identity issues rather than only promoting conversion surgery.

Conclusion:

Dr Iyengar summarized the session and concluded that setting research priorities would be crucial to understand the hysterectomy issue with more clarity. Research on long term consequences of hysterectomies on women's lives and intervention research on non-invasive alternatives are issues to delve into immediately. Similarly, the role of health insurance in hysterectomy requires further examination. She shared that most insurance packages do not cover non-hospitalized treatments; non-invasive alternatives would not be covered by insurance. She recommended the group consider ways to change perceptions of the operation as a permanent solution to gynecological problems. She also highlighted the critical need to improve medical education.

SESSION 2: Drivers of Hysterectomy: Health Systems Factors

The session was chaired by Dr Nishant Jain, GIZ, joined by Dr Ankita Shukla, Population Council; Dr K. Madan Gopal, Niti Aayog; and Dr Sylvia Karpagam, Public Health Specialist.

2.1 Dr Ankita Shukla: Hysterectomy – Unpacking State Variation.

Further analyzing NFHS-4, Dr Shukla explained that the national prevalence estimate of 3.2 had considerable variation by state and age group. The prevalence of hysterectomy amongst women in the age group of 40-49 years was as high as 22and 20 in the states of Andhra Pradesh and Telangana. Similarly, the age at hysterectomy is 30 and 31 years in these states, lower than the national average of 34 years. More than 80% of women in all states went for hysterectomy to private facility except Gujarat (69 %). The data did not indicate much difference between women from rich and poor background availing hysterectomy in private facilities from Telangana and Andhra Pradesh. However, in Bihar, higher income women sought private facilities more than poor women. At the state level, higher proportion of C-section deliveries, illiteracy and proportion of women workers were associated with higher prevalence. At the individual level, age, parity and household wealth were associated with increased odds of hysterectomy. Uneducated women were found to have higher odds of hysterectomy in all the states. In Bihar, caste and religion also played an important role in hysterectomy. Interestingly, female sterilization was significant in Andhra Pradesh only. Dr Shukla concluded her presentation by emphasizing the need of further state level data on role of insurance, effect of medical interventions like C sections and sterilization on the prevalence of hysterectomy.

2.2. Dr K Madan Gopal: Hysterectomy – Experiences from RSBY

Dr Madan Gopal introduced the basic features of RSBY for the participants and mentioned that hysterectomy became a concern when media reported an increase in hysterectomy among young women, especially in Bihar and Chhattisgarh. Reports accused hospitals of operating on women with no children, conducting un-warranted surgeries and luring beneficiaries for surgeries by touts and middleman. He shared findings from RSBY data which he indicated a "hidden demand" or unmet need for these surgeries. The majority of these operations was done at an appropriate

age and mostly for those who had longstanding, serious gynecological problems. He also noted that in many cases patient or their husbands/ in-laws may demand hysterectomy. Also, Dr Gopal noted that the number of hysterectomies is declining, after an initial rise. However, Dr Gopal acknowledged that instances of unnecessary surgeries and fake surgeries by network hospitals cannot be ruled out and needs to be investigated. In order to prevent misuse of insurance schemes, the government has introduced new regulatory measures:

- Age criteria was introduced in the system, which checks and demands approval if the age is below 40 years.
- Clinical pathways have been documented to support providers in deciding where hysterectomy is required and appropriate
- In Ayushman Bharat, hysterectomy can be claimed for only if conducted in public hospitals, or with approval from a government provider for private hospitals
- Department of Health Research are synthesizing standard treatment guidelines into info-graphics to make them adaptable and user friendly.

2.3. Discussant: Dr Sylvia Karpagam

Dr Karpagam referred to findings of a community-based study on hysterectomy in Karnataka, in which most cases had either no indication for hysterectomy or absence of adequate justification for the procedure. Indicating a lack of transparency, she noted cases from Karnataka in which patients with access to a public health facility for hysterectomy ended up being operated by a private doctor. She accused hospitals of capitalizing on people's fear in issues like hysterectomy (fear of cancer). She suggested that the system of retrospective checks should not be encouraged; checks and balances should be applied to current schemes and programs of health regularly. She speculated that the culture of surgeries would increase and similar situations would occur in heart surgeries, knee replacement, and eye surgeries etc. She also disapproved of reserving insurance claim for hysterectomy to the public sector, only as many women would be left out. She emphasized the role of media and cautioned government agencies as well as private sector to have their own regulatory system in place rather than waiting for media to step in as a "regulator" through reporting.

Discussion

Public vs Private Health Sector: Capability, Accountability and Ethicality

In response to the fact that government (through Ayushman Bharat) has reserved hysterectomy claims for government hospitals only, Dr Malhotra enquired whether our public health system is capable of catering to the large demand for hysterectomies. She suggested a mapping of all primary, secondary and tertiary

facilities to develop a network system through public private partnerships (PPP). Dr Susan Thomas, SEWA, Ahmedabad also expressed concern regarding the public sector and questioned where needy women would go for hysterectomies given the shortage of gynecologists in public facilities.

Ms Reema Nagrajan, Times of India, highlighted the importance of studying the consequences of hysterectomy at a young age and to consider even one unnecessary hysterectomy to be a grave matter as it affects a woman for life. She also asked government authorities to have a prompt audit system for such cases. Ms Thomas, using the example of the PCPNDT Act, also questioned the authenticity of regulations and strict action on doctors following unethical practices. She asked whether, in reality, cancelling a license restricts doctors or gives them freedom to practice without fear.

Dr Himanshu Bhushan, Public Health Administration, NHSRC acknowledged the difficulty of defining unnecessary procedures, and proposed the following solutions:

- Adoption of Clinical Establishment Act by states to improve accountability
- Establishment of clinical governance within facilities
- Provision of second opinion by another doctor before the surgery, as already being done in MTP.

Hysterectomy and Insufficient Data

Dr Devaki Nambiar, from The George Institute of Global Health, noted the importance of examining why the median age at hysterectomy has not changed and continues to be conducted amongst young women. Dr Reva Tripathi pointed out that the sample size used in the RSBY presentation was too small to generalize the findings. Also, she requested the group to apply a scientific temperament and use adequate data while dealing with sensitive cases and to use a correction-based audit system rather than fault finding.

Conclusion:

Dr Nishant Jain concluded the session by supporting the recommendation for a robust regulatory system for both public and private hospitals and doctors. He appreciated that the RSBY data were made available for the public to interpret and noted the importance of comparing hysterectomy data with other surgical procedures. He agreed that retrospective monitoring should not become a norm and that the government is introducing IT-based checks in current programs. Implementation of the Clinical Establishments Act will be critical. Dr Jain concluded with the suggestion that this forum develop a tool for the government to audit hysterectomy cases.

Session 3: Medical indications and Alternatives to Hysterectomy

The session was chaired by Dr Himanshu Bhushan, NHSRC, with Dr Neerja Bhatla, AIIMS; Dr Poonam Shivkumar, MGIMS; Dr Renu Makwana, Vasundhara Hospital, Jodhpur; and Dr C Nirmala, Government MC, Kerala.

3.1. Dr Neerja Bhatla: Hysterectomy - Clinical Indications and Patterns

Dr Bhatla reviewed clinical indications and patterns of hysterectomies and clubbed them into five major diagnostic categories: uterineleiomyoma (fibroids); abnormal uterine bleeding (AUB); pelvic organ prolapse; pelvic pain or infection (e.g., endometriosis, pelvic inflammatory disease, etc.); and malignant and premalignant disease. She presented data for the period 2006-07 and year 2015-16 of hysterectomies conducted at AIIMS. Data indicated that fibroids (49.6 %) were the most common reason for hysterectomies followed by the uterine prolapse (16.7 %). Cases of AUB and CIN related hysterectomy

cases had decreased in the last decade due to availability of alternatives and better response from patients to these treatments. For malignancy, ovarian cancer (37.8 %) was the most common reason for hysterectomies. The data also pointed out a slight rise in hysterectomies in the age group below 30 years, however most the hysterectomies in this age group did show malignancy indications. Dr Bhatla also indicated there has been a decrease in incidents of bilateral salpingo-oophorectomy (removal of ovary) with hysterectomies in younger women (even with malignancy) as the availability of chemotherapy and alternative treatment have improved in this period. Dr Bhatla concluded with three major recommendations. First, to increase availability of treatments and surgeries and understand their applicability through the lens of economic repercussions for the beneficiary. Second, she stressed upon the critical need to study the long-term effects of hysterectomy and ovary removal for women. Lastly, she suggested studies to examine knowledge, attitude and practice among healthcare providers regarding hysterectomy and its alternatives.

3.2. Dr Poonam Shivkumar: Experiences of Hysterectomy in MGIMS

Dr Shivkumar narrated an incident from the Mahatma Gandhi Institute of Medical Sciences (MGIMS), Wardha, in which a 17-year old girl underwent a hysterectomy without the case being noticed by the higher authorities. She was mentally challenged and could not manage menstruation; at the request of family, she had been operated on after consent of two doctors. However, that incident led to introspection at the MGIMS hospital on the use of hysterectomy and resulted in set up of a clinical strategy before a hysterectomy decision is made. MGIMS developed a clinical strategy after a robust literature review. They conducted a two-year retrospective survey in the hospital and analysed the perspectives of women and service providers involved in hysterectomy. Women's demand emerged as an important issue, which they examined deeper. Women and families considered hysterectomy as a once for all treatment to save repeated visits, expenses and inconvenience. Many women shared the fear of being left by their husbands due to these financial and physical burdens, as well as challenges such as hampered productiveness, financial implications of related morbidities, interference with sex, side effects of treatment, the attitude of not feeling hysterectomy is wrong if the family is complete, menstrual taboos and influence of community norms. Similarly, the service provider's survey indicated the following reasons: non-compliance of women to treatment; requirement of special skills and training; fear of being sued if women develop cancer post-treatment, and similar to women, an attitude of seeing no problem with hysterectomy if the family is complete. Dr Shivkumar shared that after conducting this research, the team at MGIMS accepted the flaws and limitations of their present health system and community perceptions. Accordingly, they developed the following clinical strategies:

A system of prospective analysis of hysterectomy cases was set up after ethical committee approval, as well as open audit of all hysterectomy cases conducted by one junior and one senior doctor, preferably an external doctor. Every OT list was shared on a whatsapp group and screened before deciding on surgeries. A senior doctor managed the quality improvement project to ensure all procedures were required and ethical. Post graduate doctors were sensitised about hysterectomy through a symposium, seminars and trainings. Also, village outreach programs were utilised to increase awareness in local communities. As a result, the number of hysterectomies at MGIMS declined steadily. No hysterectomy was done on women younger than 30 years and no women underwent hysterectomy without first having had undergone medical treatment such as Mirena.

Based on her experience at MGIMS, Dr Shivkumar recommended that policy include: audits of hysterectomy cases; compensation for unnecessary hysterectomy provided to women; all hysterectomies in young women be approved by the state before proceeding; alternative medicines made available in the health system; and special incentives given to facilities who conduct less hysterectomy and for appropriate indications.

3.3. Dr Renu Makwana: LNG-IUS – My experience

Dr Makwana shared her experience from her private practice in Jodhpur. She shared case histories of patients who came with high risk for hysterectomy but were counselled to try alternative methods–and treated successfully with LNG-IUS. Dr Makwana shared that around 30 percent of women suffer from excessive bleeding at some point in their life time. She explained myths and taboos towards excessive bleeding which include myths and taboos such as *kachra* blood, the result of eating spicy foods, sign of femininity, return to womanhood or an inevitable lead-up to menopause. Many women avoid treatment in fear of a prolonged, painful and extended experience and assume excessive bleeding eventually ends with hysterectomy. She advocated for improved clinical management of AUB with LNG-IUS. From her own experience, she advocated for LNG-IUS to be an effective alternative to hysterectomy with limited side effects.

3.4. Discussant: Dr C. Nirmala

Dr Nirmala focused on the importance of understanding the complex nature of hysterectomy. She emphasised that while alternatives exist, affordability, technical expertise and acceptability are still questionable and pose great challenges to both service providers and patients. Many of the alternative treatments are not covered by insurance and require repeated visits, thus resulting in higher financial implications and inconvenience for patient. Religious practices and taboos around menstrual bleeding also influence the decision to undergo hysterectomy, especially among Hindu women. The study found that most procedures were done without essential discussions between providers and patients. She noted that the Government of Kerala plans to investigate the association between hysterectomy and non-communicable diseases. She recommended continued research on trends and attitudes towards hysterectomy. She also suggested the inclusion of adverse events reporting, special packages for preventive health care, community-level cancer screening, education for women and community participation as essential steps to reduce unnecessary hysterectomy.

Discussion

Basket of Choice: Modern and Traditional Alternatives

Dr Sardeshpande noted the importance of exploring options available with alternative medicines (AYUSH) to treat menstrual bleeding. She suggested researchers and practitioners could develop an integrated approach to disease treatment and study the effectiveness of non-allopathic options.

Dr Iyengar noted that, according to a study in United States between the year 2002 and 2010, hysterectomy declined by 36 percent due to alternative treatment. Referring to data shared by Dr Bhatla, she emphasised that the high number of unnecessary hysterectomies (especially with benign indications) in India could be reduced if appropriate alternatives were offered. She emphasized the importance of strategies to discourage unnecessary hysterectomies, particularly the inclusion of alternative treatment into insurance packages.

Conclusion

Dr Bhushan summarized the importance of the session's discussion on the complexity of alternatives to hysterectomy and noted that in India, where women's voices are often silent, issues like hysterectomy should be subject to both social and medical introspection. He emphasized the importance of robust systemic data; continued research on morbidity patterns; and understanding of post -hysterectomy complications is essential. Cancer screening is already included in government programs; effective implementation will be a priority. He also acknowledged the potential of AYUSH services to improve the basket of choices available to treat women's gynaecological morbidities.

Session 4: The Way Forward

The concluding session was co-chaired by Dr Leela Visaria, former Director of the Gujarat Institute of Development Research and Dr K. Srinath Reddy, President, Public Health Foundation of India. Panelists were Dr Devaki Nambiar, The George Institute of Global Health, Ms Chhaya Pachauli from Prayas, Dr Amar Jesani,

Bioethicist; and Ms Kajal Jain, MASUM. Dr Leela opened the session by presenting her concern on high number of unnecessary hysterectomies reported, lack of follow up and the pressing need for research on many aspects of the issue.

4.1. Dr Devaki Nambiar, George Institute for Global Health

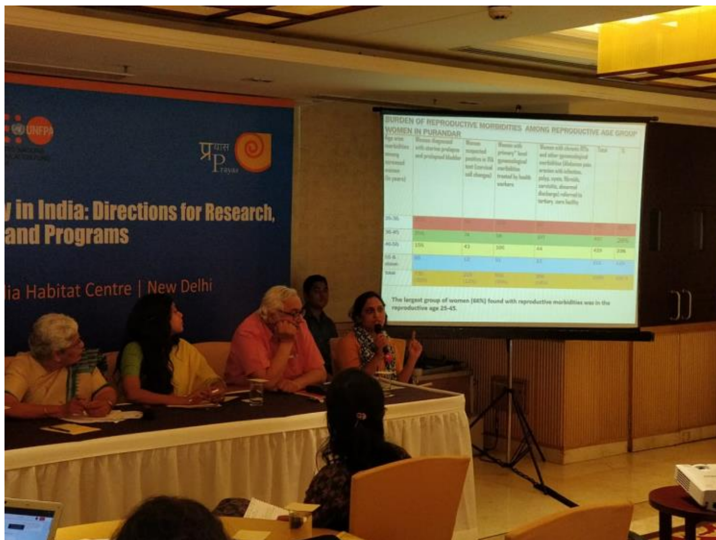
Dr Nambiar observed that, given the introduction of Ayushman Bharat and Health & Wellness Centers, it is now critical to identify where services for gynecological morbidities and alternatives to hysterectomy will be positioned. Addressing reproductive rights and unmet needs of women outside of maternal health care remain a challenge, as most are not met by either scheme at present. She raised challenges such as limited interaction between health care providers and disadvantaged women and limited capacity of the public sector and an over-burdened workforce to implement new programs. She emphasized the importance of research to examine why women choose aggressive measures over other choices. She raised issues of mistrust in the health care system, lack of knowledge and misinformed consent. Further, incentive-based structures may contribute to shortening the window of interaction for women to negotiate their own health care. Dr Nambiar noted the importance of estimating an appropriate proportion of

hysterectomy in a population and the need for audit and grievance redressal for younger women who undergo hysterectomy.

4.2. Dr Amar Jesani, Bioethicist

Dr Jesani felt that limited progress has been made in addressing hysterectomy in the last five years. The state, as an insurer, has developed schemes that involve purchasing care but without rigorous standard protocols to monitor procedures. He also noted the information gap between service providers and beneficiaries, leading to an asymmetry of power, knowledge and accountability – and ethics violations. The health system must address different health needs of women in the context of their decision- making power in the family and community. While the micro-level dilemmas of service providers may be understandable, providers must remember they have power to influence patient decisions. Evidence-based knowledge and medical expertise should drive clinical decisions, rather than patient demand or complex situations. A socially aware professional ethics should be channeled when good clinical practices are challenged by social pressure. The introspection, participation at intervention at MGIMS presented an example for both private and public hospitals to ensure that patient well-being and ethics drive clinical decisions. Dr Jesani emphasized that this is the right time, and hysterectomy is an ideal example, to advocate for comprehensive health care to be included in national level schemes. Hospitalization and alternative treatments must be combined in public insurance to ensure improved health outcomes.

4.3. Ms Kajal Jain: MASUM's Community Based Health Screening Programme



Ms Jain stressed the importance of viewing hysterectomy comprehensively, rather than as a stand-alone health issue. In her experience, women's health needs have not been addressed at the community level. Hysterectomy should be seen a symptom/result of longstanding negligence of reproductive needs by women and the health system. She shared findings of intervention by MASUM, in which 35 percent of gynecological problems could be managed at primary health center while the remaining were referred to an appropriate facility. She

advocated for the availability and affordability of alternative options for women. Using the example of cervical cancer screening, she emphasized the importance of training community health workers (ANM, ASHA) and strengthening primary health centers in order to address gynecological issues at a local level. Women often have no other option except private hospitals, where information and counseling are typically not provided. She concluded with a call to strengthen women-oriented health systems.

4.4. Dr K. Srinath Reddy, PHFI

Dr Reddy expressed deep concern with the new health schemes and questioned whether primary health care and centres would be strengthened. He noted the need to include gynecological morbidities as a part of comprehensive health care. He cautioned that the existing health workforce likely lacked both skills and capacity to address primary health care. Dr Reddy commented on the need of debate on the marketization of health care and health financing mechanisms. He suggested that before the government decides to put the burden of highly demanding services (e.g. hysterectomies) on public hospitals, it should ensure that hospitals in both sectors have similar capacity, which is not the case at present. Dr Reddy stressed the importance of technical and social audits to identify perverse incentives and discourage malpractices, and echoed calls to establish robust standards and protocols.

4.5. Chhaya Pachauli, Prayas

Ms Pachauli noted that all surgeries, not only hysterectomy, should be examined for situations wherein patients are pushed into surgery without appropriate understanding or consent. She said that increasing inclination of the governments on health insurance schemes and privatization of public health facilities through PPPs is a dangerous trend and is only going to make patients more prone to irrational treatment practices, including unnecessary surgeries and other procedures. She shared examples of Rajasthan's Bhamashah Swasthya Bima Yojana and the system's vulnerability to failure due to over dependence on the private sector.

Discussion

Dr Nirmala noted the importance of examining causes of hysterectomy and oophorectomy, the quality of sterilization and mechanisms for effective surveillance and response. Dr Bhan suggested the development of women's departments in medical colleges that examine women's health through a lifecycle approach rather than just reproductive health care. He also stressed the importance of quality improvements and accountability. Dr Bhan recommended that future consultations should involve concerned patients to ensure their perspective and engagement in policies. Dr Tripathi reflected the cost of alternative medicine of hysterectomy (including expensive hormonal drugs, costing around Rs 16 per day prescribed for 3-4 times a day) and questioned their affordability. She also noted the importance of obstetric hysterectomy as a life-saving procedure even for a 20-22 year old woman and to be cautious of using new drugs before confirmation of their safety.

Dr Iyengar supported the need to examine cost effectiveness of alternatives, research on gynecological morbidities and complications and to devise an advocacy plan. Dr Narendra Gupta raised the issue of financial sustainability of private corporate hospitals. He showed his disappointment in the low levels of achievements in term of universal health care. Dr Reddy commented that the private hospitals are in good financial health but over expanded and hence report low profitability. However, with the Ayushman Bharat Insurance Scheme, government might become a resource for the private sector to address their financial concerns.

Summary of recommendations

Of the range of recommendations that emerged, the most consistent suggestions included:

<u>Alternatives to hysterectomy</u>

1. Promote alternative treatments for abnormal uterine bleeding/common indications for hysterectomy
2. Advocate for coverage of non-surgical alternatives within health insurance schemes

<u>Monitoring and accountability</u>

3. Introduce open audits and clinical governance within facilities to approve and monitor hysterectomy
4. Audit the implementation of standard treatment protocols

<u>Research and advocacy</u>

5. Generate evidence on the long term effects of hysterectomy in India
6. Advocate for provision of gynaecological care and education on hysterectomy at the primary level

Vote of Thanks

Ms Pachauli thanked participants and noted that, as five years ago, discussions from this consultation should inform advocacy and programs to address hysterectomy in India.

ANNEXURE-I

AGENDA

Hysterectomy: New Evidence and Directions for Research, Advocacy and Programs

18 September 2018

Marigold, India Habitat Centre

10 am Welcome and objectives	Dr Narendra Gupta, Prayas
Session 1: State of the evidence	
10:15 am to 11:15 am	
Chair: Dr Kirti Iyengar, UNFPA	
Findings from NFHS-4 and community-based research	Dr Sapna Desai, Population Council
Women's perspectives on hysterectomy	Dr Nilangi Sardeshpande, Independent researcher
Discussant:	Dr Jaideep Malhotra, FOGSI
11:10 to 11:30 Discussion, followed by tea	
Session 2: Drivers of hysterectomy: health systems factors	
11:45 am to 12:45 pm	
Chair: Dr Nishant Jain, GIZ	
State-level variation in prevalence State level experience Experience from RSBY	Dr Ankita Shukla, Population Council Representative from Gujarat govt (TBC) Dr K. Madan Gopal, Niti Ayog
Discussant:	Dr Sylvia Karpagam, Public Health Specialist
12:30 to 12:45 Discussion	

Session 3: Medical indications and alternatives to hysterectomy

12:45 pm to 1:45 pm

Chair: Dr Himanshu Bhushan, NHSRC

Clinical indications and patterns	Dr Neerja Bhatla, AIIMS
Clinical strategies and perspectives	Dr Poonam Shivkumar, MGIMS
Non-invasive options in practice	Dr Renu Makwana, Vasundhara Hospital
Discussant:	Dr C Nirmala, Govt MC, Kerala

1:30 to 1:45 Discussion

1:45 to 2:45 Lunch

Session 4:
The Way Forward

2:45 pm to 4:00 pm

Co-chairs: Dr Srinath Reddy, PHFI and Dr Leela Visaria, GIDR

Panelists:

Dr Devaki Nambiar, The George Institute

Ms Chhaya Pachauli, Prayas

Dr Amar Jesani, Bioethicist

Ms Kajal Jain, MASUM

Closing Address: Dr Dinesh Baswal, Deputy Commissioner, Maternal Health, MoHFW

Open Discussion

4:00 pm Wrap up Narendra Gupta and Sapna Desai

ANNEXURE-II

LIST OF PARTICIPANTS

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