Case report

Unindicated hysterectomies in India: the aftermath

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SUMMARY

Unindicated hysterectomy is a disturbing problem in India. Women are counselled into the procedure by the fear of cancer, and by reinforcing their notion that unrelated somatic problems are solved by the removal of the uterus. This is a case of a woman from the state of Bihar, India, who was referred to us after an unindicated hysterectomy at the age of 24, performed as a first-line treatment for lower abdominal pain. This highlights the problem of rising hysterectomy in India and the lack of integrated treatment for women with the debilitating condition of chronic pelvic pain. Pelvic pain and vaginal discharge are often not indicative of pelvic inflammatory disease, and need a more considerate and broad-minded approach. Public health initiatives should take more account of women's lack of knowledge of reproductive health and make efforts to disseminate such information by the use of television, radio and newspapers in local languages.

BACKGROUND

Early marriage, closely spaced childbearing and early hysterectomy is a roadmap followed by many Indian women during their reproductive life. The second most common procedure performed by obstetricians–gynaecologists after caesarean sections, the western world has seen a reduction in the number of hysterectomies, favouring more conservative approaches.[1] While national databases and insurance claims permit large-scale audits in other nations, India is yet to witness nation-wide transparency and accountability in healthcare.[1] Regional surveys and observational studies have shown certain disturbing trends, such as younger age of hysterectomy, absence of cervical cancer screening, absence of any concrete reason for the procedure and lack of histopathological examination of specimens. Little literature on the rate of hysterectomy exists for the Indian population, and even less is known on the consequences on health and psychology.

This case describes the consequences in the life of a very young woman who underwent an unindicated hysterectomy. Such women are not infrequently encountered by physicians in India, but little is described about their plight after the surgery. Indian women's lack of awareness, an exponential shift to privatisation of healthcare, and a generally patriarchal attitude towards gynaecological issues could be reasons for the continuance of this disturbing trend.

CASE PRESENTATION

A 28-year-old home-maker from the state of Bihar, India, presented to our clinic with a plethora of problems. She had undergone hysterectomy in a small hospital in Bihar at the age of 24 for the complaints of abdominal pain, vaginal discharge and lethargy. Her doctor had assured her that her symptoms were due to a 'swollen uterus which was likely to develop cancer' and counselled her into the surgery. She was not aware of what a pap smear was, and said that she had never undergone a pelvic examination in her life. Before this, she had undergone two caesarean sections: the first was for breech presentation, and the second because she was told that normal delivery after previous caesarean was too dangerous. After the hysterectomy, she developed an incisional hernia, and underwent laparotomy for the fourth time. She then developed a sinus tract on the abdomen, with purulent discharge. She had taken multiple courses of antibiotics for the same, and was admitted on several occasions for intravenous antibiotics.

Over the past 4 years, she had visited numerous doctors and paid thousands of rupees for her persistent lower abdominal and back pain and worsening lethargy. She also had vaginal dryness with curdy white discharge, reduced libido, hot flushes and dyspareunia. These sexual problems, along with financial difficulty were causing marital strain, leading her husband to threaten divorce. The only medical records she had were a CT report with no film showing the absence of uterus and ovaries, and a barely legible medical bill: '1. Hysterectomy: Rs. 30,000, 2. Bilateral Salpingo-oophorectomy: Rs. 20,000, 3. Appendicectomy: Rs. 15,000'.

She lived in a joint family with her husband, parents-in-law and two children, both less than 11 years of age. She and her husband were educated till the 11th standard. They owned a shop, with a monthly income of around 30 000 rupees, which the patient said, was barely enough to get by. They had no insurance and every medical treatment was out-of-pocket expenditure.

On examination, her abdomen had several vertical scars which were puckered, with a sinus tract opening with serous discharge (figure 1). Her follicle stimulating hormone level was 56 IU/L, confirming surgical menopause. She reported that she often felt hopeless, helpless and worthless, and a referral to the psychologist confirmed clinical depression. She was anxious of the prospect of divorce as she was financially dependent on her husband. Moreover, in her community, it would lead to extreme ostracization, and remarriage of divorced women was almost unheard of.

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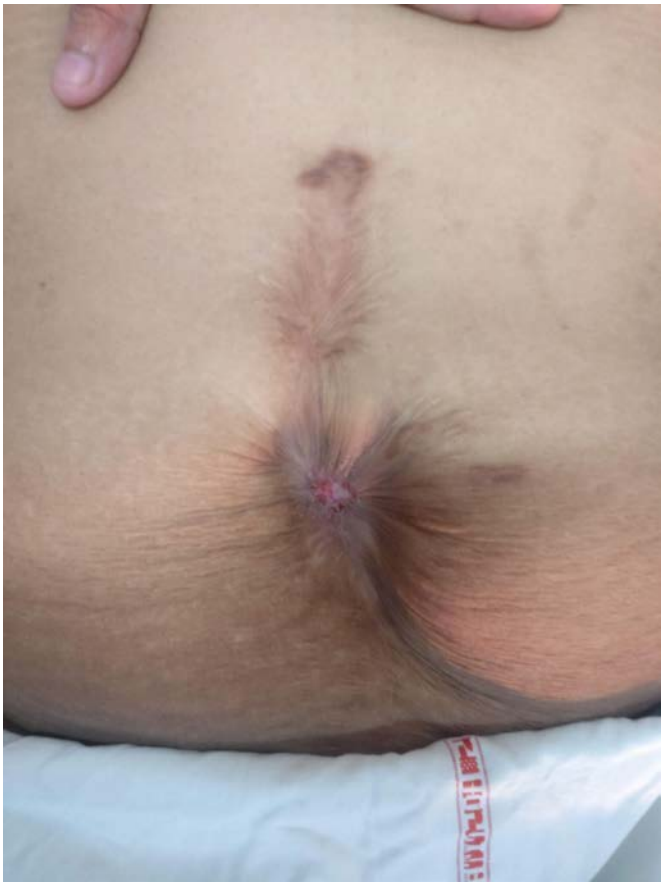

Figure 1 The (visible) scars of unnecessary surgery.

GLOBAL HEALTH PROBLEM LIST

1. There is a disturbing trend of performing unindicated hysterectomies in certain pockets of India with a disregard of ethics. The lack of transparency and medical record keeping leads to unaccountability.
2. There is a dire need of counselling services for women in India to integrate physical and psychological well-being. Chronic pelvic pain is a common problem that is ill-addressed.
3. The stigma and fear associated with vaginal discharge has a sociological basis and contributes to the misuse of medical treatment.

GLOBAL HEALTH PROBLEM ANALYSIS

This case of women being pushed into unnecessary hysterectomy is not uncommon in India. While education and awareness have lead to a declining preference for hysterectomy in the west,[1] the same cannot be said of India, where women still consider the uterus as a dispensible burden. The above case emphasises the serious complications of unnecessary hysterectomies, as well as problems and inequities in the healthcare system which plague Indian society. India is one of the 81 countries that largely contribute to 95% of maternal deaths in the world, and achieving the sustainable goal of health for all by 2030 appears a daunting task.[2] While many surveys have noted the rise of 'unindicated hysterectomies' in various parts of the country, there is a serious need to step up the measures to curb it and guide the medical task force towards where it is truly needed.

Data from the national family and health survey puts the rate of hysterectomy in India at 3.2%,[3] with significant variation between different states. For example, the rate in Bihar was 5.4%, and Andhra Pradesh had the maximum rate of 8.9%. Nearly 70% of these were done in the private sector, with notably higher rates in the less educated and rural populations.[3] In contrast, localised audit-based studies report alarmingly higher rates. In the state of Karnataka, a study aimed at tracing the foci of such activity found that nearly 50% of women who had undergone hysterectomy were less than 35 years of age, mostly from low-income families, and were coerced into the surgery at exorbitant rates with the threat of cancer. Many of these women were not even examined before the surgery, with no operative note or histopathological examination.[4] Desai *et al* estimated the rate of hysterectomy in Gujarat as 20.7 per 1000 women years, nearly four times higher than countries like the USA, Germany and Australia.[5] This compares to the study by Prusty *et al*, who found the rate to be 17 per 1000 women in Andhra Pradhesh, with over one-third of women undergoing hysterectomy below the age of 40 years.[6] In Rajasthan, a right to information petition revealed that out of 385 operations reported by three private hospitals, 286 were hysterectomies, many of which were performed in women under the age of 30, with the youngest being 18 years old.[7] While many of these are paid by out-of-pocket expenditure, it was observed that practitioners misuse government insurance schemes as well.[6 7]

The indications for hysterectomy are often vague, such as vaginal discharge, enlarged uterus or fibroids of unspecified size and symptomatology.[4–7] The factors which lead to hysterectomy have been eloquently studied by Desai *et al*.[5] These include patient-related factors such as menstrual taboos, lack of social and financial security, lack of knowledge, regarding reproduction as the sole function of the uterus and ovaries and lack of access to primary healthcare. Medical treatment of gynaecological problems may require more healthcare visits and facilities such as sonography, pap smear. Moreover, medical treatment of such problems is viewed as a recurring expense that women from economically poorer groups cannot bear. These women are very easily convinced that hysterectomy is a permanent solution, especially if they are not using any form of contraception. This social situation and 'consumer demand' encourages healthcare providers to offer hysterectomy, often as a first-line treatment, for not only gynaecological problems, but as a portrayed panacea for all health problems of women. Ovaries are often removed as a 'safety measure' to prevent the formation of ovarian cysts and possible future litigation.[5]

The original complaint of our patient was lethargy and chronic pelvic pain, both of which were unresolved after hysterectomy. Chronic pelvic pain is a debilitating and poorly understood condition which often leads to dissatisfied women frequently changing doctors, with a world-wide prevalence of 5.7% and 26.6%, but very little literature from India.[8 9] There have been studies which found a significant correlation between sexual abuse before the onset of age 15 and later chronic pelvic pain,[10 11] and this needs to be evaluated in context of the Indian population. In the context of our patient, she is presumably a case of child marriage, and while she did not report abuse, may have suffered abuse at the hands of a male family member before marriage, or even her husband after marriage. Child sexual abuse in India has been eloquently and heart breakingly delved into by the book 'Bitter Chocolate'.[12] A survey in Northern India estimated the prevalence of wife abuse, both physical and sexual, at an appalling 46%, with a strong association with sexually transmitted infections and unwanted pregnancies.[13] In addition to the inherent social problems, the integrated services of gynaecologists, urologists, surgeons and psychosocial counsellors which is essential to help such women, is often lacking, even in tertiary

care centres. The majority of such women, in the absence of sensitive counselling and a varied approach, are misled to feel that surgery (hysterectomy) is the best, only or most permanent solution.

Our patient underwent salpingo-oophorectomy as well as appendicectomy. There is clearly no justification for oophorectomy in a 24-year-old woman, particularly in the absence of surgical documentation. 'Incidental appendicectomy', the removal of a normal appearing appendix during gynaecological surgery, is routinely performed in many hospitals,[14] but the decision to perform it is highly controversial. The American College of Obstetricians and Gynecologists states that 'The decision to perform elective coincidental appendectomy at the time of gynaecologic procedures should be based on individual clinical scenarios after a discussion of risks and benefits with the patient'.[15] Our patient was not even informed of the various procedures that she underwent.

Vaginal discharge is a frequent cause of visits to the gynaecologists in India, and is often associated with unrelated somatic complaints like headache, tiredness and dizziness.[16] It has deeper sociological and anthropological meaning and often does not correspond with genital tract infection.[1] Ayurvedic teaching describes genital secretions as a purified source of energy, and the loss of this leads to loss of energy, illness and even death.[17] This has manifold implications. First, the failure to understand that not all self-reported discharge is disease leads to over-treatment. Second, it forms an opportunity to create awareness of cervical cancer, which, as highlighted in this report, women are receptive to, although out of fear, in this case. Third, it propagates sexual and reproductive health taboos, making women feel that they are 'dirty', or that the uterus is responsible for vaginal secretion that leads to illness and hence its removal will cure all their troubles. This is a frequent cause of recurring medical expense which makes women and healthcare provides alike turn to hysterectomy as a permanent solution.

We tackled this case with an integrated approach: we initiated hormone replacement therapy and counselled the couple about their sexual problems, including the use of lubricants. Our patient was taught physiotherapy exercises which partially alleviated her pain. We treated the skin sinus by a minor surgical procedure.

This case could be construed as the result of centuries of abuse of power against women and misogyny. There are very few studies highlighting the role of gender in medicine in India, and one can only assume the reality from the limited facts. The proportion of women who are part of the medical task force is quite dismal. Estimates by the WHO place the country-wide male:female doctor ratio at 5:1.[18] This has significant interstate variation. For example, in the state of Bihar (where our patient is from), the percentage of allopathic doctors who are women is hardly 5%. Even more disturbing is the fact that nearly 50% of the medical fraternity who practices allopathic medicine does not even have a medical qualification. Our own patient stated that her surgeon was a male doctor. There is no literature on the gender distribution of gynaecologists in India, and such a study may be impossible due to the various types of degrees in India, including diplomas from private and government institutions, and MD (doctor of medicine), and lack of a unified body of obstetricians and gynaecologists. A possible dearth of certified gynaecologists has also lead to general surgeons, a male-dominated specialty, to perform the role of obstetricians and gynaecologists, including caesarean sections and hysterectomies.

The abuse of the health anxieties and doubts of women is indeed a public health issue, particularly in a country that is still struggling with pressing problems like maternal mortality and cervical cancer screening. This problem requires aggressive tackling from many perspectives. Access to reproductive healthcare in the primary setting must be ramped up. Information about sexual health, highlighting the functions of various organs should be disseminated through popular mass media in local languages. Recently, there have been several movies which highlight and attempt to abolish menstrual taboos in India, but these may not be reaching the target population. Many women undergo surgical treatment without even realising the disastrous consequences, and need to be informed better. Unfortunately, the concept of informed consent is taken very lightly in India, especially where rural, illiterate women are concerned.

The Indian Medical Association (Medical Council of India) takes action against healthcare providers with unethical practice. However, there have been instances in which a doctor has had a license cancelled in one state, only to re-establish practice in another state, due to varying laws and lack of a unified licensing examination. A new bill called the National Medical Council Bill is under way, which aims to eliminate corruption in the present medical body by having a government elected council. Addition of non-medical personnel, such as existent in other countries like UK, could reduce medical malpractice. It also aims to create more doctors by creating a 'bridge course', which trains nurses and paramedics for a stipulated period so they can prescribe medication. Such proposals have been met with much scepticism by the medical taskforce, but it is clear that some radical change is needed in the system. Most importantly, as doctors, we should receive more training regarding medical ethics and

Patient's perspective

I had lost all hope. I am forced to go from hospital to hospital for the past 4 years, but my problems have only gotten worse. My in-laws and husband are looking for another wife because they say I have become too much of a burden

Perspective of a fellow doctor

Consent lo, nahi lo, ek hi baat hai, patient toh haan hi bolegi. Husband ko samjhao bas. (Whether you take consent or not from the patient, it's the same thing. She will agree to everything. Just explain it to her husband.) (Words spoken by a male general surgeon who wanted his patient to undergo hysterectomy uterus while she was under general anaesthesia. Pre-operative consent had not been taken.)

Learning points

- Newton's law holds true in medicine: every doctor's action and decision has a consequence and we must try to foresee these in every patient.
- Chronic pelvic pain requires a sensitised approach that often needs to probe deeper than the textbooks.
- It is a doctor's duty to guide women that hysterectomy for benign conditions is often the last and not the first resort, and certainly not a permanent one.
- There is an urgent need to spread information about reproductive and sexual health among the underprivileged populations, so that these women can help themselves by making informed choices. This should be done by mass media and by doctors themselves.

human rights so that we can guide women to make appropriate informed choices.

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