

area of economic rehabilitation leaves the survivors with hardly any options but to suffer the indignities of dole distribution.

As per the guidelines followed by the claim courts, survivor claimants have to prove their cases beyond reasonable doubt to be able to receive compensation. Given that medical prescriptions issued to the survivors rarely mention history of gas exposure and that in many instances prescriptions have not been issued by doctors, it becomes difficult for claimants to establish their case. This is further compounded due to the deep suspicion with which the judges view each case. As a result, claimants in death cases have to face interrogations that require them to recall and repeat details of the pain, suffering and death of their loved ones under humiliating circumstances. This has led to some survivors to remark that instead of Union Carbide it is the victims of the multinationals who are being treated as culprits. For each case of claim, hearings continue for as long as a year and the psychiatric consequences of such prolonged humiliating and brutalising experience are bound to be serious.

Survivors have also to cope with the gradual development of a macabre scenario that surround them. They see doctors making money as do lawyers government officials, medicine shops money lenders, photocopy 'wallahs', etc while the patients get no better; they find Warren Anderson, the former chairman of the Corporation charged with manslaughter with a non-bailable arrest warrant issued against him and still being able to avoid the courts while their sons get locked up at the police station for protesting against such unlawful behaviour, and so on. They find themselves a part of a black comedy. Such an existence is bound to have an impact on the minds of the survivors.

— Satinath Sarangi

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REVIEWS

Women's Testimonies vs Medical Opinion

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The Hysterectomy Hoax by Stanley West with Paula Dranov; Doubleday, New York; 1994; pp 214; price not mentioned.

Hysterectomy: Whose Choice? by Valerie Colyer Farfalla; Random House, Australia, 1990; pp 126; price not mentioned.

IN the past few years there has been an attempt to look at reproduction, reproductive technology, women's body and biology from women's point of view. There have been many individual and collective efforts in this direction all over the world including different parts of urban and rural India. Yet there are issues which have not yet been thought of, probably because of the the urgency other issues demand. And then it is incidents, sudden and important, that begin a number of new debates. For example, the horrible act of mass hysterectomies on mentally handicapped women from a government-run home in Shirur, Maharashtra, has raked up the issue of hysterectomy as a surgery. These hysterectomies performed on very young women (one of whom was just 13 years old) had also raised the question of what could be the effects of removal of the uterus. Was the uterus, removed apparently in these cases to help these women look after their menstrual hygiene, only there for the purpose of reproduction? Did the uterus or other reproductive organs have no role and interaction with the other systems in the body? Did the organ play no active role in the overall health of the woman?

Doctors carrying out the surgery were insistent that hysterectomy was a common enough surgery; and, that the uterus had no other role than creating a nuisance for these 'mentally retarded girls'. While defending this 'common' practice their logic was that one had to weigh the risks of the procedure against its possible benefits for 'these' women. The major benefit, they reckoned was relieving the women of the 'unnecessary filth' of menstruation and helping those looking after these women to cope with the 'dirty' excretion of menstruation. In the understanding of the medical practitioners and those supporting them, these women were not fit to reproduce and so for them the uterus was redundant, it just had 'a nuisance value'. Hence nothing could be more beneficial than removing the uterus at whatever cost.

We, however, fail to look at any of these as benefits for the women. For us the debate rested on issues of responsibility of the state and society

towards these persons with special needs. Such reductionist technological solutions could not in any way resolve the social problems involved, they could just provide convenience to others around these women. This also showed a very restricted view of the human being and the human body, both.

The trouble further was that the medical practitioners kept insisting that there was no surgery-related risk with hysterectomy. They insisted that it was an operation routinely carried out and had hardly any side effects. Knowing the way medical profession and medicine has ignored women's experiences with regard to the use of other medical interventions, especially those related to reproduction, we were wary of these claims. We started looking around for testimonies of women who had undergone the surgery and came across the two revealing books, under review here. One was *The Hysterectomy Hoax* by Stanley West (with Paula Dranov, a noted infertility specialist and chief of reproductive endocrinology at St Vincent's Hospital in New York city and the other, *Hysterectomy: Whose Choice?* by Valerie Colyer Farfalla, a Melbourne journalist writing extensively in the area of women's health.

West's book begins with the following sentences:

You don't need a hysterectomy. It can do you more harm than good. Those are strong words, but the fact is that more than 90 per cent of hysterectomies are unnecessary. Worse, the surgery can have long-lasting physical, emotional and sexual consequences that may undermine your health and well-being.

With these startling statements, the book goes on to explain what is hysterectomy, what its possible after effects are and the available alternatives for the disorders that could lead to surgery otherwise. He states that women have reported effects of the surgery time and again but the medical experts have dismissed these as psychological. In fact, he says that

except when dealing with women's problems, doctors are trained never to attribute symptoms to psychological factors unless we have ruled out all possible physical causes

Our complaints being termed psychological is common experience for us as women. Be it dysmenorrhoea or menopausal problems we had always been told it was in our mind and had nothing to do with the physical state of our body. Yet now reasons are being found also in the changes in the body which even gave rise to the psychological states of depression and mental tension.

In the case of removal of the uterus there is yet another aspect. Modern medicine as practised today ascribes only one function to the uterus, that of conception. So all women who are over the reproducing age or all those who are not considered fit for reproduction like the mentally handicapped are recommended removal of the uterus as a solution to most of their major or minor reproductive health problems. Without hesitation we are also told that there is no 'need' for the uterus in the body so why leave it behind and

be exposed to the possibility of contracting cancer. The fear of cancer and the faith in the doctor's knowledge, opinion and ability is what convinces women to undergo surgery in cases where their opinion is sought. There are many instances, as in the case of the women from Shirur, when even this consent is not considered to be important.

West narrates the incident of a 22-year-old woman who came to his clinic with a complaint of not getting her periods since she was 19 when she underwent a surgery for ovarian cysts. She had also not been feeling well with complaints of hot flashes, joint aches fatigue, headaches, depression, no urge for 'sex' because it hurt, and so on. She had moved residence and so could not go to the hospital where the earlier surgery was performed. On examination West found that she did not have any pelvic organs at all. her uterus, fallopian tubes, ovaries, all were missing. During her previous surgery everything had been removed and she had not even been told about it. Appalled, West tried to find out why this had been done. There was no pathological problem and yet the surgery was performed probably to give some practice in hysterectomy to some student attending the clinic. Besides the horror of this uninformed surgery, West says that the incident provided him personally with new insights.

Although this young woman was unaware of the fact that she was hysterectomised, the complaints that she was reporting were the same as that of other women who had undergone hysterectomies. They were similar to the complaints that were being brushed aside as psychological with no basis. This incident became a starting point for West who then seriously started following up the complaints after hysterectomy. He found a pattern in the complaints and he reports that today there exists evidence that when the ovaries are removed, the absence of estrogen creates a number of problems like increased risk of cardiac diseases, depression, reduction in bone density and reduction in libido. These are in addition to the complications that may arise due to the surgery itself.

What then has come to light in the last few years is that even if the ovaries are not removed, their functioning deteriorates faster than usual until most of the above symptoms are also seen in women whose ovaries have not been removed. The implication of this sudden induced menopause especially on young pre-menopausal women can be quite alarming and distressing. And yet these operations continue to be carried out. According to West between 1965 and 1987, the mean age of women undergoing surgery was done was 42.7 years.

West gives the various reasons for which hysterectomies are normally done and also lists the other viable, effective treatments for these conditions. In the US 30 per cent of the hysterectomies are for benign fibroids many of which would respond to medication or subside on their own. The other major reason accounting for almost 25 per cent of the operations is

endometriosis, a complaint that is becoming more widespread in recent times. Recurrence of endometriosis after the hysterectomy is quite common and so the surgery offers relief in only a few cases. Besides this in 20 per cent of the cases the surgery is done to remove a prolapsed uteri, a complaint which can be treated by alternative means.

The only condition in for which, according to West, hysterectomy is inevitable, is cancer, and only 10 per cent of the operations are done for this reason. He claims that the surgery is obsolete and "does not even necessarily give relief". In the bargain it can result in new problems induced by the surgery. Throughout his book West has tried to provide information needed to 'avoid hysterectomy'. This information provided by a doctor along with the full acknowledgement of the commercial interests of most doctors who insist on hysterectomy, would be vital to all women. And as he rightfully concludes,

Just as basic to full autonomy is control of your body and the right to make decisions about your health and health care on the basis of all available information, free from pressure, scare tactics, and outdated doctor knows best paternalism. It is time we doctors stopped deassembling healthy women. But nothing will change until more women look their doctors in the eye and calmly state their determination to remain intact women.

This collective consciousness and an effort to generate knowledge through our shared experiences finds expression through Valerie Farfalla in *Hysterectomy: Whose Choice?* West is a sensitive doctor no doubt, sensitive to women's pain and relationship with their bodies but the approach and analysis yet remains confined to the medical aspects of hysterectomy. But hysterectomy is not just a medical option. It is an intervention into a bodily function which almost determines women's existence in society. And so, as in the case of other technologies related to reproduction, the issue is not just of medical after effects.

The complex interaction of our body, its biological function and ourselves, the socially defined selves determines also what would be the after-effects of the surgery. Even if the womb is not consciously related to our identity as a woman, it needs a special effort to suddenly get used to the absence of menstruation, a process that has been an indicator of our womanhood. Similarly, even if heavy bleeding due to benign fibroids may not be an indicator of a fatal state as in cancer, the discomfort of that bleeding could be quite detrimental to the person herself.

In such a situation although it is important to know the medical and physiological after effects of the surgery, this is not sufficient information and preparation in case one has to go in for a surgery, even the process of taking the decision is facilitated with knowledge of all these other influences and reasons that affect all our bodies. Valeria Farfalla's book written with support and information from Hysterectomy Support Group in Melbourne, Victorian Endometriosis Association and Cervical Cancer Support Group serves this purpose.

The first part of the book deals with topics similar to those dealt with in *The Hysterectomy Hoax*, that is, information about what is hysterectomy, when is it necessary, what are the alternatives to it, what are its physical complications. Then are sections that are important and different which deal with topics like 'Facing the Personal Consequences' and 'Changes in Life'. These are crucial in dealing with hysterectomy because,

While physical complications can be a problem after hysterectomy, sexual dysfunction, loss of self-esteem and alteration in a woman's perception of her own femininity may have more serious long term consequences.

These experiences are very subjective and quite often conflicting. They are very dependant on the reasons why the surgery is decided upon, the alternatives available to the woman, the support and counselling she is able to get before and after the operation a number of factors all of which have to be taken note of before making such a major intervention into a person's body, into her life.

Judith, in her early forties, said she was devastated after her hysterectomy for cervical cancer because the biopsy report she tracked down after the operation showed no sign of cancer ... She still has ambivalent feelings about sex, reproduction and her psychological life... Sara now unable to have children after her hysterectomy, feels guilty because her husband won't have the joy of parenthood unless they adopt a child... On the other hand, Eva, a German born dentist, has never looked back since her hysterectomy 18 years ago. "It has been a good thing. I have a very good sex life — even better than before."

The book abounds with such experiences of women—experiences reflective of the state of preparedness for each woman. And through these apparently contradictory experiences the book clearly highlights the importance of taking all these factors into account while arriving at a decision and while evaluating the after-effects. It clearly emphasises that we have to accept not only as a physical side effect but also as a state of mind that has to be dealt with when losing organs that are part of one's body; organs, which society almost makes us believe, that are the reasons for our existence. However rational and radical our individual thought process, the impact of these messages from society cannot be just ignored and forgotten. It has to be taken cognition of and dealt with first.

The feeling of grief, a changed outlook towards one's body, especially towards sexuality, a new experience of living — all of these are issues that need to be addressed and efforts made to deal with them positively. This is the contribution that women's health groups have made in all areas of women's health and so too in hysterectomy. Our bodies live in a socio-cultural reality and so the impact of all changes in it has also to be seen in this reality and efforts have to be made to make living a positive experience in an overall sense.

Realising this we feel there are two important aspects of this whole debate. Hysterectomy is a major physiological intervention and the physical implications of removing the uterus have also not been fully explored.

In the light of this it is extremely irresponsible on the part of those proposing hysterectomy for the women with a mental handicap, to say that this is a common surgery and has no side effects. For some women taking these risks without adequate information, and without trying out other methods of dealing with the so-called problems is even more questionable. Such callous indifference on the part of the doctors has to be challenged. At the same time it is important that we investigate what is the implication of hysterectomy for any woman living in this socio-cultural milieu. We also need to find out the extent of its prevalence and the reasons for which it is performed. Only through this process can we evolve our own mechanisms and processes to be able to extend support and strength to each other while facing a situation in which this choice has to be made.

Victims or Perpetrators?

Sandhya Srinivasan

Medicine Betrayed: The Participation of Doctors in Human Rights Abuse, Report of a working party of the British Medical Association; Zed Books in association with BMA, London; 1992.

MEDICAL training does not include a study of the political and social circumstances in which doctors practice. And rarely does it dwell on ethics, on educating doctors of their special responsibilities to their patients, the dangers of misusing their special skills. And the potential for abuse is carried to the extreme when the doctor becomes the accomplice of the state.

Medicine Betrayed is the British Medical Association's second publication on doctors' participation in human rights abuses. The first, published in 1986, established that such involvement was not all that rare. Doctors were known to participate in planning and assisting torture; mistreating prisoners; committing healthy people to psychiatric care, etc. This second report takes a closer look at the circumstances in which torture, and medical involvement in it occurs and at the different ways in which doctors can get involved in torture, both judicial and extra-judicial.

The working group received written and oral testimony and interacted with individuals as well as medical and human rights organisations. After discussing the different aspects of such abuses, it makes recommendations to doctors and medical associations on how to prevent them. The appendices list the stands of various international organisations. The essence of these recommendations is the principle that the doctor's paramount interest is in the patient's welfare, and not the objectives of the state.

The book discusses a number of reasons why doctors get involved in torture — from fear of punishment to the belief that the victim deserves it.

Besides these explanations, which could apply to anyone, the bureaucratisation of the doctor's role often allows him/her to avoid taking a stand.

There are many degrees and types of medical involvement in torture, but the most obvious — and easiest to condemn — is the direct form, when s/he uses skills to inflict pain, mental or physical. But the more insidious role a doctor plays is as the torturer's accomplice — ensuring that torture is carried out without killing the victim. This could be confirming that a victim is fit to undergo further torture, or monitoring the torture to make sure it is not overdone, or treating the victim in between sessions, to enable him to undergo further pain. There is also the doctor who turns a blind eye to evidence of torture, whether by ignoring substandard care to prisoners or giving false or deliberately inconclusive post-mortem reports.

While much torture is done with the tacit, but not open, approval of the government, it is equally important to look at the role doctors play in state-sponsored and socially legitimised violations of human rights. The report looks at three examples in particular — corporal punishment, capital punishment and force-feeding of hunger strikers — where alleviating the distress of a legal act could involve a compromise of medical ethics.

In the first case, doctors are kept on hand, to certify the prisoner fit for punishment, to determine when the prisoner can no longer tolerate the pain, and to treat the injured prisoner. The committee points out that doctors cannot ethically be part of this or any other punitive machinery. Everyone is ready to call amputations and public whippings barbaric, feudal practices. But capital punishment is practised by 'civilised' societies. The examples cited here are primarily from the US, where doctors have participated in executions despite the American Medical Association's opposition.

It might be argued that doctors should be involved to make the death as painless and swift as possible. But even when a doctor does not administer capital punishment, s/he can be made to aid the procedure — by certifying a prisoner fit to undergo capital punishment; treating the prisoner to make him fit for execution; witnessing the execution to confirm that it has succeeded. The BMA condemns all medical participation in all aspects of capital punishment, save the final certification of death, insisting that this take place some time after the execution, and away from the execution site.

On the question of medical treatment of hunger strikers, it is seen as a doctor's duty to revive a critically ill person. When that person chooses to die, should a doctor stand by and watch, revive the hunger striker, even against his/her wishes? The BMA asserts the patient's right to refuse food to the point of death, as a method of protest. Doctors should keep in mind the best interests of the patient, not of the state. And a doctor who feels unable to follow the prisoner's wishes should hand over charge to another doctor.

While noting doctors' extensive involvement in human rights violations, the BMA acknowledges that they are often unwilling accomplices