

WOMEN AND HEALTH

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GYNAECOLOGICAL DISORDERS

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WOMEN & GYNAECOLOGICAL DISORDERS

The existence of gynaecological problems of women has been systematically under estimated and mismanaged.

Crimes of negligence are usually committed quietly specially when it is patriarchal society which has constantly undermined the status of women. The reasons have been several main of course is:

- *discrimination against women resulting in negation of women, their contributions, and their problems;

- *the eclipsing of all other womens health problems by aggressive Population Control activities in the name of MCH;

- *negation of self and their own problems by women themselves due to priority given to the needs of their husband and children even when suffering with acute pain and severe discomfort for prolonged periods;

- *the presence of double standards in our society results to in many innocent housewives being made vulnerable to STD and AIDS from their own husbands. These men in many situations are victims themselves of distorted development patterns which force men to seek employment in heartless cities far removed from hearth and home. Since sexual matters and matters related to 'private poits', are private matters, women continue to suffer in silecne, the pain, the discomfort, and discharge and disparunia (pain during intercourse).;

- *ignorance about the causation of gynaecological problems, infact ignorance of the basic anatomy and physiology of the body made worse by prevailing myths makes matters worse eg. that intercourse with a young virgin girl is a treatment of venereal disease.;

- *unlike male problems, due to the nature of female anatomy gynaecological infections and problems become obvious only after they have long passed the early stages.;

- *difficulty in examination partly due to the womens own hesitation and lack of adequate equipment eg. speculum, examination tables, travelling and adequate privacy required for any such examination further delays the diagnosis which is crucial for proper treatment;

- *inadequate training, functioning, timings and gender of the health personnel at health institutions, inadequate diagnostic and therapeutic facilities to deal with the gynaecological diseases from the very common menstrual problems, leucorrhea, genito urinary infection to STD, AIDS, etc.

There is a need of sensitivity and openness about dealing with gynaecological disorders because women's hesitation or embarrassment to seek medical care often results in the infections becoming too far spread and too serious.

With the incidence of STD going up, with women with ulcers or cervical lesions becoming more predisposed to pick up HIV infection, with non availability of adequate diagnostic facilities for common leucorrhoeas or for 'Papsmear' for cancer of cervix, the commonest cancer among Indian women, lack of adequate medicines to treat even if the diagnosis is made, makes the situation worse.

Lack of privacy even for bathing, toilet facilities, lack of adequate water, lack of adequate menstrual care due to myths, ignorance or result in the problem of gynaecological diseases being found in a much higher incidence. In a community based study 92% women had been found to be affected, according to Dr. Rani Bang's Community based Epidemiological study in Gadchiroli District in Maharashtra. The study had found that average incidence of gynaecological problems at the time of the study was 3.2 per person.

Dealing with gynaecological problems is not merely to effectively treat pain and suffering but work towards preventing it, by ensuring availability of the health facilities, of trained health personnel, but using it as a tool to demystify and demolish existing myths and challenge some of the negative practices, and work towards women learning to accept and respect themselves and their womanhood in spite of what Manu Smriti alleges and what 'Eve' is alleged to represent. Women have been blessed with the gift of creation, this should not become a woe because of repeatedly inflicted unwanted pregnancies, where attempts at terminating the pregnancy create health hazards for the women, or the mere exercise of 'child birth' ends with injury and gynaecological infection, needless surgery and consumption of irrational and hazardous drugs, contraception and consequences of conception becomes her responsibility alone and she must pay the price.

Efforts are helping in understanding of their own female anatomy, their common health problems, ways of preventing them and managing them has to be ensured, through popular education. Creation of 'Sharir Ki Jaankari' by the Sathins of Ajmer and health workers like Dr. Sathyamala, published by KALI is a very good example since the problems affect the health of so many women those involved in issues of women whether it be education, organisation or the highly funded AIDS programmes, the question of preventing and treating gynaecological disorders specially STD etc. has to be put on the agenda.

Awareness about gynaecological disorders will undoubtedly result in questioning the roots of many of these problems eg. with STD & AIDS it will result in confronting the issues related to responsible sexual behaviour and meaningful relationships and not just practice of 'safe sex' where in place of caring, sharing, concern and genuine regards and respect for the 'partner' is an exercise in irresponsible, self gratification where women are treated as mere tools or sex objects.

Dealing with gynaecological disorders like STD & AIDS requires serious questioning of the patriarchal diseases.

Issues that arise are many, is it violation of wifely duty when a women exhausted or unwell says 'no' to her husband and denies him his sexual pleasure. If it is she who must take full responsibility for the use of the consequence of the usage of contraceptive technologies eg. insertion of IUCD, when her gynaecological infection is not first or at least simultaneously treated, or long acting hormonal preparation when she is highly anemic and has bleeding problems. When she must bear the consequence of conception or abortion does she have any say over her own body? Is she in a position to say no and not be made to feel guilty for it or punished for it.

In a society where male double standards are very well known where the price paid for is always by the woman, there is a need to question these double standards and work towards responsible and caring, attitude and behaviour towards women and relationships with them.

In this era of 'disposables' women cannot be allowed to be treated as 'consumable' 'disposable' sexual commodities, and unless these issues are dealt with seriously treating STD & AIDS like 'water borne', 'vector borne disease' or diseases caused by 'dioplet infections is being unrealistic.

The health personnel concerned about the issues of women's health specially STD, AIDS must strengthen the hands of the women, by helping them help themselves, to gain self awareness, self confidence, skills and knowledge so as to be able to prevent gynaecological disorders as far as possible or seek medical help when needed and refuse any exploitation in the name of medicine eg. repeated Dilatation and Curettage, ultra sounds, pumping of hormones, when they are not needed. The pain and suffering of chronic Pelvic Inflammatory Disease only the victim knows. The pain of infertility is different - it is not physical but psychological and social - where a woman unable to bear a child is faced with harassment and humiliation sense of rejection and negation. Probably in

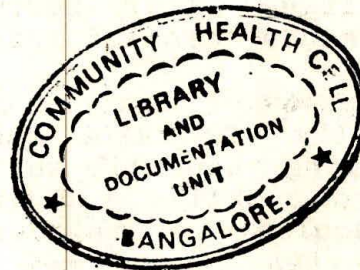
no other problem do women suffer so much from their loved ones from society and themselves as they feel like failures. Women go from pillar to post repeating needless investigations many times over often recommending doubtful treatments with over confidence.

Dealing with causes of infertility and humane and management of infertility is very much needed with simple guidelines and simple list of referral centres and centres where babies are awaiting adoption.

Seeking freedom from gynaecological disorders would be a major step in responsible self assertion and empowerment of women which will not merely in greater contribution of women in being able to lead healthier lives but to their families and society to which they contribute significantly anyway.

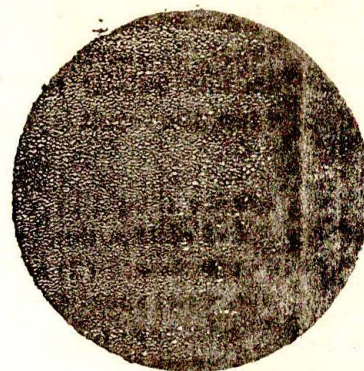
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HIGH PREVALENCE OF GYNAECOLOGICAL DISEASES IN RURAL INDIAN WOMEN

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Summary

A population-based cross-sectional study of gynaecological and sexual diseases in rural women was done in two Indian villages. Of 650 women who were studied, 55% had gynaecological complaints and 45% were symptom-free. 92% of all women were found to have one or more gynaecological or sexual diseases, and the average number of these diseases per woman was 3.6. Infections of the genital tract contributed half of morbidity. Only 1% of the women had undergone gynaecological examination and treatment in the past. There was an association between presence of gynaecological diseases and use of female methods of contraception, but this could explain only a small fraction of the morbidity. In the rural areas of developing countries, gynaecological and sexual care should be part of primary health care.

Introduction

MATERNAL and child health care is one of the eight basic components of primary health care in the Declaration of Alma-Ata. In some programmes, a more focused approach has been advocated and promoted—termed selective primary health care or child survival revolution. There is now concern about the health care of women during

pregnancy and childbirth, and prevention of maternal mortality has been identified as a priority. By contrast, little attention has been given to the reproductive health of non-pregnant women. In third world countries, such women tend to encounter the health care system only when they are the target of family planning programmes.

The term gynaecological diseases is used in this paper to denote structural or functional disorders of the female genital tract other than abnormal pregnancy, delivery, or puerperium. One reason for the relative neglect of gynaecological care is a failure to appreciate the extent of unmet needs in rural areas. Most of the data are from hospitals or clinics and are highly selective; they give no idea of the rates in the population. The few population-based studies have focused only on specific disorders—ie, cervical cancer (chosen for study because of hospital experience), vaginal discharges, and genital infections (based on family planning clinic data). We are unaware of any population-based study of the whole range of gynaecological diseases in developing countries. An additional reason for lack of information on these disorders is the extreme scarcity of female doctors in the rural areas of developing countries.

Traditionally women from these areas are very reluctant to talk to or be examined by male doctors for gynaecological or sexual disorders. Nurses and paramedical workers are not trained to deal with gynaecological diseases; so the result is near total absence of care.

In the present study we sought to determine (1) the prevalence, type, and distribution of gynaecological diseases in rural women; (2) awareness and perceptions of the women about their gynaecological and sexual disorders; and (3) the proportion of women who has access to gynaecological care.

SUBJECTS AND METHODS

Study Area and Sample Population

Gynaecological inquiry and examination is a very sensitive matter for rural women in India. One cannot randomly select a few women from a large population and descend upon them. Hence it was decided to make villages the units of study.

The investigation was conducted in Gadchiroli district, a backward district of Maharashtra state. Two villages were selected on the following criteria: socioeconomic composition similar to that of the average village; leaders who could understand the nature of study and would persuade the women to participate; prevalence of gynaecological diseases not known to be atypical.

Village A had a population of 1406 and village B 2200. They were located 20 km from the district town and from each other. Both had perennial roads. A primary health centre with two male doctors was located in village B while a small mission hospital, run by the nurses was located in village A. Thus both the villages had good access to primary health care, though the nearest gynaecologist was at the district town.

Female social workers, village leaders, and volunteers invited all females who were aged 13 years and above or had reached menarche to participate in the study, whether or not they had symptoms.

Investigations

A field camp was set up in the village, first in A then B, with facilities for interview in privacy and pelvic examination, pathology laboratory, and operating theatre. A base pathology and bacteriology laboratory was established at the project

headquarters 20 km away. The study team (a female gynaecologist with 10 years' experience as consultant, a physician, a pathologist, a laboratory technician, a nurse, and female social workers) visited the field camp and conducted the study. The women who were found to have diseases were offered treatment.

First, information was obtained on personal details, socioeconomic status, perceptions and practices as regards gynaecological symptoms, past experience of care and obstetrical, gynaecological, and sexual history. The women then had a general physical examination including speculum examination and bimanual examination of the pelvis; unmarried girls with an intact hymen had rectal rather than vaginal examination. The following laboratory investigations were done (apart from vaginal specimens omitted in the never married): urine and stool tests; haemoglobin; peripheral smear for typing of anaemia and for parasites; VDRL test; sickling test with 2% sodium metabisulphite; urine culture and antibiotic sensitivities when necessary vaginal smear microscopy and gram staining; vaginal and cervical cytology with Papanicolaou stain, culture and antimicrobial sensitivity of vaginal swab.

Diagnostic terms and entities were those in the International Classification of Diseases, 9th revision. Vaginitis was diagnosed when the vaginal wall was visibly inflamed and the vaginal smear showed at least 5 pus cells per high-power field. When smear microscopy, gram staining, or culture revealed no pathogenic organisms, it was labelled vaginitis of unknown origin. Syphilis was diagnosed when the VDRL test was positive in 1:1 dilution or more. Pelvic inflammatory disease was diagnosed when adnexae were palpable and tender on vaginal examination, with or without restricted mobility of uterus. Jeffcoate's criteria were used for various other gynaecological conditions.

Anaemia in females was defined as a haemoglobin of 11.5 g/dl or less. Iron deficiency was diagnosed on the basis of hypochromia and microcytosis in peripheral smear. Vitamin A deficiency was diagnosed by identification of conjunctival xerosis or Bitot's spot. Sick cell disease was diagnosed by the sickling test, but homozygous disease and trait could not be distinguished, in the absence of electrophoresis.

n Gynaecological and Sexual Complaints
(*n* = 650)

Complaint	Frequency	%
Vaginal discharge	88	13.5
Burning on micturition	60	9.2
Childlessness	36	5.5
Scanty periods	82	12.6
Irregular periods	4	6.9
Profuse periods	32	4.9
Amenorrhoea	132	20.3
Dysmenorrhoea	98	15.1
Dyspareunia	43	3.6
Other	63	9.7

Because of the sensitive nature of the cultural norms of these traditional societies, we aimed at a conservative 50% coverage of the eligible women. In the event, 654 out of 1104 (59%) turned up to participate and the investigations were completed in all but 4. Although every effort was made to persuade both symptomatic and symptomless women to participate, selection might have arisen. We therefore visited a 26% random sample of non-participant women at home to record their personal, obstetrical and contraceptive histories, presence or absence of gynaecological symptoms (vaginal discharge and menstrual disorders), and reasons for non-participation.

The data were analysed by use of the SPSS-PC package on a PC-XT computer.

RESULTS

The mean age of the 650 women was 32.11 years (SD 13.46), 92 (14%) were unmarried, 462 (71%) were married and living with husbands, 28 (4%) were separated, and 68 (11%) were widows. Thus 551 women were married at the time of study or had been in the past. 281 (44%) were farmers, 149 (23%) were landless labourers, 93 (14%) were housekeepers, 21 (3%) had regular jobs, 46 (7%) students, and 55 (9%) were in other occupations. 436 (68%) were illiterate; 84 (13%) had schooling up to 4th standard, 52 (8%) up to 7th standard, and 65 (10%) up to 10th standard, and 8 (1%) had college education.

299 (46.0%) belonged to middle castes and 123 (18.9%) to lower castes; 138 (21.3%) were of tribal origin and 28 (4.3%) from nomadic tribes; and 62 (9.2%) were of other castes or non-Hindu.

28 (4%) of the subjects had not reached menarche, 468 (72%) were menstruating, and 154 (24%) had reached menopause. The mean gravidity was 3.99 (SD 2.77) and mean parity was 3.75 (SD 2.74). 48 women were pregnant at the time of study. Out of 462 women who were married and living with their husband, 254 (55%) were using one of the following contraceptive methods: condom 5, Copper-T 7, withdrawal 2, safe period 2, pills 5, abdominal tubectomy 24, laparoscopy tubectomy 58, vasectomy 151; thus female contraceptive methods were used by 94 at the time of study and had been used by a further 29 in the past, total 123.

Table II-Characteristics of participants compared with 25% Random Sample of non-participants

Characteristic	Participants (<i>n</i> = 650)	Non-participant sample (<i>n</i> = 105)
Mean age (yr)	32.11	43.3
Gravidity	3.99	3.84
Gynaecological symptoms		
Vaginal discharge	14.5%	8.25%
Scanty periods	12.6%	16.4%
Irregular periods	6.9%	14.9%
Profuse periods	4.9%	4.5%
Dysmenorrhoea	15.1%	13.4%
BOH in ever-married	37.6%	51.5%
Current use of female contraception in ever-married	18.2%	11.36%

A total of 360 women (55.31%) had one or more gynaecological or sexual complaints (table I). In addition, many complained of two non-specific but related symptoms—low backache (197) and lower abdominal pain (86). The characteristics and symptoms of those who participated did not differ greatly from those of the random sample of non-participants (table II). The main reasons for non-participation were: no gynaecological complaints 27/105; "I am too old for such things" 17/105; frightened of gynaecological interview of examination 16/105, out of village at time of study 15/105; unmarried, so did not want to be examined 4/105.

Premarital sex among the unmarried was diagnosed when the hymen was torn and the

Table III—Prevalence of gynaecological Diseases among women with and without gynaecological symptoms (Excluding pain in lower Abdomen and Backache)

	Symptomatic	Symptoms-free	Total
With diseases	335	244	599
Without diseases	5	46	51
Total	360	290	650

Table IV—Selected Gynaecological Diseases versus past or present use of Female contraceptive methods in ever married ($n = 558$)

Diagnostic groups	Contraceptive history present ($n = 123$) No (%)	Contraceptive history absent ($n = 435$) No (%)
Menstrual diseases	92 (74.8)	202 (46.4)
Sexual problems	16 (13.0)	28 (6.4)
Vaginal infections	120 (97.6)	352 (80.9)
Cervical diseases	102 (82.9)	292 (67.1)
Pelvic inflammatory diseases	59 (49.0)	100 (23.0)

vagina easily admitted two fingers (girls and women in this area do not use tampons). On this evidence 43 out of 92 (36.7%) of the unmarried girls had had sexual intercourse.

The most common non-gynaecological conditions found in the survey were anaemia (in 91%), iron deficiency anaemia (83%), sickle cell disease (7%), Vitamin A deficiency (58%), filariasis (12%), pulmonary tuberculosis (2%), leprosy (10%), and urinary tract infection (4%).

History of gynaecological examination was used as an indicator of professional gynaecological care in the past. Only 51 (7.8%) had such an examination.

Table III gives the prevalence of gynaecological diseases in women with and without symptoms. As an indicator of gynaecological diseases, gynaecological symptoms had a sensitivity of 59%, a specificity of 90%, positive predictive value 99% and negative predictive value 16%.

Table IV indicates that gynaecological diseases were more frequent in women with a contraceptive history. Of the 12 who had had tubectomies, 54 (66%) attributed symptoms to this procedure

compared with 16 of 151 blaming their husband's vasectomy. The numbers with intrauterine devices (7) were too small for comment.

DISCUSSION

In this cross-sectional survey, the prevalence of gynaecological or sexual diseases (92%) and the average number of such diseases per woman (3.6) were remarkably high. Infections constituted 50% of the burden—vaginitis, cervicitis, pelvic inflammatory diseases—and the rates would doubtless have been even higher if we had used more refined tests. Menstrual disorders from another big group and infection of the genital tract may be a contributory cause here. Fibroid uterus was very rare, and not a single case of carcinoma was found.

The very high prevalences of iron deficiency anaemia (83%) and vitamin A deficiency (58%) were due to the poor economic status of the area in general and of women in particular. The area is endemic for filariasis and leprosy.

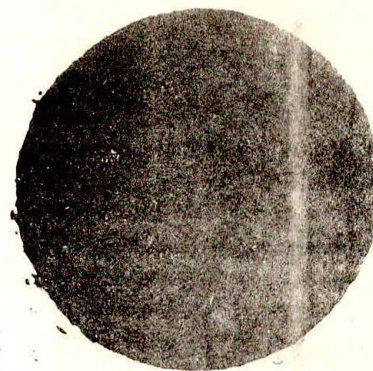
One noteworthy finding was that even symptomless women were very likely to have reproductive tract disease (table IV). Symptoms are thus an insensitive tool for screening. In the presence of a high prevalence rate. The negative predictive value is also very poor. The gynaecological complaints volunteered by women during history-taking were often underestimates—especially with regard to vaginal discharge and menstrual troubles—because of the concepts of normality. Thus only 98 women complained of excessive pain during menstruation but on careful inquiry 269 were found to experience dysmenorrhoea.

There was some truth in the women's perception that contraception causes gynaecological troubles—there was a statistically significant association between certain gynaecological diseases and past or present female contraception. But this can explain only a small proportion of the morbidity since 78% of the ever-married women had never used any such contraception, yet had a high prevalence of diseases.

Unfortunately the diseases that do no kill tend to be neglected. The non-neoplastic gynaecological diseases come in this category, but they could give rise to difficulty in occupational and domestic work.

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OF SHAME AND SORROW: WOMEN IN SILENCE

Manisha Gupte

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The fact that women's access to health care is poor, needs no proving. The shortcoming of the Indian Health Care System, [which sees women only as mother or potential mother is also now more or less accepted by progressive persons in the people's health movement. Even the watered down MCH programme does not effectively reach out to poor, working class, especially rural women. Last year, in the *mfc* bulletin of May, 1989, I have tried to point out some of the direct reasons as to why rural women do not receive good maternal health services.

To compound the tragedy, the woman is completely neglected by public health services. Issues that are not directly related to reproduction and fertility are conveniently swept under the carpet. Because of the anti-nationalist policy of our Government, infertility either as a physiological or psychological problem does not merit due attention. Violence against women, be it through wife battering, harassment by husband's family, rape or incest is either outright rejected or is candled in an atmosphere of mistrust and anti-woman bias.

This article is based on some of the invisible sufferings of women that require sensitive

handling by the medical profession. Naturally, all problems are not covered here. The experiences here are limited to one's own personal encounters with the shame that rural women harbour towards themselves and their own bodies, and the resultant pain that they undergo. All the case studies presented here are confined to a rural tahsil in Pune District in Maharashtra State.

The most common ailments that women in our area suffer from are white discharge, prolapsed uterus, weakness, anaemia, aches—especially back-aches, menstrual irregularity, genital and urinary infections, infertility and a variety of mental illness such as depression, anxiety, hysteria, nervous breakdown, a death wish upon oneself and schizophrenia.

Women wait for unbelievable long periods of time before they seek medical aid for their problems. One woman around 40 years of age, came to the primary health centre with a history of leucorrhoea that started 15 years ago! Though she may not be the rule, the nurses said that on an average women come to the health centre after 6 months to three years of suffering where white discharge is concerned. Sometimes women present

with a mixed problem—menorrhagia for 10-15 days, followed by white discharge. The cycle repeats almost every month.

Sometimes a copper—T induces white discharge, not to mention heavy menstrual flow. There are instances where women also forget about the copper—T insertion and it is detected inside their bodies when they come for other gynaecological problems. In one unforgettable case, Sr Sable of the PHC narrated how a young primiparous came for her delivery. She was accompanied by her 70 years old grandmother. This grandmother became good friends with the nurse and on the third day confided to her about bleeding and how that was a constant source of embarrassment. When the nurse said that an internal examination was required, the old woman further confided that she had a loop inside her! The nurse naturally was greatly surprised. It turned out that 40 years ago when her last son was born a loop was inserted and she had never come back to have it removed. Not surprisingly, the nurse found out that the woman was not only bleeding, but that "there was a frothy black, foul smelling discharge, along with pus". The loop, probably a Dalkon shield, was withdrawn amidst great difficulty and pain. The nurse strongly recommended that the doctor should examine her, but the old woman staunchly refused. "Through all my deliveries, I have never let a male come close to me, and I can't be put to shame in the last few years of my life", She said. She walked away with some vaginal pessaries and vitamin tablets. One can't help suspecting that she may well have been one of the many women who silently suffer from cervical carcinoma.

Women who have delivered at home and who have returned to work immediately after delivery often suffer from prolapses—rectal or uterine, according to the local health workers. They also state repeated pregnancies as a contributing factor. Often untrained delivery attendants (mothers, neighbours) get a woman in labour to bear down unnecessarily during the first stage itself. Random tears are not sutured in home deliveries and later on in life, women suddenly realise that they have a prolapse. Our experience has shown that most often women don't seek any remedial treatment

for prolapses. Unless they have trouble in a subsequent pregnancy they silently continue to suffer the discomfort and embarrassment. After our Mahila Mandal meetings, sometimes a woman will call us aside and then with tremendous shame will venture to tell us about her white discharge or prolapse. Often she has sought no medical treatment, earlier. Sometimes, she has, but the white discharge continues. The nurses in the health centre have never, to date, seen a doctor treat both, husband and wife for white discharge. Women are often given only oral treatment, due to the patients aversion of having to introduce vaginal pessaries, oneself. Thus, in course of time, she is reinfected and the cycle continues, until the woman gives up in sheer helplessness. When women come repeatedly with a history of vaginal discharges, health workers speak contemptuously about their bad hygiene and that intensifies the shame.

Most women refuse internal examination even by a nurse. This makes diagnosis difficult and so often the doctor prescribes without having had a chance to diagnose properly. The nurses said that besides being shy of the doctor, consultant work of home, on the fields or on EGS sites makes it very difficult for women to visit health centres. The only time when women ever come to health centres, they said, was during the summer, when agricultural activity ceased. Some women who have been married for 20-25 years have never stepped out of the village, except to go to their natal families, once a year. Those who live in wadis (clusters) away from the village, come into the village only 3-4 times a year mainly for social or religious functions. Their menfolk bring in the grocery and since they have work to do throughout the day, it is never considered necessary for them to leave except to go to EGS sites, often away from the village. Thus during festivals, women tend to come to the health centre in a "might as well go there" kind of attitude. Obviously, they don't come back to continue a prolonged treatment.

Lack of access to safe abortions is also a great health hazard for woman. Pre-marital and extra-marital relations are very rampant here, as

they are everywhere else, and it is a distressing sight to see a fifteen years old undergo an unsafe abortion. Interestingly, when we were asking women if a pregnancy detection kit was a felt need here, two women discreetly made enquiries about such a facility being immediately available, and both of them were not cohabiting presently with their husbands: one was widowed and the other deserted.

Recently an unmarried teenaged girl was being forced by her mother to undergo an abortion at the hands of a local abortionist when she found out that the daughter was pregnant. The girl, scared, confided in a nurse, who examined her and told her that she was about four months pregnant. After much counselling, the girl was taken to Pune city and an MTP was conducted at Sassoon hospital. Not everybody is as lucky. Various indigenous abortifacients are used - the dangerous ones being mild poisons administered orally and neem sticks being used to insert into the uterus. The efficacy of the less dangerous methods is not yet clear, because abortions are a stigmatised and taboo topic.

Childlessness is another major cause of trauma for women. Whether the couple is infertile, whether the children are dead or whether only daughters are born, the main brunt is borne by the woman in question. Various traditional methods are tried including visiting shrines and fasting to fighting off the 'voodoo' allegedly performed by another childless woman! A young woman who had recently lost her only child was in severe psychological tension. She came with clear 'symptoms' of pregnancy: amenorrhoea, nausea and vomiting. When she was examined, the nurse realised that she wasn't pregnant. On closer questioning, the nurse found out that she hadn't even cohabited with her husband for over six months. The young woman said that the parents-in-law didn't allow their son to sleep with or even speak to his wife, and having lost her baby, she was feeling very lonely. She said "I'm somehow hoping that I have another baby".

If one sees the women who occasionally get possessed by a wide plethora of malevolent

gods and goddesses, one can clearly see that a low majority are childless women, deserted women, and post menopausal women. When a local exorcist was asked to why there were such few "normally cohabiting mothers" in the crowd, she laughed and said 'where is the time available to those women? When you lack something, you turn to god.'

Infertility, either of oneself or of husband (after improvement in the latter case) is thus a cause of great concern, because women fight other women. Constantly suspicious of the motives of other childless women, the woman retaliates with her own voodoo, and thus solidarity between two victims is not possible.

Impotency of one's husband is also borne with shame and in silence. One woman, after twenty years of marriage confided in a health worker and asked if there were any tablets available to cure his impotency. She had, to date, kept silent but since no child was born, the in-law were now coaxing their son to remarry. Another sixteen year old woman, extremely impoverished has just run away from her husband's house, back to her natal family. The husband is impotent and during the two years of marriage, she was ill-treated by her sister-in-law because "she would disclose the fact to someone! She had never been allowed to meet her parents after the wedding for the same reason. When she recently convinced her husband to undergo a checkup; which he did, the in-law threatened to murder her. Today the doctor is refusing to give her the report, though he has orally said that the husband requires "corrective surgery", and the in-law have now sent her a legal notice. They have also been spreading rumours about her immoral behaviour!

A forty year old woman, came to the PHC with leucorrhoea. She was pregnant for the first time. Curious, the nurse questioned her about such a late conception. The husband, a perpetual womaniser, has never cohabited with her. Only during the past one year did he ever approach his wife. "I don't care if a kitten or puppy is born to me", the woman said "but let me enjoy the bliss of motherhood".

She begged the nurse not to repeat the story to her husband, for fear that he would neglect her once again.

A rich landlord's daughter-in-law was also being treated for heavy white discharge. She was her husband's first wife. The husband, a truck driver, is notorious for womanising. Since they were childless, he renounced, and now both wives are simultaneously pregnant. She raved and ranted about her husband's behaviour, yet she said that she was glad to be pregnant.

The indignity that women are subjected to by their husband's constant womanising also is a helplessness that they have to go through alone. Women often complain of 'burning sensation' after intercourse. One woman, whose husband is bigamous and an alcoholic asked if 'heat' from him was being transferred to her. The local word for STD especially syphilis is 'garm' or heat.

Another young girl narrated a horrifying experience when a few days after her delivery her husband beat her to unconsciousness, because she refused to sleep with him. He said "I haven't married you so as to worship you" and then he raped her. He regularly visits prostitute women. She was being treated for 'burning sensation'.

A CHG's daughter, barely eighteen years of age was seven months pregnant, their husband is jeep driver and the in-law know about his womanising. "Would we have got ourselves a stupid daughter-in-law like you, if he had been straight" they would ask her. Last year, she had a miscarriage and now she is worried that her baby might be infected. She herself had such a heavy discharge that she was "even embarrassed to sit down for fear of staining herself". The mother, being a health worker, was keen not to send the girl to her husband until she was completely cured. Within a week of our conversation, however, the husband came after her, and the daughter immediately returned, saying that "it was the only way to stop him from going to other women".

Not all women want to cohabit sexually with their diseased husbands. Only they have no

choice at all. One woman saw some blood on her husband's genitals. The husband, also a jeep driver has two mistresses. This woman pleaded with us to ask her husband not to touch her. "I don't care what he does out of house as long as he leaves me alone". She said that's easier said than done. She is extremely worked up about his behaviour and recently she had a nervous breakdown. She has attempted suicide on three occasions. To make matters worse, her husband is jealous of any male that she speaks to and he viciously beats her, very often.

Another woman, 35 years of age and whose children are now grown up has a similar sorrow. "My husband often brings other women to my own bed to humiliate me". She has severe gynaecological problems: periods stretching over a fortnight each time, while discharge and burning 'like chillies' after intercourse. A drunkard, her husband is also jealous by nature, and however much she pleads of him to let her alone, he won't listen.

Very few women, with clear symptoms of STD approach the PHC for treatment. Also, when widows or deserted women need contraceptives, including sterilisation, they are, quite understandably, reluctant to approach the Government Health Center. In one case, a childless deserted woman came to us for a laparoscopy, saying that she had two children and so she now wanted to get sterilised. Often, women from our area will go outside to get a sterilisation performed as two widows recently did. They went to the neighbouring tehsil, stayed at the PHC for seven days and came back sterilised. Sterilisation however does not protect a woman from contracting STD, and a few months ago, a health worker found two women, one widowed and the other deserted, both suffering from STD. In spite of motivation, they refused to come to the PHC for treatment.

The attitude of women, caught in an awkward situation, is quite ambivalent as far as the health workers are concerned. "If we detect a tricky pregnancy and help women to have discreet abortions, they pretend not to recognise us afterwards".

(Ctd page No. 8)

Sexually Transmitted diseases : a growing menace

S V Morankar

All over the world, sexually transmitted diseases (STDs) are a serious problem; India is no exception. During the past two decades, the number of diseases grouped under STDs has grown from big five (syphilis, gonorrhoea, chancroid, lymphogranuloma venereum and Donovanosis) to more than twenty. A number of clinical syndromes are known to be secondary complications of STDs: acute and chronic inflammations of male and female genital tracts, genital cancers, infertility, hepatitis and even AIDS. In 1985, over a million cases were reported to have attended STD clinics in India; their break-up is as follows: syphilis (30.5%), chancroid (25.9%), gonorrhoea (18.8%) and non-gonococcal urethritis (13.3%). Maharashtra has the dubious distinction of having the highest incidence of STDs; Tamilnadu and Gujarat are not far behind.

I propose to discuss briefly the origin and transmission of STDs in and around Pune, and various social and cultural factors which have contributed to an increase in the incidence of STDs. These observations are based on an in-depth discussion with four medical practitioners and the functionaries of one primary health centre in Pune district. These health workers have treated STD cases in their clinics in an area covering about 30,000 population.

Young adults, married as well as unmarried aged between 18 and 25 years, form the biggest group at risk. Each practitioner sees and treats atleast 3-4 fresh cases of STD per week. The majority of cases contract infection from one of the three sources: urban, rural or contacts during travelling.

The practitioners identified Pune as the main urban source for the transmission of STDs since a large number of prostitutes are available there. Prostitution is also prevalent in urban centres nearby. The rural youngsters, naive and gullible as they are, often visit prostitutes when they come to urban centres only to go back with STDs. Strange though it may sound, the popular Ganesh festival in Pune breeds an alarming number of

STDs almost year after year. So do *Jatras* and *Tamashas* in villages when the STDs suddenly show a positive swing. People who have visited urban prostitutes and who have developed STD also frequent these women in rural areas only to infect them further. These women in turn pass on the disease to 'first-timer's'.

Prostitution is not restricted to Pune city and urban areas but with rural areas in Western Maharashtra getting rapidly industrialised, it has started spreading there too. As an ANM supervisor with a long experience of working in PHCs told us, the prostitutes are steadily migrating from Pune to these virgin areas in search of 'business'. What is even more alarming is the observation of local medical practitioners that the clandestine sexual activities among widows, divorced/deserted women, unwed girls and economically poor married-women is showing a phenomenal increase. Indeed, the sexual perversions have taken such an ugly turn that sexual promiscuity and extra-marital relationships apart, incestuous relationships are also surfacing in rural areas.

The roadside *dhabas* and motels, where truck drivers and their assistants usually eat their meals and retire overnight have also developed as new centres for prostitution and large number of STDs owe their origin to these centres.

The local medical practitioners have observed that STDs are no respecter of economic class: rich and poor have been equally found to have affected with STDs. Particularly vulnerable are unmarried adolescents. They develop morbid fears about their potency—borne out of sheer lack of sex education—and in order to prove their manliness or virility, they visit prostitutes only to come back with STDs. Many a marriage here had to be postponed because of pre-marital sex-induced STDs and the doctors had to prevail upon these youngsters to undergo full treatment before marriage. Since the parents are usually oblivious of these diseases in their grown-up children, the doctors often have tough time explaining them as to why they wish to have marriages postponed.

Since, by and large it is males who get themselves treated for STDs, the number of women infected but untreated—is gradually swelling. The health practitioners usually motivate married men with STDs to have their spouses treated simultaneously but this seldom happens and hardly 1-2% couples see their doctor for full treatment. To evade embarrassing probing from the elders in the family, STDs in women—all too often passively contacted are kept a closely guarded secret. And yet it is invariably the wife who takes the blame.

Further, *Garmi*, as STDs are here colloquially called, is usually attributed by a mother-in-law to her daughter-in-law's indulgence in "too much tea" or "hot and spicy meals". The daughter-in-law is generally forbidden to sleep with her husband nor is she permitted—at times even actively discouraged—to go to a doctor to seek cure. This unfortunately leads to a very piquant situation: intra-marital relationships are irreparably broken, new extra-marital affairs develop and STDs simply proliferate!

Repeated, and mixed, infections are common and have been noted in as high as 25% cases.

(Ctd. page 4)

A nurse said that sometimes they can almost guess that a women patient has some grave problem back home, but that it is not possible to do anything about it. "Women are suspicious and afraid. They feel that we may misuse the information about their personal problems or even that co-incidentally we may be relatives of their husband's families. They are also scared about the consequences of speaking out their problems." Women, who are victims of stark violence already, are reluctant about speaking out for fear of "what can happen between the four closed walls of their homes". As a cynic aside, the nurse said "when we are ourselves unable to stop our husbands from beating us, we can hardly help patients."

A vicious circle of silence, shame and sorrow is thus set into motion. The health system

Even such drastic advices as "next time you might as well loose your penis" or "we will have to chop off the diseased organ next time" fall on deaf ears. Only a quarter of STD cases receive full treatment; majority discontinue treatment midway through. This may cause, and has already contributed to, drug resistance. Access to over the counter drugs and antibiotics is easily possible. The repeat cases seldom see their doctors/health workers. Instead, they would directly go to a chemist, manage to hoodwink him by showing an old prescription and thus would get self-treated. The inadequate and self-treatment is obviously not without dangers but there is little that the health workers can do to stop it.

So what then is the solution? The health practitioners strongly feel that sex education to adolescent boys and girls and students in their pre-college days should help. It might help boys resist the temptation of going for a 'potency test', girls won't easily go astray and the number of unmarried mothers and unwanted pregnancies would fall too, with a substantial reduction in the number of STDs.

is inadequately equipped to deal with violence against women, or with disorders that can't be cured with quick medication. On the other hand women who suffer can neither speak nor approach the health services. Shame towards one's body is not restricted to *leucorrhoea*, or childlessness it is also manifested through stigma of menstruation and child birth. As principle actions in the struggle towards their own liberation, it is only a progressive organisation of women that can give voice to women's fear and shame, then proceed to question the inadequacy of the health care delivery system to hear out these demands. It is only through a forceful voicing of our problems outside of our four walls that can reduce our persistent fears about what can happen to us inside them.

Why Women Hide Them

Rural Women's Viewpoints on Reproductive Tract Infections

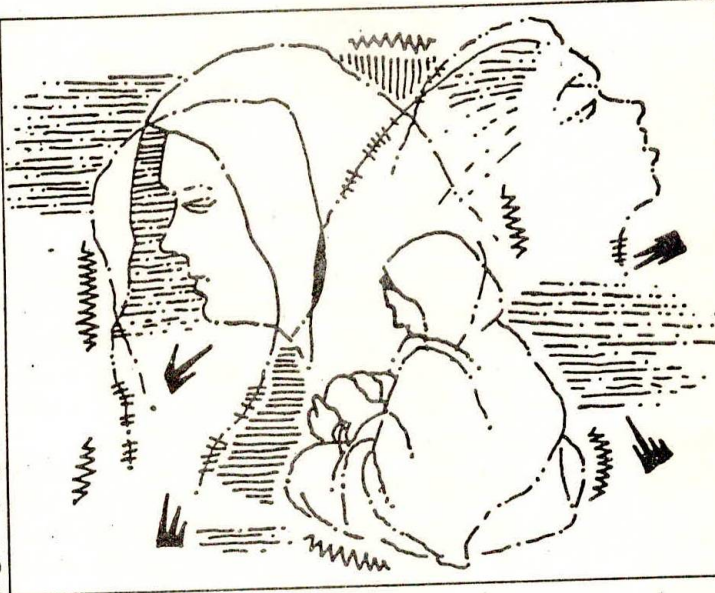
Rani Bang and Abhay Bang
with the
Search Team

Gadchiroli is a remote district of Maharashtra, where we run a small non-governmental organisation called *Search*. Four years ago, through a community based study, we discovered that gynaecological diseases were a major cause of illness among the village women, already burdened with poverty and oppression. Since then we have tried to develop a programme for reproductive health care. Through women's group meetings and cultural

jathas, an attempt has been made to create awareness and interest among them regarding issues like Reproductive Tract Infections (RTIs) and other gynaecological diseases, unwanted pregnancies and abortion, adolescent health, sex education and reduction of childhood mortality. In an area of 58 villages, we have trained community-based health workers like nurses and Traditional Birth Attendants (TBAs) to diagnose and treat RTIs apart from giving related health education.

Sex and reproductive life is a very private and secret matter in Indian society. These illiterate rural women have honoured us by sharing with us their private lives.

Through our community based study of gynaecological diseases, we



found that 92 percent of women interviewed and examined in the two study villages had gynaecological diseases, half of which were RTIs. Only 7.8 percent of these women had ever received medical care for gynaecological problems. Women had their own world of beliefs and practices in relation to RTIs. They had only marginal interaction with the medical care system.

RTIs cover a very broad field encompassing many aspects of reproductive life. Women do not have any medicalised concept like RTI. This is an abstract concept for them. The reality for them is what they experience and suffer. When 30 men and 32 women were asked to list women's health problems in the order of their

perceived importance, 95 percent put white discharge as the most important and common problem. One woman said, "Like every tree has flowers, every woman has white discharge. Except that it's not soothing like a flower." In the study of gynaecological diseases, we found that 75 percent of women examined had white discharge. I have chosen to focus only on women's views on white discharge as the major manifestation of RTI. These views were

unravelling during four group discussions with 60 women, interviews with couples, interviews with 22 key informants, especially TBAs, open ended interviews of 65 women, and from the perceptions of the 654 women examined and interviewed in our previous gynaecological study.*

Twelve synonyms are frequently used in our area to describe white discharge. This shows how important a role it plays in the lives of women. White discharge is experienced as clothes getting wet or stained or starchy or passing white sticky discharge during urination or defaecation, or by smell. A few women said, "One feels as if bubbles

* R.A. Bang et al., *Lancet*, January 14, 1989, p.85.

are coming out." The profuse discharge is sometimes called "white menstruation". One TBA confided that she goes around in the village, and watches the hanging linen of women. From the stains, she can determine who has white discharge. White discharge is also diagnosed if a woman is feeling weak for any reason or if the urine collected in a container shows white sediment at the bottom.

Women have their own classification of white discharge into five categories, each with distinct characteristics and different significance. There is a hierarchy of seriousness among them. One called *pair*, which means blood stained discharge, is supposed to be most serious and an omen of death. This intricate classification shows that the village people have closely observed and thought hard about white discharge.

The perceived cause of white discharge is heat bursting out from inside the body. This heat may be caused by a woman having an inherently defective constitution, or it may enter the body through intercourse with an alcoholic or promiscuous husband. On noticing white discharge, women often conclude that their husbands must have slept with another woman or visited *bhut khana* (haunted house), which means the red-light area. If the husband does not have a problem, the woman is supposed to have caught it from a premarital or extramarital relationship. Consumption of food supposed to be hot is also said to cause or aggravate this heat. Unfortunately, most of the nutritionally rich foods such as milk, cream, eggs, meat are sup-

posed to be hot and hence are avoided by already mainourished women. It is difficult to say whether this is a cultural conspiracy to keep women away from nutritious food or a consolation because they can't afford to eat these costly foods anyway. Twenty five percent of women, mostly those who have used female methods of contraception (specially IUD and tubectomy), said that these methods result in white discharge. Weakness due to any cause is also supposed to cause white discharge. When there is profound weakness or *swapna vikar*, that is, dreams of sexual intercourse, or when the white discharge becomes chronic and does not respond to treatment, then it is attributed to witchcraft or black magic.

The site of origin of white discharge is believed to be somewhere in the pelvis but independent of the uterus. One TBA even said that there is a separate sac (bladder) for white discharge.

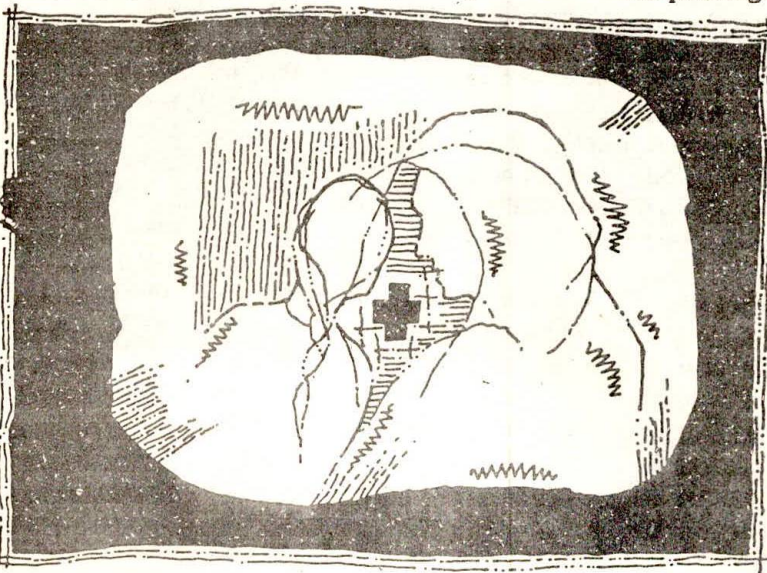
Doctor's Perceptions versus Women's Perceptions

When we first discussed among ourselves studying gynaecological diseases in rural women, a guest professor of gynae-obstetrics at John Hopkins University remarked that it

was not a problem worth studying because in his view, "Women may continue to pass white discharge but how does it matter? It is an innocuous symptom like nasal discharge!" But how do rural women feel about this symptom? The perceptions of this expert and those of rural women about the ill effects of white discharge are diametrically opposed. Our community based study vindicated the perceptions of the village women. In the original gynaecological study, 654 women were asked "Is white discharge a disease?" and 90.4 percent of women replied "Yes, it is a disease and quite a serious disease." Women believe that this is a chronic disease which drains energy and blood from the body and leads to severe weakness and ultimately death. Women described 29 types of ill effects. The more important among these were weakness, anxiety, and guilt feeling, pain, loss of libido, dyspareunia and genital discomfort.

A woman comes to the clinic. I ask her, "What is the problem?" She answers: "Weakness". When, I ask her, "Do you have white discharge?" She almost always says "Yes". (95 percent of women with white discharge come complaining of "weakness".) The

perceived relationship between white discharge and weakness is so close that they are used interchangeably. This is probably for two reasons. Women strongly believe that white discharge drains off body energy and leads to weakness (*kamjoori*, *ashaktipana*). This belief is rooted in the philosophy of Ayurved — the ancient life science of India,



which emphatically states that semen is concentrated energy and its loss in men leads to incapacitating weakness. Loss of white discharge from a woman's body is supposed to have a similar consequence.

This 'weakness' is an all encompassing term — it is physical, mental and sexual weakness. Thus the term weakness carries wider meaning than is generally perceived by most doctors or health professionals. There is another reason for the symptom of white discharge being interpreted as weakness. A woman often has a profound sense of guilt and shame when she has white discharge. The woman herself, her husband, and village community all may conclude that she had an extramarital relationship. The husband scolds, "*bhosadichi, konasobat nijall asen mhanun asa jhala*" (You woman with large vagina, you must have slept with someone else.) If the husband develops the symptom first and the wife later, then the woman is supposed to have contracted it from her husband. But this is again shameful, because it is as a sign that the woman's husband is not satisfied with her and hence his interest is wandering. Thus, white discharge is always associated with guilt feelings.

White discharge is often accompanied by a loss of libido ("*akarshan kami hote*" — attraction becomes less), discomfort and dyspareunia, feeling of shame, guilt and anxiety. Together with weakness these all result in a disturbed sexual and marital relationship. A woman pleads with her husband not to have sex with her either because she does not have the desire or because she believes that her husband would contract the disease and would also become weak by having sex with her. But the husband usually becomes furious and abuses her by saying something like "*Tula kaun keli? nusta zopun rahanyasathi*

aan khanyasathi?" (Did I marry you only to feed you and rest?) or "*He ka sangate rand! Dekhi jayegi tabyet, ab to chahiye!*" (Bloody woman what nonsense are you speaking? I shall see about my health later on. Right now, I want sex.) Women complain, "Men don't want to spare us a single night. They are very arrogant!"

One TBA and her daughter-in-law complained that the daughter-in-law had white discharge, loss of libido and dyspareunia, but her husband would not listen. The mother requested her son to avoid sex with his wife but the son flatly refused and retorted to his mother, who is a widow, "*Tumhi navhata ka kela? Ata mala sangate rand! Tule nahi bhetala tar mee bee tasachrahukay?*" (Didn't you have sex with my father? Now, since you don't get it, you want to deprive me also?)

White Discharge and RTIs

The community based study of gynaecological diseases in rural women showed that out of 553 women examined, 414, that is, 74.86 percent had white discharge.

In these 414 women, we found.

- Cervical erosion in 89(21%)
- Cervicitis in 155(37%)
- Endocervicitis in 57(14%)
- Pelvic Inflammatory Diseases in 133(32%)
- Bacterial vaginitis in 254(61%)
- Candida vaginitis in 155(37%)
- Trichomonas vaginitis in 71(17%)
- Senile vaginitis in 17(4%)
- Vaginitis (unknown origin) 23(5%)

When the question "When should a woman with white discharge seek treatment?" was asked in the group and individual interviews, all the respondents said that white discharge should be treated immediately as soon as it appears because if not treated, it progresses rapidly and may lead to serious complications and ultimately death. But from our gynaecological study, we noted that only 7.8 percent

of women had gone to the modern medical care system for treatment of gynaecological diseases. How do we explain this? Non-availability of doctors in rural areas, cultural inhibitions in consulting male doctors for gynaecological diseases, lack of time, money and support contribute to a very low proportion of women seeking medical care. But the major obstacle is the reluctance of women to admit that they have white discharge. Thus in our gynaecological study, 74.86 percent of women were found to have white discharge but only 125, that is, 22.60 percent had complained of white discharge despite careful enquiry by the gynaecologist. When probing questions were asked why did these women hide their complaint of white discharge? Over half (60.1 percent) of these women said that they felt too shy to tell the doctor as they thought I might suspect their chastity; 25 percent of the women said that, as a doctor, I should have detected it myself, and 15 percent said I should have myself assumed it as most of the women have this problem.

Why Women Hide It

Because of its perceived link with promiscuity, women try to hide it. Sometimes "*Sota fodat nahin*" — the woman does not disclose it herself. Other women in the family, when they notice the stains on clothes while washing, report it to her mother-in-law. Women don't easily disclose the complaint of white discharge to other women to try to prevent the news spreading throughout the whole village.

The hierarchy of sources of care is as follows. Home remedies are invariably tried first on the advice of an old experienced woman or a TBA. Next comes *vaidu* — the village herbalist. If there are sexual dreams and also sleeplessness along with white discharge, then it is supposed to be caused by witchcraft or black magic and hence

the help of a *mantrik*, a healer who uses witchcraft, is sought. If all these fail and if the husband shows concern and the family has resources, then a doctor, generally a private practitioner, is consulted. Since there are practically no female doctors or gynaecologists in rural areas, internal pelvic exams are not done and the diagnosis and treatment is based only on a description of the symptoms. Even in trying to explain the symptoms, there are communication barriers. A woman cannot describe her genital symptoms openly to a male doctor so she speaks obliquely in symbolic language. The doctors, trained in western medicine, being unaware of the hidden meaning of these subtle symbols, fail to appreciate the woman's real problem. Thus when she says she has weakness, the doctor treats her as a case of anaemia, leaving her problem of white discharge untouched.

Women even have preventive herbal therapy for white discharge. The tender shoots of a tree called *katsawari* are consumed by women and are also given to their young daughters to prevent the occurrence of white discharge in future. This practice is so widely prevalent that now it is difficult to find this tree in the forest because its shoots are nipped at an early stage.

Women have described to us nearly 40 types of indigenous treatments for white discharge. They are widely used and believed to be effective. But Shrimati Walabai, the oldest and the wisest TBA in our area, confided to me that the modern medicines given to them (TBAs) by *Search*

for treating white discharge are far more effective than the traditional remedies. Who knows the truth?

Most of the women believe that their husband should also be treated simultaneously, as he could be both the cause and an additional sufferer of the illness. But usually husbands refuse to seek care if they don't have symptoms. If men have a symptom of urethral discharge, they get very upset and seek treatment quite early.

Conclusion

Rural women in developing countries are carrying an unbelievable burden of gynaecological diseases, especially RTIs. A policy maker at the Indian Council of Medical Research once questioned our statement



that gynaecological problems are a major cause of ill health of women. "If rural women have white discharge, so what?" was his remark. Our study of gynaecological diseases and the perceptions of women about their gynaecological problems show that such policy makers are wrong. It is an unfathomed iceberg which can no longer be ignored. White discharge is the number one health concern of women. All of us must take note of this and respond to it.

RTIs in women is not a mere microbiological infection. It is interconnected with complex cultural factors. The solutions for prevention and treatment of RTIs take these factors

into account. Hence, the approach developed by *Search* to deal with reproductive health has attempted to evolve a programme with four components—study of perceptions and practices of women and men, medical and epidemiological study of gynaecological diseases in women, health education using methods like women's awakening and health *jatra*, and lastly the training of village-based health workers and TBAs for diagnosis and treatment of RTIs.

Propagation of contraception in women with RTIs is adding to the distress. The poor women already are suffering from inflamed vaginae, eroded cervixes and infections in and around uteri. Imagine the agony they

suffer and the bad reputation it brings to family planning when a foreign body like an IUD is inserted in her under such conditions. By rejecting contraception, poor women of the Third World are

sending signals to policy makers in Delhi, Geneva, New York and Washington — "No contraception is acceptable without gynaecological care."

We professionals have tended to reduce women's health problems to convenient, narrow programmes depending on our expertise. Sometimes it is family planning, sometimes it is maternal mortality, and sometimes it is abortion. Women's lives know no such compartments. That is why we have repeatedly appealed to health care providers, asking them not to speak of just maternal health but to speak of women's health, women's total reproductive health. □

Oxford Textbook of Medicine

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Infectivity. The estimated figures for infectivity vary but is commonly assumed to be around 50 per cent. After a single exposure the figure is nearer 25 per cent.

Some control measures. The main source of case finding is the more intensive use of serological tests for syphilis as already mentioned. Another valuable control measure is contact tracing, which is very variable in different countries, but should be standard practice everywhere. Its use across international borders should be developed with proper safeguards to preserve confidentiality. Other measures which should prove valuable are the education of the young without inducing anxiety, the education of doctors, and encouraging regular check-ups of high-risk individuals such as homosexual men and prostitutes. The obligatory antenatal blood test for syphilis should continue. A more controversial suggestion is to treat contacts of infectious syphilis epidemiologically in certain situations, e.g. promiscuous individuals, known defaulters, and those who may infect their regular consort if not treated.

These measures can be expected to uncover up to 75 per cent of all cases of syphilis.

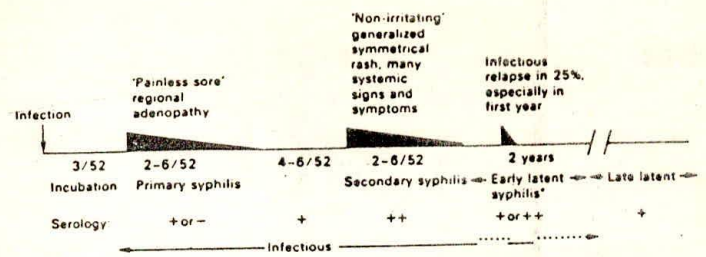
Persistence of treponemal forms. Persistence of *T. pallidum*-like forms in the CSF, aqueous humour, lymph nodes, and other tissues in penicillin-treated patients with late or late latent syphilis has been reported from several centres. The same phenomenon is the basis for relapses after penicillin treatment in borreliosis (see page 5.295). In some cases, the forms may have been non-pathogenic treponemes or artifacts, but in others rabbit inoculation confirmed them to be pathogenic *T. pallidum*. These treponemes appeared to be fully sensitive to penicillin in animal experiments.

Their presence in the aqueous humour or CSF might be explained by the low concentration of antibiotics in these locations. This is not the case in lymph nodes and other tissues and as yet there is no explanation for their persistence. As these cases are very rare there appears to be no need to change our ideas about treatment or prognosis.

The natural course of untreated syphilis. *T. pallidum* penetrates the abraded skin and intact mucous membrane. Within hours it becomes disseminated via the blood stream and lymphatics and is beyond any effective local treatment. The incubation period is traditionally given as 9–90 days but in practice it is around three weeks (range: two to six weeks). The time depends on the size of the inoculum, sexual practice, and hygienic measures. A single treponeme leads to the longest incubation period. The primary lesion develops at the site of contact and heals in two to six weeks. In a proportion of patients a secondary stage appears six weeks after the primary lesion has healed but there may be an overlap of the healing primary and the onset of the secondary stage. In some cases the period between these stages can be prolonged to several months. The main characteristic of the secondary stage is a generalized, symmetrical, painless, and non-irritating rash. In about 20 per cent infectious relapses occur during the following year (range: one to four years). In the rest, the latent asymptomatic period follows and may persist for life in at least 60 per cent. In 30–40 per cent a third late destructive stage develops. Its more benign form involves only the skin, mucous membranes, and bones. In the serious form the CNS, aorta, and other internal organs are affected. The major events are shown in Figs. 1 and 2.

The course of untreated syphilis has been investigated in the now famous Oslo study (1891–1951) when almost 2000 patients with early syphilis were left untreated and studied. Approximately 1000 patients were finally analysed with the following results: relapsing secondary syphilis was observed in 25 per cent; cardiovascular syphilis was diagnosed in 10.4 per cent; CNS lesions in 6.5 per cent; and gumma of the skin, mucous membranes, or bone in 16 per cent. A total of 23 per cent died as a direct result of syphilis. Serious late syphilitic complications were twice as common in men than women.

This study is open to several criticisms. The study was completed before all the patients had died and thus some late complications



*Pregnant women may infect the fetus in early latency and during the early part of late latency

Fig. 1 The course of untreated early acquired syphilis.

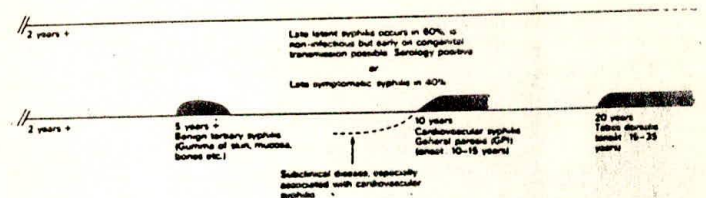


Fig. 2 The course of untreated late acquired syphilis.

Asymptomatic neurosyphilis is present in 20 per cent and 20 per cent of these develop clinical neurosyphilis.

Cardiovascular syphilis starts subclinically many years earlier and when clinically apparent, it is in fact in an advanced state.

Prognosis: Gumma heals spontaneously in a few years. Cardiovascular syphilis is usually fatal without treatment. Neurosyphilis: general paresis has a poor prognosis without treatment, meningovascular syphilis commonly responds well to penicillin, tabes progresses slowly but penicillin has no obvious influence.

Overall mortality of untreated syphilis: 20–30 per cent.

may have escaped inclusion. The study took place at a time when many patients died young mainly due to tuberculosis and once again late complications may have been underestimated. Finally, the disease was already changing as noted elsewhere and the change was particularly marked in the incidence and severity of the late stage. If a similar study could be undertaken at present, the results might be quite different, and the Oslo study is by now of greater historical interest than of practical value in predicting the fate of patients with untreated syphilis.

In the more recent Tuskegee study of Negro males with latent syphilis, it was found that one third died of late syphilis, mostly due to cardiovascular lesions. In post-mortem investigations aortitis was present in 40–60 per cent, far in excess of the clinical diagnosis, supporting the view that the cardiovascular lesion is the most important and lethal late syphilitic complication. Though the death rate directly attributed to late syphilis is around 30 per cent in several studies, the incidence may be higher as there is some evidence that the patients are more prone to other diseases including hypertension. In all the more recent reports the incidence of CNS syphilis and gumma is lower than in the Oslo study, confirming that a change is taking place in the evolution of the disease.

Clinical features

Primary syphilis. The first sign is a small, painless papule which rapidly ulcerates. The ulcer (chancre) is usually solitary, round or oval, painless, and often indurated (Fig. 3). It is surrounded by a bright red margin. It is not usually secondarily infected, a feature of all open syphilitic lesions of any stage. The reason for this might repay investigations. *T. pallidum* can be demonstrated in the serum from the sore which is easily obtained after slightly abraded the base. In heterosexual men the common sites are the coronal sulcus, the glans, and inner surface of the prepuce but may be found on the shaft of the penis and beyond. In homosexual men the ulcer is usually present in the anal canal, less commonly in the mouth (Fig. 4) and genitalia. In women most chancres occur on the vulva, the labia, and more rarely the cervix when it is liable to be overlooked.



Fig. 3 Large primary sore. Note the even shape and the absence of secondary infection.

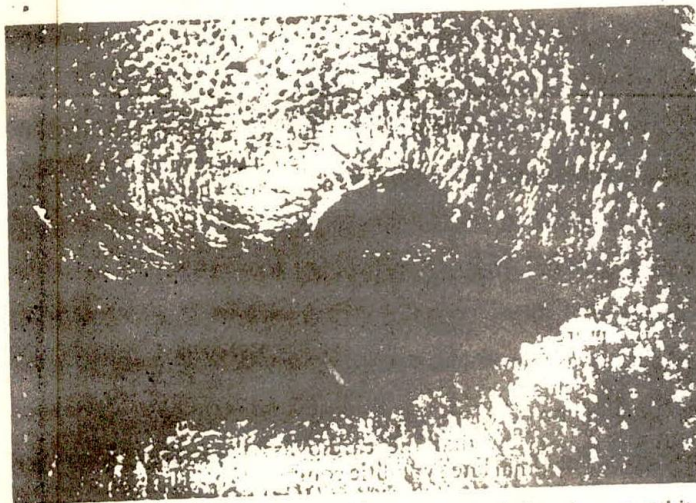


Fig. 4 Healing primary sore of the lip with some induration around it.

Extragenital chancres usually involve the lips when they become large and associated with some oedema, other sites are the mouth, buttocks, and fingers. The regional lymph nodes are invariably enlarged a few days after the appearance of the chancre and with genital sores they are *bilaterally* involved. The lymph nodes are painless, discrete, firm, and not fixed to surrounding tissues.

Atypical primary sores are not uncommon and depend on the size of the inoculum and the immunological status of the patient; thus a small inoculum usually produces a small atypical ulcer or papule and looks trivial. This may also be the case in patients who had previously treated syphilis and may be dark-field negative.

Histologically the chancre shows perivascular infiltration with plasma cells and histiocytes, capillary proliferation, and obliterative endarteritis and periarteritis. The affected lymph nodes contain numerous treponemes, a depletion of lymphocytes, follicular hyperplasia, and histiocytic infiltration. If *T. pallidum* cannot be recovered from the primary sore, it may be possible to demonstrate it from the needle aspirate of the regional lymph node.

Differential diagnosis. All genital sores must be regarded as

syphilitic until proven otherwise, especially when they are solitary and painless.

Genital lesions which must be differentiated from primary syphilis are:

1. Genital herpes (see page 5.327), which is much more common than syphilis in either sex. It is characterized by a crop of painful or irritating vesicles which develop into shallow erosions. In the first attack there is also painful inguinal adenitis.
2. Traumatic sores. These are painful, irregular and may become secondarily infected.
3. Erosive balanitis. These are inflammatory, irregular erosions which may become purulent in the uncircumcised.
4. Fixed drug eruptions. These are macules or occasionally ulcers following various drugs, especially tetracyclines.
5. Chancroid (see page 5.305). This is mostly seen in the tropics, presents as painful, superficial, 'soft chancre', which is often multiple with painful suppurative regional adenitis.

Other conditions which may have to be considered are scabies, Behçet's syndrome, granuloma inguinale, and lymphogranuloma venereum.

Secondary syphilis. The lesions are numerous, variable, and affect many systems. Inevitably there is a symmetrical, non-irritating rash and generalized painless lymphadenopathy. *Constitutional symptoms* are mild or absent; they include headaches, which are often nocturnal, malaise, slight fever, and aches in joints and muscles. The rash is commonly macular, pale red, and sometimes so faint as to be appreciable only in tangential light. It may be papular and sometimes squamous (Fig. 5). Pustular and necrotic rashes are rarely seen in temperate climates but still occur in tropical regions. The later the secondary rash develops, the more exuberant it becomes. The distribution of the rash can be of great diagnostic help. It usually covers the trunk and proximal limbs, but when it is seen on the palms, soles, and the face, syphilis should always be high on the list of probable causes (Figs. 6 and 7). In warm and moist areas such as the perineum, external female genitalia, perianal region, axillae, and under pendulous breasts, the papules enlarge into pink or grey discs, the *condylomata lata*, which are highly infectious (Fig. 8). *Mucous patches* in the mouth and genitalia are painless greyish-white erosions forming circles and arcs ('snail-track ulcers'). They too are very infectious.

Meningism and headache are due to low-grade meningitis which can be confirmed by a raised cell count and raised protein in the CSF.

Less common lesions include *alopecia* and *laryngitis*. *Syphilitic hepatitis* is usually associated with a marked rise in serum phosphatase. There are non-specific inflammatory changes in liver biopsy material which are quite unlike those found in viral hepatitis. A *nephrotic syndrome* may develop and glomerular immune-complex deposits have been observed.

Pain in the bones, often worse at night, is usually due to *periostitis*. *Uveitis* may be seen both in secondary and tertiary syphilis.

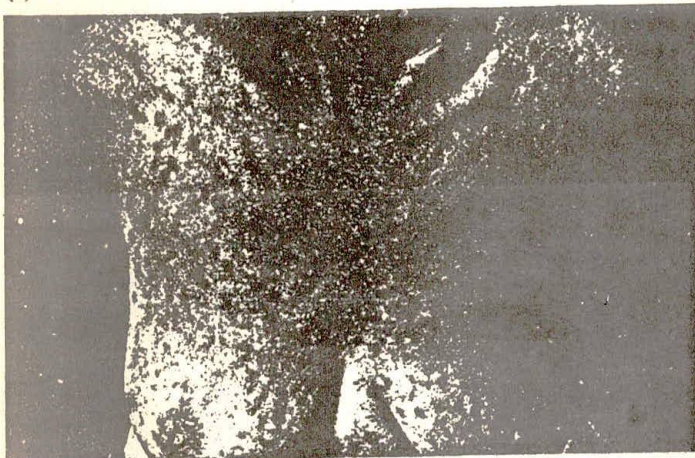
In about one fifth of patients *recurrent infectious episodes* occur especially during the first year after the secondary stage.

All these lesions disappear spontaneously and leave no evidence behind. It was repeatedly suggested in the older literature that extensive skin lesions had a protective effect and that late lesions of the CNS or aorta were less likely in such cases. It was believed that this was due to elaboration of significant amounts of protective antibodies by the skin lesions but no formal proof of this interesting idea has been presented. If true, one might further speculate that the extensive and prolonged skin lesions so prominent in all types of non-venereal syphilis may be a factor protecting these patients from the severe complications of the late stage.

Latent syphilis. By definition the patient is asymptomatic with normal CSF findings but positive serology for syphilis. It is arbitrarily divided into *early* and *late latent* syphilis. Infectiousness does not stop with the advent of latency as women may continue to give



(a)



(b)



(c)

Fig. 5 (a) and (b) Secondary papular syphilitic rashes; (c) Late secondary/early tertiary papulosquamous lesions.



Fig. 6 Secondary papulosquamous rash of the soles.

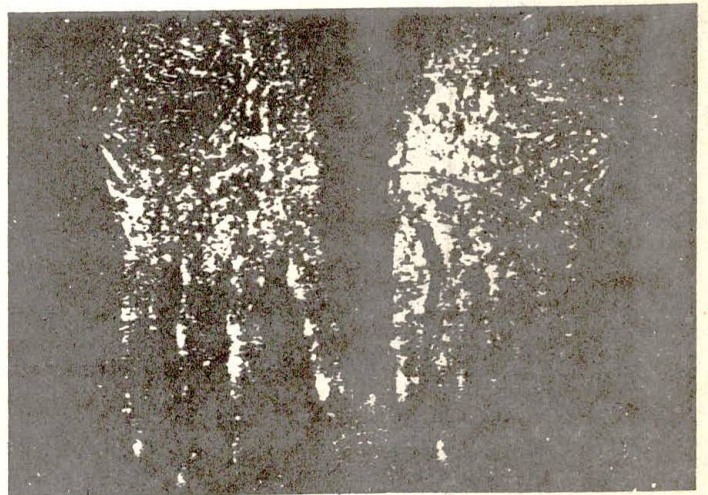


Fig. 7 Secondary rash of the palms.

birth to congenitally infected infants during the early latent stage and for at least two years into the late latent stage. Approximately 60 per cent of patients remain latent for the rest of their lives. The only evidence of syphilis being positive serology with a usually low titre. The rest develop clinical late syphilis but autopsy studies indicate that a higher proportion has subclinical infection especially of the cardiovascular system.

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Fig. 8 Condylomata lata.



Fig. 9 Multiple gummatous ulcers. This is a typical site.

Late syphilis (tertiary syphilis). This includes late latent syphilis already referred to, benign tertiary syphilis, involvement of viscera, the CNS, and the aorta.

Benign late syphilis. 1. Cutaneous gumma. The gumma is a chronic granulomatous lesion which is usually single but may be multiple or diffuse (Fig. 9). Histologically there is central necrosis with peripheral cellular infiltration of lymphocytes, plasma cells, and occasional giant cells with perivascularitis and obliterating endarteritis. *T. pallidum* is present and can be demonstrated by rabbit inoculation. Clinically it starts as a slowly progressive painless nodule which becomes dull red and breaks down into one or several indolent punched-out ulcers. The base has a 'wash-leather' appearance and is remarkably free from secondary infection (Fig. 10). It often resembles other granulomatous conditions. It heals slowly from the centre, which may become depigmented, whilst the periphery shows hyperpigmentation. Eventually a paper-thin scar forms. This combination of pigmentation, depigmentation, and atrophic scars can be of considerable retrospective diagnostic help. The sites preferentially involved are the face, legs, buttocks, upper trunk, and scalp. The process may be more superficial producing papulosquamous lesions which include the palms and soles. It too heals with the typical scars already described.

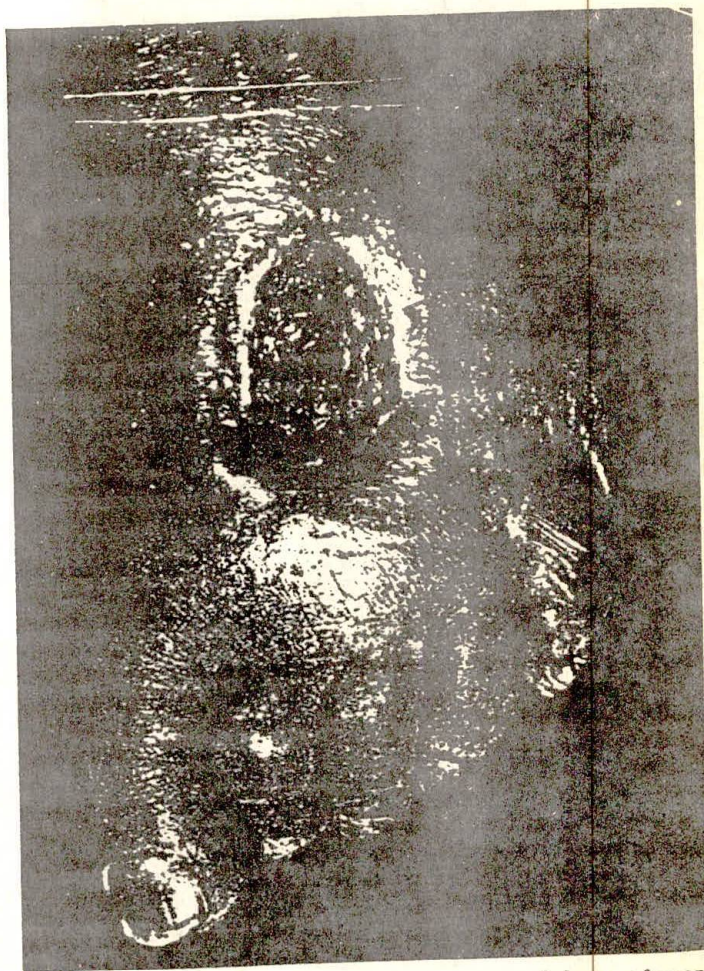


Fig. 10 Single gumma. Note the punched-out ulcer and absence of secondary infection.

2. Mucosal gumma. These are most commonly seen in the oropharynx and involve the palate, pharynx, and the nasal septum. They tend to be destructive causing perforation of the hard palate and the nasal septum. In the pharynx and larynx they tend to lead to severe scarring. The most serious lesion is the diffuse gummatous infiltration of the tongue leading first to a general swelling of the

Syphilis

organ, then due to loss of papillae to a smooth red surface (Fig. 11). After a while the poor blood supply produces necrotic white patches on the dorsum of the tongue and this leucoplakia has a strong tendency to become malignant: thus regular check-ups with biopsy are necessary (Fig. 12). Penicillin has no effect on the progress of syphilitic glossitis at this late stage.

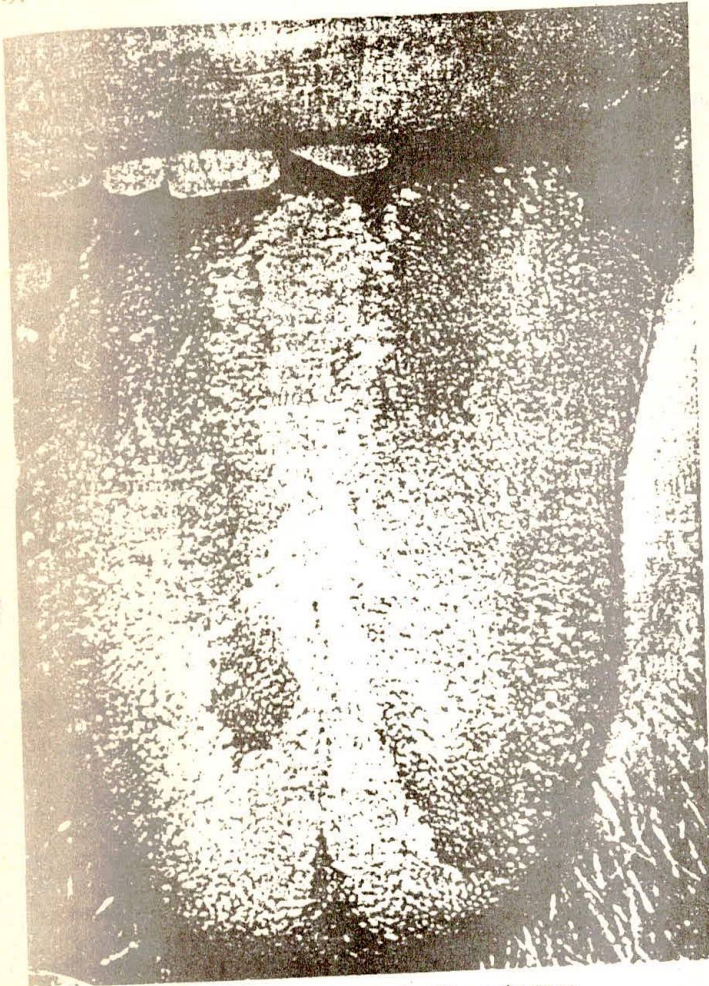


Fig. 11 Late syphilitic glossitis, early stage.



Fig. 12 Syphilitic leucoplakia of the tongue: premalignant.

3. *Late syphilis of bones.* Osteoperiostitis of long bones such as the tibia and fibula causes thickening and irregularities which may be diffuse as in the 'sabre tibia' or localized and evident as a circumscribed bony swelling. Unlike most other syphilitic lesions, those of the bone are often painful, the pain being worse at night. Very rarely the process breaks through the skin producing a chronic 'syphilitic osteomyelitis'. Lesions of the palate, nasal septum, and the skull are destructive leading to bone defects of the hard palate and nasal septum, and multiple osteolytic lesions of the skull.

Differential diagnosis. 1. Mucocutaneous gumma. The superficial skin lesions may have to be differentiated from fungal skin lesions, psoriasis, and bromide and iodide rashes. The deep gummata may resemble deep mycoses, sarcoidosis, tuberculosis, leprosy, granuloma inguinale, lymphogranuloma venereum, reticulosis, and epithelioma of the skin.

Serological tests for syphilis, which must include specific reactions such as the FTA-ABS, prompt response to penicillin, and possibly evidence of syphilis elsewhere should clarify the diagnosis.

A case history might serve to illustrate an important principle: A woman of 55 had a large painless ulcer overlying the tibia. The lesion was secondarily infected. All the blood tests for syphilis were positive and a diagnosis of gumma was made (in spite of the bacterial infection which is unusual). Penicillin cleared the bacterial infection but there was no further progress. Biopsy showed it to be an epithelioma.

It is not uncommon to see patients with ulcers or nodes of the skin or various organs and a positive serology for syphilis. A diagnosis of syphilis is made, treatment is given, and only after obvious therapeutic failure is the diagnosis reconsidered and malignancy found. Positive blood tests for syphilis may be coincidental and as late symptomatic syphilis is rare whereas malignancy is not this differential diagnosis should always be taken into account.

2. *Late syphilis of bones.* Conditions to be considered include primary and secondary carcinoma, Paget's disease, chronic osteomyelitis, tuberculosis, and leprosy. All forms of non-venereal syphilis except Pinta give rise to similar lesions.

Visceral syphilis. This is not common and response to treatment is variable. Late syphilis may involve the liver, eyes, stomach, lungs, and testes.

1. *Liver.* Multiple gummata of the liver give rise to irregular hepatomegaly ('hepar lobatum'), which may be asymptomatic. Symptoms may result from pressure on bile ducts or blood vessels or destruction of liver parenchyma. Antisyphilitic treatment is reported to lead to accelerated fibrosis with distortion of the liver architecture and an increase in symptoms ('therapeutic paradox'), but the available data are too scanty to confirm this.

2. *Eyes.* Uveitis, choroidoretinitis or optic atrophy may sometimes be the sole feature of late syphilis. Uveitis can also develop during early syphilis. Response of the late form to penicillin is poor. Optic atrophy is further discussed under neurosyphilis.

3. *Stomach.* Single or diffuse gummatous infiltrations of the stomach have been described and are said to respond to antisyphilitic treatment.

4. *Lungs.* Single or multiple gummata are rare and respond to treatment.

5. *Testis.* Gummatous infiltration and dense fibrosis may produce smooth painless enlargement of a testis. Testicular sensation is lost. In the only case seen by us penicillin had no effect.

6. *Paroxysmal cold haemoglobinuria.* Syphilis is a rare cause of this haemolytic anaemia (see Section 19).

It is often claimed by patients who had recent treatment for late latent syphilis that it improved their well-being. This may be a psychological reaction but it is also possible that it is due to an effect on subclinical visceral lesions. The warning given earlier against undue delay in the diagnosis of malignant disease because of misleading positive serology for syphilis which is coincidental, applies even more strongly in this section.

5-7 per cent of patients and it is therefore not advised. These alternative drugs have not been fully evaluated or compared with penicillin to assess their value and some of their drawbacks, notably the poor concentration in the brain and in the fetus are briefly mentioned in the table on treatment.

Table 2 Recommended treatment for syphilis

Diagnosis	Treatment
Primary, secondary, latent syphilis and early re-infections	aqueous procaine penicillin G 900 000 units/day \times 8 days; some advise 1 million units/day \times 8 days i.m. <i>If allergic to penicillin:</i> erythromycin stearate 1 g twice daily \times 14 days or tetracycline hydrochloride 2 g daily \times 14 days <i>If pregnant and allergic to penicillin:</i> erythromycin as above
Asymptomatic or symptomatic neurosyphilis*	aqueous procaine penicillin G 900 000 units/day \times 14 days i.m. or aqueous penicillin G 12-24 million units/day \times 10 days i.v. <i>If allergic to penicillin:</i> erythromycin stearate 1 g twice daily \times 30 days or tetracycline 2 g daily \times 30 days
Cardiovascular syphilis or benign tertiary syphilis†	aqueous procaine penicillin G 900 000 units/day \times 10 days i.m. <i>If allergic to penicillin:</i> erythromycin or tetracycline as above
Early congenital syphilis (including suspected early congenital syphilis)	aqueous penicillin G 50 000 units/kg \times 10 days i.m. (use only penicillin in congenital syphilis). If mother received erythromycin during pregnancy, treat the infant with a course of penicillin
Late congenital syphilis	aqueous penicillin G—dose according to age and equivalent to acquired syphilis of the same stage
Interstitial keratitis	0.5% prednisolone eye drops, 1 drop 1-2 hourly until condition controlled
Optic atrophy (congenital or acquired)	penicillin as for late stage
Eighth nerve deafness	penicillin as for late stage + corticosteroid
Iridocyclitis (early or late)	penicillin as for the appropriate stage + 1% atropine eye drops; consult ophthalmologist
Syphilis of the tongue	penicillin as for late syphilis and consult ENT specialist for regular follow-up

* In patients with gumma of the larynx, late neurosyphilis, especially general paresis, and cardiovascular syphilis, especially with angina try to minimize any Herxheimer reaction by covering the first injection of penicillin with corticosteroid started the day before injection

† In patient diagnosed as symptomatic cardiovascular syphilis consult cardiac surgeon from the start with a view to possible cardiac surgery (removal of coronary ostial stenosis, aortic valve replacement, repair or replacement of aneurysmal aortic segment). If there is congestive heart failure treat it before giving penicillin

The optimal dose or duration of treatment with penicillin or the other drugs has not been established and therefore a great variety of treatment schemes have been put forward but the results appear to be similar. This suggests that a fair degree of variation is permissible. The general tendency is to treat with larger doses and over a longer period of time in the later stages of syphilis and some prefer to repeat the course. There is no convincing evidence that large, much extended or repeated courses give any added benefit.

There is good experimental evidence that serum concentrations of penicillin should be at least 0.03 μ g/ml and should be maintained for 7-10 days and that troughs in the concentration should not exceed 15 hours.

Some physicians prefer a single injection of the long-acting benzathine penicillin (2.4 million units) for the sake of simplicity, but the

concentration reached is low and does not give a useful level in the CSF, also the injection is quite painful. Others repeat this dose a week later. We prefer not to use this preparation; in exceptional circumstances where a patient is unable to attend more than once and is unable to continue treatment elsewhere, it may be justified but as an alternative one could give the full course of erythromycin or tetracycline.

Procaine penicillin has several advantages over other penicillin preparations and is preferred by many. In some centres the course is 1 million units/day for 10 days in others it is given for 20 days though evidence that such a prolonged course gives better results is lacking.

Procaine penicillin in 2 per cent aluminium monostearate (PAM) has a prolonged action and was used extensively by the WHO in their mass campaign against non-venereal syphilis with good results. It is still being used for venereal syphilis in a few centres.

Penicillin reactions. All patients receiving penicillin injections should be kept in the clinic for 15-20 minutes as severe reactions needing immediate treatment will develop well within this period. An emergency tray to deal with anaphylactic penicillin reaction must be readily available wherever penicillin is given. It should contain ampoules of 1:1000 adrenaline solution, syringes and needles, intravenous hydrocortisone, injectable antihistamine, aminophylline, an airway, respirator (Ambubag or Brooke's respirator), and oxygen with face mask or nasal catheter.

Prevention of penicillin reactions. Some 3-5 per cent of the population in the UK are allergic to penicillin and it is essential to enquire about this and if there is a history, penicillin must not be given. This fact should be displayed prominently on the cover of the medical notes and the patient told to inform any doctor who may wish to give this antibiotic. Careful history taking may, however, show that the 'allergy' to penicillin is doubtful, e.g. the rash antedated the giving of penicillin and may have been due to one of the childhood infections. It is quite common to be told that patients who apparently did have a penicillin reaction, had no problems when the antibiotic was inadvertently given subsequently. In such cases we still prefer to avoid giving penicillin.

Clinical features. The most serious reaction is *anaphylactic shock* appearing immediately or within a minute or two after the injection. The more immediate the onset, the more severe the attack. The patient becomes unconscious, stops breathing, and becomes pulseless. Very rarely the patient dies immediately. A fatal outcome is estimated to occur one or two times per 100 000 injections. In the more moderate reaction the patient feels faint with acute anxiety and a feeling of impending death; there may be oedema of the face, possibly with an asthmatic attack, soon followed by urticaria. Arthralgia and some pyrexia may develop. The urticaria is liable to last one to two weeks.

The commonest form is the delayed reaction when urticaria appears days after injection or oral penicillin. Arthralgia and fever may develop.

Sometimes a local reaction around the injection site is seen. It can be urticarial but is more commonly a painful red swelling and usually responds to rest. It is best to discontinue the course as recurrences are otherwise common.

In some patients a hysterical episode follows an injection and may be due to procaine or possibly inadvertent intravenous injection. It passes off spontaneously.

Treatment of the anaphylactic reaction. The patient is laid flat with feet up and head down. Blood pressure and pulse are monitored throughout. Adrenaline 1:1000 (0.5-1.0 ml) is given intramuscularly without delay. If bronchospasm develops, 250 mg aminophylline in 10 ml water is administered by slow intravenous injection. Intravenous hydrocortisone may also be tried (Efcortisol, Solu-cortef) and may be repeated. Some prefer intravenous antihistamine (Piriton injection 10-20 mg). Adrenaline, nevertheless is the mainstay of treatment. If there is no response, the cardiac arrest team is summoned. If recovery is slow, the patient should be

serological tests for syphilis should be taken at the outset and again two or three months later.

Oropharyngeal gonorrhoea is more common in homosexual men than other groups of patients and throat cultures are the only means to make this diagnosis.

Uncomplicated gonorrhoea in females. The commonest sites involved are the endocervix, followed by the urethra and rectum; the latter can be the only site yielding gonococci. Before puberty the vaginal epithelium can support the growth of gonococci but after puberty the fornices may be the only area of the vagina capable of being infected; however, there is no consensus of opinion on this. Trichomonas vaginitis is commonly associated with gonorrhoea when the profuse discharge may overshadow gonococcal infection, therefore patients with trichomoniasis should be carefully screened for gonorrhoea.

Clinically, at least half the women have no symptoms and little or nothing abnormal is seen on examination. The rest have a variable discharge which is not characteristic. Some patients complain of dysuria and some have proctitis. The majority of women seek medical attention because their sexual partner has gonorrhoea.

Screening women at risk for gonorrhoea is of proven value in detecting and treating asymptomatic carriers and thus reducing the infectious pool.

Local complications. Occasionally the paraurethral glands (Skene's glands) are infected. More important is involvement of Bartholin's glands producing unilateral *Bartholinitis*. The gland and its short duct is situated in the posterior third of each labium majus. The duct becomes infected and often obstructed when an abscess forms. It is seen as a forward projection of the vulva and the inflamed mass eventually becomes fluctuant and will burst through the inner surface of the labium minus unless the patient can be treated.

Vulvitis is more characteristic in children with gonorrhoea. Signs of mild *trigonitis* may be present.

Pelvic inflammatory disease (PID). This is the commonest and most important complication of gonorrhoea in women. Gonococcal PID appears to be much more frequent in the USA than in the UK, possibly reflecting the differences in the incidence of gonorrhoea in the two countries. Gonococcal PID is more readily recognized than the non-gonococcal form and is estimated to occur in 10–15 per cent of untreated women with gonorrhoea. Whether this estimate is correct is uncertain when one recalls that more than half of women with gonorrhoea are asymptomatic and may not seek medical advice and an unknown number have minimal PID which is unsuspected and discovered by chance during investigation for infertility. In a proportion of women with chronic vague lower abdominal pain due to PID, clinical examination is unhelpful and the diagnosis can only be made on laparoscopy.

The infection ascends from the cervix through the uterus to the mucosa of the Fallopian tubes which it colonizes, producing a purulent exudate which accumulates and may spill into the peritoneum. The Fallopian tubes enlarge and become oedematous. If the infection is not checked early on, the mucosa of the tube is irreversibly damaged. This acute salpingitis is the basis of PID.

Clinical features are more clear-cut than in non-gonococcal PID (see page 5.319) and the disease is usually more acute. The onset is sudden with:

1. Lower abdominal pain and tenderness which is often bilateral.
2. Reflex spasm of the lower abdominal muscles.
3. Fever which is usually over 38 °C.
4. Leucocytosis of over 20 000/ml.
5. An onset which commonly occurs during or immediately after a period which may be more severe and prolonged than usual and can be regarded as already part of the illness.
6. Examination reveals marked tenderness in one or both iliac fossae.

7. At pelvic examination, movement of the cervix from side to side induces pain in *both* tubes (unilateral infection is unusual).

8. Bimanual palpation of the lateral fornices elicits severe pain and at a later stage when a tubal abscess has formed, the tubes can be felt as smooth sausage-shaped structures, and later still if pus collects in the pouch of Douglas, this too can be felt as a boggy mass.

There are, however, a number of patients in whom symptoms and signs are indefinite and the diagnosis can only be made by laparoscopy. The gonococcus may be isolated from the cervix and other genital sites but this is not always the case. If there are grounds for suspecting a gonococcal aetiology e.g. if the sexual partner had gonorrhoea recently, one should treat without delay. Luckily if the patient is diagnosed as non-gonococcal PID when in fact the gonococcus is the cause, the treatment is likely to include antibiotics which are effective in both types.

Treatment. This is essentially medical: (a) bed rest until fever and pain have disappeared, which means admission of most patients to hospital; (b) penicillin in large doses. Details of drug treatment are given in Table 2; and (c) watch for bowel obstruction in the early days.

Generally the patient improves in 48 hours of antibiotic therapy and should be clear within two weeks. If there is no rapid response to medical treatment, the patient should be re-assessed in consultation with the gynaecologist.

Surgery is rarely needed. Indications are: (a) doubt about the diagnosis. Especially when appendicitis cannot be excluded, laparotomy should be performed. If salpingitis is confirmed, the abdomen is closed; (b) when rupture of a pyosalpinx is suspected; (c) intestinal obstruction; and (d) development of a pelvic abscess which should be drained early to reduce the incidence of severe chronic PID.

Late complications. These are more common when treatment has been delayed or was inadequate and in severe bilateral infection. They include reduced fertility, infertility, greater tendency to tubal-pregnancy, recurrence of salpingitis because the damaged mucosa is non-functional and cannot keep the tubes clear; the infections are no longer due to the gonococcus which has been eliminated during the original course of antibiotics. Chronic PID, sometimes with acute exacerbations, is essentially characterized by chronic lower abdominal pain and deep dyspareunia. If such a patient fails to respond to repeated courses of antibiotics, radical surgical clearances may have to be considered.

Differential diagnoses include tubal pregnancy, acute appendicitis, acute pyelonephritis, infected ovarian cyst, septic abortion, endometriosis, intestinal obstruction, and non-gonococcal salpingitis.

Oropharyngeal gonorrhoea in both sexes. Infection at this site is getting more common due to an increase in orogenital sexual contact especially in homosexual males where incidence figures of 10–20 per cent have been reported. It is usually asymptomatic though some patients have signs of pharyngitis or tonsillitis. The diagnosis rests on a positive culture.

Disseminated gonococcal infection in both sexes. The incidence varies greatly in different regions of the world. It is uncommon in the UK and frequent in the USA. Women, especially pregnant women, are slightly more often affected than men. The *gonococcal strains* responsible differ in important respects from other strains by being exceptionally sensitive to penicillin and to the complement mediated bactericidal action of normal serum and by belonging to a limited number of autotypes. These strains are frequently associated with asymptomatic gonorrhoea in men. Host factors are also involved as strains causing disseminated gonorrhoea do not usually give rise to disseminated disease in sexual contacts and in some patients a deficiency of the sixth, seventh, and eighth components of complement is present.

Clinically there is a wide spectrum of symptoms ranging from the

Table 2 Treatment of complicated gonorrhoea

Diagnosis	Treatment	Comment
1. Acute gonococcal PID <i>mild</i>	procaine penicillin 2.4 million units i.m. plus probenecid 1.0 g followed by oral ampicillin 0.5 g q.i.d. × 8 days	
2. Acute gonococcal PID <i>severe</i>	aqueous crystalline penicillin G 10 million units/day i.v. until improving (usually 48 hours) then: ampicillin by mouth 0.5 g q.i.d. × 8 days or procaine penicillin 2.4 million units b.d. until improving (approx. 48 hours) then ampicillin as above	<i>none of the treatments used in gonococcal PID are ideal</i> a case can be made for giving tetracycline as well as penicillin in the treatment to deal with mixed infections of gonococcal plus non-gonococcal PID
3. PID in patient allergic to penicillin	spectinomycin 2 g or cefuroxime 2 g i.m. t.i.d. until marked improvement followed by doxycycline 100 mg t.i.d. × 8 days or co-trimoxazole tabs. 2 t.i.d. × 8 days or erythromycin lactobionate 600 mg i.v. t.i.d. until marked improvement followed by erythromycin stearate orally 500 mg t.i.d. × 8 days	cephalosporins: cross allergy with penicillin in about 5%
4. Chronic severe PID	if repeated courses of antibiotics are ineffective radical surgical clearance should be considered but with every effort to save at least part of an ovary	
5. Perihepatitis	as for PID which is commonly present	
6. Bartholinitis	ampicillin 0.5 g q.i.d. until resolved; aspirate if abscess has formed; if that fails, marsupialize	treat as early as possible to prevent abscess formation
7. Disseminated gonorrhoea, <i>mild</i>	ampicillin 3.5 g orally plus probenecid 1.0 g orally followed by ampicillin 0.5 g q.i.d. × 8 days	highly sensitive to penicillin: if clinical picture suggests disseminated gonorrhoea but the organism is not isolated, treat just the same; prompt response supports the diagnosis
8. Disseminated gonorrhoea, <i>severe</i>	aqueous crystalline penicillin G 5–10 million units/day i.v. until improved (usually 48 hours) followed by ampicillin 0.5 g orally q.i.d. × 8 days or benzyl penicillin 1.2 million units i.m. q.i.d. × 2 days followed by oral ampicillin as above	
9. Disseminated gonorrhoea but patient allergic to penicillin	doxycycline 100 mg t.i.d. × 8 days or co-trimoxazole tabs. 2 t.i.d. × 8 days	
10. Gonococcal meningitis or endocarditis (may be part of 9)	crystalline penicillin G i.v. 10–20 million units daily until clear	highly sensitive to penicillin
11. Acute gonococcal epididymitis	ampicillin 0.5 g orally q.i.d. or doxycycline 100 mg t.i.d. or co-trimoxazole tabs. 2 t.i.d.	until resolved (average 7–10 days)
12. Urethral stricture	should be under the care of the urologist who may decide to treat conservatively by regular urethral dilatation or by plastic restorative surgery	if ambulant, to wear scrotal support during the day

Table 3 Treatment of gonorrhoea in infants and children

Diagnosis	Treatment	Comment
1. Gonococcal ophthalmia neonatorum	locally with penicillin eye drops (10 000 units/ml) at once and then after every feed plus procaine penicillin 300 000 units/day i.m. × 5 days	isolate infant with mother to prevent cross infection of other infants: start treatment without delay; treat mother and trace and treat her sexual contact
2. Gonococcal arthritis neonatorum	procaine penicillin 300 000 units/day i.m. × 5 days	treat mother and trace and treat her sexual contact
3. Vulvovaginitis of girls under the age of puberty	ampicillin syrup or paediatric suspension 250 mg t.i.d. × 5 days in children under 10 years; 500 mg t.i.d. × 5 days over 10 years	test and treat the parent or person responsible for the infection

are Gram-negative and for final identification the carbohydrate fermentation test, preferably the new rapid method, is necessary. We also suggest that screening for β -lactamase production should be routinely employed to allow speedy contact tracing and appropriate treatment of all patients and their contacts infected with β -lactamase-producing strains.

Delayed fluorescent antibody staining (DFA). Staining smears from suspected colonies provides another method of identifying gonococci but is complex and requires many safeguards to be entirely reliable. For these reasons it is not entirely satisfactory for routine work.

Results incorporating all these procedures can be expected within three days.

Antibody sensitivity tests should be performed periodically to recognize sensitivity changes in a community. If any hitherto successful treatment fails to cure 95 per cent of uncomplicated gonorrhoea a change of treatment is indicated.

Serum tests for gonorrhoea. The GCFT and many newer serological methods have not much to offer in routine laboratory work.

Treatment. There are differences in the type of antibiotics used, the favoured mode of administration, and dosage schemes between individual clinics in a country and even more markedly between countries though the antibiotic sensitivity patterns are comparable. The results, however, appear to be similar. This suggests that a fair degree of latitude is permissible in the treatment of gonorrhoea.

Another factor which forces one to vary treatment is the ability of the versatile gonococcus to increase its resistance to a variety of unrelated compounds. The treatment suggested in Tables 1, 2, and 3 is based on experiences at many centres but may need frequent up-dating.

Follow-up examination. *In the male with uncomplicated gonorrhoea.* The patient is asked to return if the signs do not clear promptly after treatment and at any time should they reappear. Otherwise he is examined one week after treatment for gonococcal and non-gonococcal urethritis. If at that time there is no evidence of gonorrhoea it is unlikely to return unless the patient is reinfected. If there is PGU, this is treated. A final test which includes a second blood test for syphilis is performed two months later.

In practice many patients default once the symptoms and signs have disappeared.

In the female with uncomplicated gonorrhoea. Cure is indicated by two sets of negative cultures taken at weekly intervals after treatment and a final test including the second blood test for syphilis two months later. If rectal gonorrhoea was also found initially, rectal cultures should be repeated at every attendance as persistence of gonococci at this site may occur.

In patients of either sex with rectal or pharyngeal infection two negative cultures taken at weekly intervals after treatment and a second blood test for syphilis two months later are satisfactory. Thus on average patients with uncomplicated gonorrhoea need attend the hospital only three or four times.

With high risk patients such as promiscuous homosexual males and female prostitutes the same routine is followed. Three-monthly check-ups are recommended.

Prognosis. At present all patients with uncomplicated gonorrhoea can be cured. If they fail on one antibiotic an effective alternative can be found. Routine screening for β -lactamase-producing organisms will ensure that patients infected with such strains will receive the appropriate treatment at the earliest opportunity. Non-gonococcal infections associated with gonorrhoea may cause problems. Post-gonococcal urethritis responds to tetracycline as readily as NGU alone but there have been no large-scale studies comparing recurrence rates or those of complications between PGU and NGU. Reiter's disease can follow PGU.

The prognosis in complicated gonorrhoea is good except in the case of pelvic inflammatory disease and the rare gonococcal

meningitis and endocarditis which are potentially fatal diseases. In gonococcal endocarditis the valves may be rapidly destroyed and valve replacement may become necessary.

Some control measures. Measures which are of proven value in containing the infection include:

1. Contact tracing by fully trained personnel.
2. Readily available, accessible and well-publicized clinics in strategic positions dealing specifically with sexually transmitted diseases.
3. Large-scale screening programmes of women. These have been remarkably successful in the USA in finding new cases and reducing the infectious pool. They may be valuable in regions with endemic gonorrhoea but may have less scope elsewhere.
4. Health education: studies have shown a wide-spread ignorance amongst young people but also of young doctors due to lack of teaching the subject.
5. Epidemiological treatment, especially of women and homosexual men. This proved valuable in our experience and is also the policy in the USA.
6. Regular check-ups of high risk individuals.

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Genital candidiasis

G. W. Csonka

Definition. Genital candidiasis (candidosis, moniliasis, thrush) is an infection usually due to *Candida albicans* causing vulvovaginitis in women, balanitis or balanoposthitis in heterosexual men, and anorectal infection in homosexual males.

Aetiology. In 98 per cent *C. albicans* is responsible, in the rest one of the other *Candida* species are isolated. The yeast grows as a non-capsulated oval blastospore which reproduces by budding. *In vivo* and in culture, elongated thin hyphae may develop.

Epidemiology. The fungus can be found anywhere on the human body but most commonly in the mouth, nails, vagina, and anorectal canal. *C. albicans* is an opportunist and exists often as a saprophyte becoming pathogenic under certain host conditions which include pregnancy, diabetes, administration of antibiotics, corticosteroids, and possibly oral contraceptives. The wearing of nylon pantihose creates a moist, warm environment which encourages fungal growth. In a proportion of women none of these factors is found.

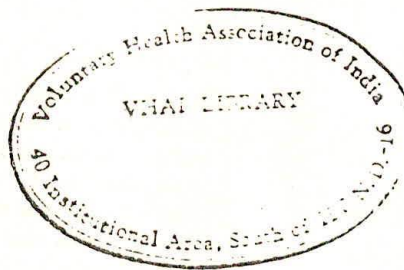
It is apparent that in many female patients, genital candidiasis is not sexually initiated though it may subsequently be transmitted sexually to the male partner. In men, sexual transmission is the rule.

Prevalence. The infection is worldwide and appears to be increas-

THE NEW **OUR BODIES, OURSELVES**

A BOOK BY AND FOR WOMEN

The Boston Women's
Health Book Collective



A TOUCHSTONE BOOK

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Changes We Can Make Now

Although some medical professionals maintain that the only solution for our current STD epidemic is to develop a preventive vaccine, others believe that we can and should attempt to contain the diseases now.

It is possible to reverse the trend toward an increased incidence of gonorrhea. Several European countries and China have done so by educating the people about prevention, symptoms, testing and treatment. Sweden, by promoting the condom, has reduced the incidence of STDs without restricting sexual activity.

In order to use the tools we have now, we need to change the attitude that STD is a punishment for "immoral" sex. We must demand and initiate public education programs without moral overtones in our schools and communities. There are some nonjudgmental films, pamphlets and brochures (see Resources), though few deal with preventive measures women can use. We can distribute them in public places such as libraries, schools, movie houses, social centers and health facilities; we can talk with friends, parents and children to make sure they have as much accurate information as possible. We can support women's centers as they work for more complete sex and health education. When our society accepts sexuality it will be more likely to encourage STD prevention.

Practitioners must learn more about STDs. Self-testing kits have been developed and should be made available. More paramedics and lay health workers should be involved in running community screening programs to make tests, screening and treatment available to all economic and social groups. We can ask for routine screening tests for STD when we go for medical care; medical workers will be more apt to include tests automatically if a large number of clients request them.

SEXUALLY TRANSMITTED DISEASES: SYMPTOMS AND TREATMENT*

Gonorrhea

Gonorrhea is caused by the gonococcus, a bacterium shaped like a coffee bean, which works its way gradually along the warm, moist passageways of the genital and urinary organs and affects the cervix, urethra, anus and throat. You can transmit this disease to another person through genital, genital-oral and genital-

rectal sex. You can get a gonorrhea infection in your eye when you touch it with a hand that is moist with infected discharge. A mother can pass it to her baby during birth. Occasionally very young children can contract gonorrhea by using towels contaminated with fresh discharge. More frequently, children with gonorrhea are found to have been sexually abused. Evidence of gonorrhea has also been found in donor semen used for artificial insemination.¹⁰

The disease is more likely to persist and spread in women than in men. Untreated gonorrhea can lead to serious and painful infection of the pelvic area called pelvic inflammatory disease (PID). Seventeen percent of the women known to have gonorrhea develop PID; of these, 15 to 40 percent become sterile after just one episode.

A less common complication is proctitis, inflammation of the rectum. If the eyes become infected by gonococcal discharge (gonococcal conjunctivitis), blindness can result. Disseminated gonococcal infection, rare but serious, occurs when bacteria travel through the bloodstream, causing infection of the heart valves or arthritic meningitis. Gonorrhea can be treated at any stage to prevent further damage, but damage already done usually cannot be repaired.

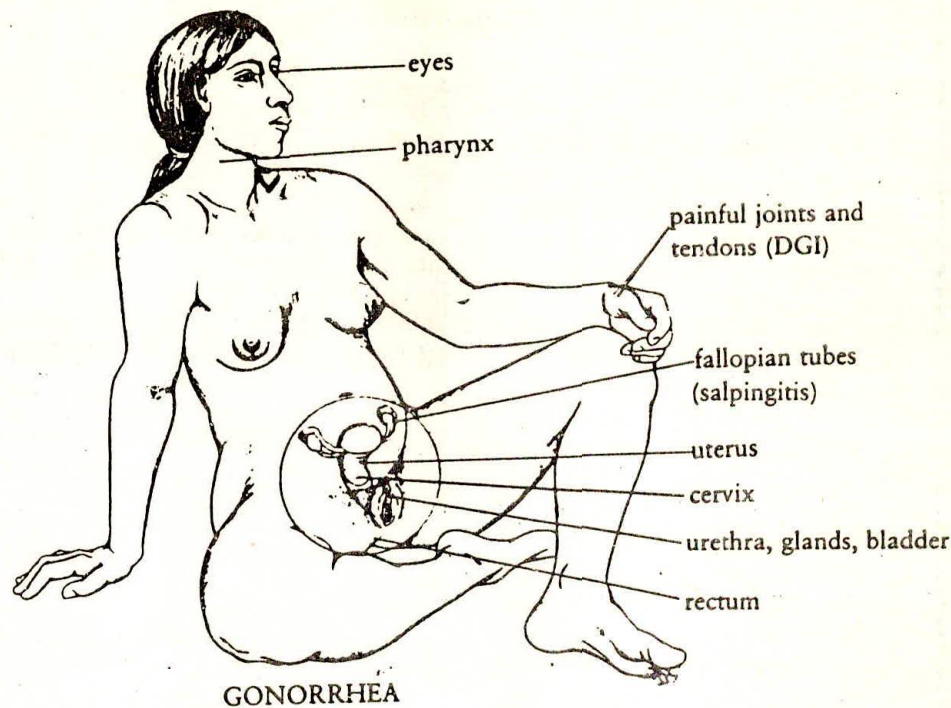
Remember, it is important to use preventive measures, since a woman often does not have early symptoms. By the time pain prompts her to see a doctor, the infection has usually spread considerably. A woman who has had a hysterectomy can be infected in the cervix (if it is left), the anus, urethra or throat.

Symptoms

Although women often have gonorrhea without any symptoms, as many as 40 to 60 percent don't notice symptoms because of their mildness, or confuse them with other conditions. Symptoms usually appear anywhere from two days to three weeks after exposure. The cervix is the most common site of infection. In cervical gonorrhea, a discharge develops which is caused by an irritant released by the gonococci when they die. If you examine yourself with a speculum you may see a thick discharge, redness and small bumps or signs of erosion on the cervix. You may at first attribute symptoms to other routine gynecological problems or to the use of birth control methods like the Pill. The urethra may also become infected, possibly causing painful urination and burning. As the infection spreads, it can affect the Skene's (on each side of the urinary opening) and Bartholin's glands. Vaginal discharge and anal intercourse can infect the rectum. Symptoms include anal irritation, discharge and painful bowel movements. If the disease spreads to the uterus and fallopian tubes, you may have pain on one or both sides of your lower abdomen, vomiting, fever and/or irregular menstrual periods. The more severe the infection, the more severe the pain and other

*For more information about tests, drugs and how STDs affect men than we can include in this chapter, see "A Book About Sexually Transmitted Diseases," listed in Resources under Booklets, Pamphlets and Reprints.

SEXUALLY TRANSMITTED DISEASES



Christine Bondante

symptoms are likely to be. These symptoms may indicate PID.

Gonorrhea can also be spread from a man's penis to a woman's throat (pharyngeal gonorrhea). You may have no symptoms, or your throat may be sore or your glands swollen.

One to 3 percent of women with gonorrhea develop disseminated gonococcal infection (DGI). Symptoms of DGI include a rash, chills, fever, pain in the joints and tendons of wrists and fingers. As the disease progresses, you may have sores on the hands, fingers, feet and toes.

Men's Symptoms

A man will usually have a thick milky discharge from his penis and feel pain or burning when he urinates. Some men have no symptoms. Gonorrhea in a man is often confused with nongonococcal urethritis (NGU), which also produces a discharge and requires a different drug for cure. If you have had sex with a man who has a discharge from his penis, get him to go for a test right away. His discharge can be tested and diagnosed the same day. If he does not have gonorrhea or NGU, then you will not have to take unnecessary medication.

Testing and Diagnosis

It is important to be tested before taking medication, because a test done while treatment is being given is not accurate.

Don't douche right before a test, because you can wash away the accessible bacteria, giving a false negative test result. The gram stain and the culture are two standard tests for gonorrhea in current use. A woman can have them done during a pelvic examination or a throat exam. The widely used gram stain is very accurate for symptomatic men but only 50 percent accurate for women and asymptomatic men. In this test a smear of the discharge is placed on a slide stained with a dye and examined for gonorrhea bacteria under a microscope. If your regular male partner's test is positive, you may want to be treated at the same time regardless of the test results.

The culture test (more reliable, but it takes longer) involves taking a swab of the discharge, rolling it onto a special culture plate and incubating it under special laboratory conditions for sixteen to forty-eight hours to let the gonorrhea bacteria multiply. Even the culture test can be inaccurate, primarily because it is difficult to maintain specimens in good condition during transportation to the lab. Test accuracy also depends greatly on which sites are chosen for testing. If you have the most commonly affected sites (cervix and anal canal) cultured, there is about a 90 percent chance of finding any existing infection. (Many women with gonorrhea also have trichomoniasis and/or chlamydia.) The swab from the cervix is the best single test, about 88 to 93 percent accurate. About 50 percent of women with infected cervixes also have infection in the anal canal. If you have had a hysterectomy, ask for a urethral culture, too. If you have had oral-genital sex, ask for a gonococcal throat culture. Ask what kind

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of medium is used for culturing. Thayer-Martin or Transgrow are best.

Often women will have both tests, the gram smear for initial screening and the culture test to confirm the diagnosis. If the smear is negative but you have definitely been exposed to gonorrhea, you may want to be treated anyway while waiting for the results of the culture to come back.

Even though these tests are not completely reliable, they are the most widely available in physicians' offices and clinics. If you have any doubts as to how accurate the results of your test were, try to have someone else do one or come back again within a week or two, the sooner the better.

Other Tests

The FDA has recently licensed two new tests for gonorrhea. The *Eliza technique* (trade name Gonozyne) detects antigens to the gonorrhea bacteria in cervical, anal or urethral specimens. This test can be performed in one or two hours, but the technology is more complicated and much more expensive than that of the culture test. Currently, medical practitioners still prefer the culture test when they have a good laboratory nearby to do it.

The second test, the *Gonosticon Dri-Dot test*, is cheap enough (about one dollar) for office use, but it is not yet widely available. The test involves examining a patient's blood for antibodies to gonorrhea. According to the Center for Disease Control, which does not recommend the test, there are two problems with this procedure: one is that a blood test cannot detect a recent infection because antibodies take time to build up in your system; another is that if antibodies from a previous infection are present, the test may give false results. Some doctors, however, recommend the test on the basis that it may be useful for diagnosing women who have abdominal PID or arthritis as a result of gonorrhea.

Another test, not yet approved, is the *Transformation test* (also called the C Test). It detects infection in a cervical specimen by isolating DNA from gonorrhea bacteria. Research is being done to see if this method could be adapted for use in a self-test kit, perhaps using a tampon to collect specimens. No field trials have been conducted to date. So far, it is cheaper and simpler but not quite as accurate as the culture test.

A *monoclonal antibody* test, also not yet approved, shows great promise for diagnosing gonorrhea in one to two hours. For this, a smear of the infected area is exposed to mouse antibodies and is examined under a fluorescent microscope for evidence of the bacteria.¹¹

Treatment

Many physicians prescribe medication before the culture test is back or diagnosis is certain for three

reasons: tests are not always accurate; the physician is not sure you will come back; and the sooner the gonorrhea is treated, the easier it is to cure. Ask about medication for your partner.

On the other hand, some places refuse to treat you, even when you are certain of infection, until a positive diagnosis is made. One argument in favor of waiting for test results is that you should not take antibiotics unnecessarily. Also, NGU, often confused with gonorrhea, is treated with tetracycline rather than penicillin, so it is important to know which infection you have. If you are not sure which you have been exposed to and don't want to wait for the results of the culture, ask to be treated with tetracycline, effective for both gonorrhea and NGU. If you decide to wait for the culture test results, you must consider whether or not it will be easy for you to return for possible later tests and treatment.

An IUD may make cure more difficult since it helps spread infection and increases the chances of getting PID. Have your IUD removed before treatment.

High-dosage injections of penicillin or high oral doses of ampicillin or amoxicillin are the usual treatments for gonorrhea. Injected penicillin can also cure syphilis still in the incubation stage. You may also receive oral probenecid, a drug which slows down the urinary excretion of antibiotics and allows them to remain in the bloodstream in high enough concentrations to do the job.

Some doctors recommend tetracycline as a treatment of choice because it avoids the risk of serious side effects of allergy to penicillin. Its disadvantage is that you must take it regularly for two weeks or so for it to be effective. Tetracycline also has a high failure rate in cases of anal and rectal gonorrhea. For more information on these drugs and possible undesirable effects (such as yeast infections), see "Drugs Women Should Know About" and "A Book About Sexually Transmitted Diseases," listed in Resources.*

Over the past twenty-five years, gonorrhea has required increasing doses of penicillin to cure, and new strains of gonorrhea have emerged which are resistant to the drug. In 1972, 22 percent of the strains of gonorrhea were resistant to penicillin. That number has now dropped to 4 percent. One strain, penicillinase-producing *N. gonorrhea* (PPNG), remains highly difficult to treat. Soldiers stationed in the Far East brought it back with them to the U.S.† In this case, the gonococcal organism produces an enzyme (penicillinase) that destroys penicillin, making the drug

*Those of African and Mediterranean ancestry should check for sensitivity to sulfa drugs and probenecid. Pregnant women should not take tetracycline.

†Outbreaks of STD have always been clearly related to war zones, where normal life is disrupted, where women are raped or forced to earn a living through prostitution and where medicine is available only through a black market.

SEXUALLY TRANSMITTED DISEASES

useless for treatment. Tetracycline is also ineffective. If a culture indicates PPNG, other medications such as spectinomycin, cefoxitin and cephalosporin will be prescribed.

Test for Cure

Every woman treated for gonorrhea should have two negative culture tests, including a rectal culture, a week or two apart before considering herself cured. If cultures remain positive, get retreatment with another antibiotic such as spectinomycin and a culture for PPNG. Pockets of infection in reproductive organs may be difficult to cure. If your partner has gonorrhea, you can become reinfected very soon after a cure, so it's crucial that he be tested and treated as well.

Gonorrhea and Pregnancy

Pregnant women should receive at least one routine gonorrhea culture during pregnancy. A pregnant woman with untreated gonorrhea can infect her baby as it passes through her birth canal. In the past, many babies went blind due to gonococcal conjunctivitis. All states now require the eyes of newborns to be treated with silver nitrate or other antibiotic drops in order to prevent this disease, even when the mother is sure she does not have gonorrhea and knows the treatment is unnecessary.

Chlamydia

Until recently, the bacterium *Chlamydia trachomatis* was thought to affect only men, causing half of the cases of male nongonococcal urethritis (NGU), while women were silent "carriers." Now we know that chlamydia can cause very serious problems for women, including urethral infection, cervicitis (inflammation of the cervix), PID and infertility as well as dangerous complications during pregnancy and birth. (See below.) It has been linked to some cases of Reiter's syndrome (an arthritic condition) and cervical dysplasia (precancerous changes in cervical cells). If you practice anal sex, this organism can cause proctitis (inflammation of the rectum).

Chlamydia is transmitted during vaginal or anal sex with someone who has the infection. It can also be passed by a hand moistened with infected secretions to the eye, and from mother to baby during delivery.

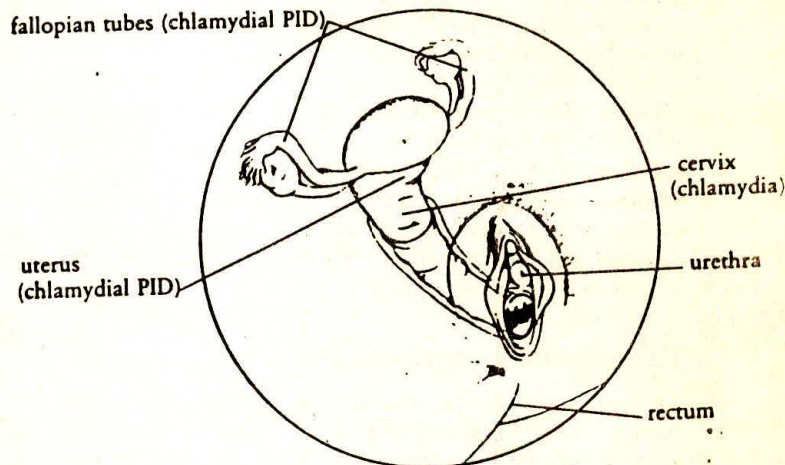
Ureaplasma

If your partner has NGU, you can also become infected by *Ureaplasma urealyticum* (also called *T-Mycoplasma*), transmitted separately from or together with chlamydia. It has been found in the genital tracts of many apparently healthy people who have no symp-

toms of infection. While ureaplasma causes up to one-quarter of the cases of NGU in men,* it is not generally thought to cause cervicitis or PID in women.† However, some researchers believe it can cause other genital tract infections and pregnancy complications (see below).‡¹²

Symptoms

Women often don't know they have these infections. The cervix may or may not appear inflamed upon examination. If you have no symptoms, you must rely on your partner to tell you if he has symptoms or has been diagnosed for NGU. Women who do have symptoms may experience dysuria (painful urination), cystitis, a thin vaginal discharge and/or lower abdominal pain ten to twenty days after exposure.



CHLAMYDIA AND UREAPLASMA

Chlamydia can also be transmitted to the eyes via the hands.

Christine Bondante

Men's Symptoms

Men will usually have a burning sensation upon urination and a urethral discharge that appears one to three weeks after exposure. Symptoms may be similar to those of gonorrhea, but are usually milder. The incubation period is also generally longer—at least seven days. About ten percent of men have no symptoms, even though they can still transmit the disease. Fre-

* Fifty percent of cases of NGU are caused by chlamydia, 25 percent by ureaplasma and 25 percent by as yet unidentified organisms.

† Some researchers dispute this assumption.

‡ A less common but related organism, *Mycoplasma hominis*, may cause infections leading to PID and, according to some researchers, infertility and/or premature birth.

quently only one member of a couple will have symptoms, while the other carries the infection. Both partners must be treated to prevent passing the disease back and forth.

Many practitioners are not yet aware of the dangers of chlamydia. In addition, because chlamydial infection is so easy to confuse with gonorrhea and other diseases, they often misdiagnose it. They also overlook women's symptoms or attribute them to other causes.

It started out as cystitis. A few months later I started having fever, chills and a lot of pain in my lower abdomen. The doctor never said anything about the possibility of chlamydia or PID. Instead they did tests for gonorrhea, which were negative. After six months of being really sick, they gave me ampicillin, which didn't help. They kept saying, "There's nothing wrong with you. You must be having emotional problems." After nine months I had a good case of PID, which they called "a little pelvic infection." It wasn't until my husband came down with symptoms of NGU that they took me seriously and treated us both with the right drugs.

Remember, the usual treatment for gonorrhea is *not* effective against these organisms. If you think you have been exposed to NGU, wait for the results of a test before accepting treatment for gonorrhea. If you can't wait or don't want to come back, make sure to be treated with tetracycline, effective against both gonorrhea and these organisms.

Testing and Diagnosis

At present there is no *widely* available test specifically for chlamydia or ureaplasma. Sometimes a skilled lab technician can diagnose chlamydia by a Pap smear. In most cases, if you or your partner has a discharge, you will be tested for gonorrhea, and if that is negative, the practitioner will diagnose NGU/MPC by elimination. Incubation of the disease is also a clue. NGU takes longer to show up than gonorrhea, although the time period can vary, depending on whether chlamydia, mycoplasma, a combination of the two, or other bacteria are causing the infection. Some experts think that when a man suspects he may have NGU, he should have his seminal fluid (obtained by masturbation) checked.¹³ The CDC, however, maintains that a urethral smear is the only accurate test. Tests for chlamydia and ureaplasma involve taking a swab from the cervix and culturing the specimen, and are performed only at large medical centers and some public health laboratories. For information on where to get tested, call your public health department. Unfortunately, these cultures are expensive (thirty-five to forty dollars). For these reasons, many physicians are reluctant to recommend them. Some prefer to wait until a woman's partner develops symptoms of NGU. This trend may be slowly changing, particularly when women

are pregnant. The blood tests presently available for chlamydia are currently considered too impractical for widespread use.

New Tests

The FDA recently approved a *monoclonal antibody* test for chlamydia that the manufacturer reports is 92 to 98 percent effective and gives results in less than an hour. The test uses a cervical smear. It should become widely available in 1984 and be much less expensive than the culture test. If the test performs as expected it is likely to replace the culture test in a few years (see p. 274).

Treatment

Tetracycline is the standard treatment for chlamydia and ureaplasma infections. Doxycycline and minocycline, also prescribed, are much more expensive and can cause serious negative side effects. Erythromycin is often prescribed when tetracycline cannot be given. Sulfa drugs such as sulfamethoxazole-trimethoprim (Septram, Bactrim) are effective against chlamydia but not ureaplasma. Many of the other antibiotics commonly used for STD infections, including penicillin, are not effective. People with chlamydial eye infections are treated with local antibacterial agents such as chlortetracycline.

Take all the medication prescribed, or the infection may come back at a later date, cause more trouble and be harder to get rid of. Usually it clears up within three weeks. If not, go back to the practitioner, who will prescribe a different antibiotic or a longer treatment time. Regular sexual partners should take tetracycline whether or not they have symptoms. Because 10 percent of ureaplasma is resistant to tetracycline, some practitioners recommend a follow-up culture one to four weeks after treatment.

Before taking any antibiotics, check with your doctor about possible undesirable effects.* Pregnant women should not take tetracycline. Avoid alcohol until the infection is cured, as it may irritate the urethra. Use condoms until you and your partner are cured. If you seem to keep having recurrent episodes of chlamydia or MPC and antibiotics have not cleared up the infection, you may have another bacterial infection or possibly a stubborn case of PID.

Chlamydia, Ureaplasma and Pregnancy

Recent studies indicate that 8 to 10 percent of all pregnant women may be infected with chlamydia¹⁴ which, if untreated, can then be transmitted to the baby during birth. Infected babies may develop conjunctiv-

* See note, p. 270, regarding sensitivity to some of these drugs.

itis or pneumonia. Chlamydia has also been linked to miscarriage, ectopic pregnancy, premature delivery and postpartum infections. Because of these risks, testing for chlamydia may soon be recommended for all pregnant women.

Because ureaplasma has also been strongly implicated as a cause of infertility, miscarriage and premature birth, some researchers feel that any woman with a history of infertility or ectopic pregnancies should be tested for ureaplasma as well.¹⁵

Herpes

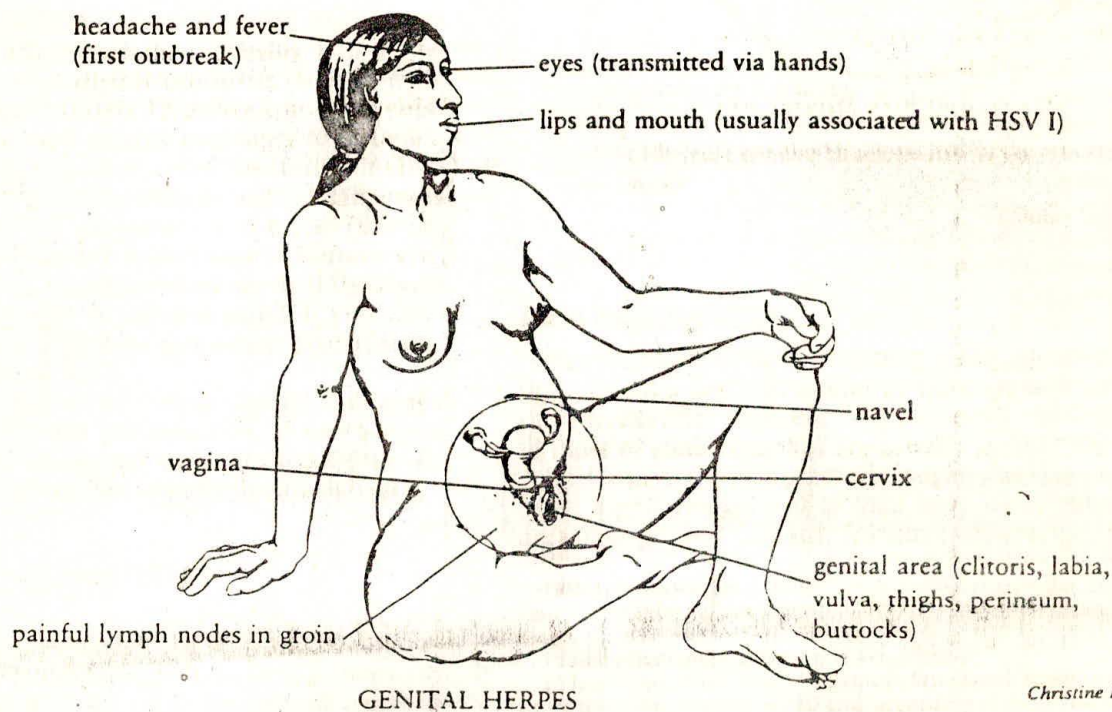
Herpes (from the Greek word "to creep") is caused by the herpes simplex virus, a tiny primitive organism whose nature is still more or less a mystery. The virus enters the body through the skin and mucous membranes of the mouth and genitals, and travels along the nerve endings to the base of the spine, where it sets up permanent residence, feeding off nutrients produced by the body cells. There are two types of herpes simplex (HSV) viruses. Type I (HSV I) usually is characterized by cold sores or fever blisters on the lips, face and mouth, while Type II (HSV II) most often involves sores in the genital area. While HSV I is usually found above the waist and HSV II below, there is some crossover, primarily due to the increase in oral-genital sex. In this chapter we will be concerned with genital herpes.

You can get herpes during vaginal, anal or oral sex with someone who has an active infection. You can spread it from mouth to genitals (or eyes) via the fin-

gers. It can also be spread through linens and towels, although this happens rarely. Although the disease is normally contagious only from the time the skin reddens until the sores crust over, herpes can possibly be transmitted when no symptoms are present, but the chances of this happening are minuscule.

Symptoms

Symptoms usually occur two to twenty days after a primary exposure, although some people may not have symptoms or may not be aware of them until much later. An outbreak of herpes usually begins with a tingling or itching sensation of the skin in the genital area. This is called the "prodromal" period and may occur several hours to several days before the sores erupt, or it may not occur at all. You may also experience burning sensations, pains in your legs, buttocks or genitals and/or a feeling of pressure in the area. Sores then appear, starting as one or more red bumps and changing to watery blisters within a day or two. Blisters are most likely to occur on the labia majora and minora, clitoris, vaginal opening, perineum and occasionally on the vaginal wall, buttocks, thighs, anus and navel. Women can also have sores on their cervix, which usually cause no discernable symptoms. Ninety percent of women have sores on both vagina and cervix during a first infection. Within a few days, the blisters rupture, leaving shallow ulcers which may ooze, weep or bleed. Usually after three or four days a scab forms and the sores heal themselves without treatment.



GENITAL HERPES

Christine Bondante

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While the sores are active, you may find it painful to urinate, and you may have a dull ache or a sharp burning pain in your entire genital area. Sometimes the pain radiates into the legs. You may also have an urge to urinate frequently and/or a vaginal discharge. You may also have vulvitis (a painful inflammation of the vulva). During the first outbreak, you may also experience fever, headache and swelling of the lymph nodes in the groin. The initial outbreak is usually the most painful and takes the longest time to heal (two to six weeks).

Men's Symptoms

Men may experience pain in the testicles during the prodromal period, followed by sores which usually appear on the head and shaft of the penis but can also appear on the scrotum, perineum, buttocks, anus and thighs. Men can also have sores without knowing it, usually because they are hidden inside the urethra. There may also be a watery discharge from the urethra.

Recurrences

Some people never experience a second outbreak of herpes, but most people (75 percent) do, usually within three to twelve months of the initial episode and usually in the same area of the body. Recurrent episodes are usually milder, last from three days to two weeks and usually do not involve the cervix. They often seem to be triggered by stress, illness, menstruation or pregnancy. Most people find that the number of yearly recurrences decreases with time. Because recurrent herpes is associated with lowered resistance, some people believe the infection can lead to secondary infections such as trichomoniasis, bladder infections, venereal warts, yeast infections and vaginitis. Poor diet and drugs that weaken the immune system (such as caffeine, speed, birth control pills and diet pills) may also make you more susceptible to recurrences. People who are deficient in B-vitamins or who are unusually tense seem to get more frequent recurrences. Recent studies show that HSV II is much more likely to recur than HSV I.¹⁶

Testing and Diagnosis

You and your practitioner can usually diagnose herpes by sight when the sores are present, although herpes is occasionally confused with chancroid, syphilis or venereal warts. Several lab tests confirm the diagnosis or indicate the presence of herpes even when no sores are active.

The Tzanck Test

This test is similar to a Pap smear. A scraping is taken from the edge of an active sore, smeared on a slide sprayed with a cell fixative and sent to a lab for

evaluation. A fairly accurate method of diagnosis, it can be used for both men and women, and is inexpensive (three to fifteen dollars). It cannot differentiate between HSV I and HSV II.

Viral Culture

A viral tissue culture can be taken using living cells to grow the virus. This test has an advantage in that it can distinguish between Herpes I and Herpes II, but it is expensive (about forty-five dollars) and few laboratories or doctors are equipped to perform it. The test is more accurate than the smear and should be done when the sores first appear.

Other Tests

You can get a blood test to measure the level of herpes antibodies in the blood. (Once you have been exposed to the virus, your body manufactures antibodies to fight off the infection.) For this test, two ampules of blood are drawn, one during the initial attack and the second two to four weeks later. If you have herpes, the second sample will show a much higher antibody level. (It takes about two weeks to build antibodies.) This test is only effective when performed during the initial attack of herpes. Later, the test results are difficult to interpret. This test costs thirty-five to fifty dollars and may not be covered by all federal or state medical assistance programs. Some public health departments in metropolitan areas, however, provide the test free of charge.

A *monoclonal antibody* test is being investigated now to determine how accurate it is. It still cannot detect latent cases (see p. 272).

Treatment

At present there is no medical cure for herpes, although researchers are investigating vaccines, antiviral therapy and immune-system stimulants.* In the meantime, keep sores clean and dry. If they are very painful, you may want to get a prescription for xylocaine cream or ethyl chloride. If you are having an outbreak of genital herpes for the first time, your practitioner may prescribe a new antiviral drug called acyclovir (trade name Zovirax). Acyclovir seems to reduce pain and viral shedding (the period during which the virus is infective) but it does not delay or prevent recurrences and it won't help if you already have the disease. Acyclovir in oral form may prevent recurrences, according to one study, and should be approved for use by the FDA in 1984.¹⁷ It is still not considered a cure, however.

*In the past few years more than thirty experimental treatments for herpes have been tested and found ineffective in clinical trials. For a list of these experimental treatments, some of which are still used, and other information, send for "Questions and Answers on Genital Herpes," Technical Information Services, Division of Sexually Transmitted Diseases, CDC, Atlanta, GA 30333. It is free.

SEXUALLY TRANSMITTED DISEASES

Another promising experimental treatment involves the use of laser beams which, when applied to sores within forty-eight hours of a first outbreak, may help prevent recurrences. This method also seems ineffective for women who already have recurrent herpes.¹⁸

Self-Help and Alternative Treatment

When sores first appear, take warm sitz baths with baking soda three to five times a day. In between, keep sores clean and dry. A hair dryer helps to dry sores. Sores heal faster when exposed to air, so wear cotton underpants or none at all. If it hurts to urinate, do it in the shower or bathtub or spray water over genitals while urinating (using any plastic squeeze bottle). When sores break, apply drying agents such as hydrogen peroxide or Dom Burrows, which is available in drugstores. For pain relief, take acetaminophen (e.g., Tylenol) or aspirin.

Many women have found the following alternative treatments very helpful for herpes.* They may or may not work for you. Because some of the products mentioned below must be purchased at a health food store, they may be expensive. We suggest that you pick one or two. Remember, all are most effective when combined with good nutrition and rest. (If you are pregnant, don't take medicinal teas or high doses of Vitamin C without consulting your practitioner.)

1. Echinacea is a blood-purifying plant. Capsules made from it are available at health food stores. Take two capsules every three hours, make a tincture and apply (one teaspoon every two hours for three to four days) or make a soothing tea (four cups a day).

2. Take 2,000 milligrams of Vitamin C or two capsules of kelp followed by sarsaparilla tea (four to five cups during the day).

3. Chlorophyll (in powder form) and wheatgrass are good antiviral herbs. Drink them with warm water. Also, eating blue-green algae (3,000 milligrams daily) may be helpful.

4. Lysine is an amino acid that many women find very effective in suppressing early symptoms. If you stop using it, symptoms may reappear. Take 750 to 1,000 milligrams a day until sores have disappeared. Thereafter take 500 milligrams a day. Lysine seems to work by counteracting the effects of arginine (a substance found in foods such as nuts—especially peanuts—chocolate and cola) which stimulates herpes. During any herpes episode it is wise to avoid arginine-rich foods.

5. Zinc: take five to sixty milligrams daily.

6. Grape skins may be antiviral. Some women recommend eating red grapes.

7. Acupuncture treatments administered at the first signs of an attack sometimes prevent recurrences. Fingertip stimulation of acupressure points in the feet may also prevent outbreaks (three thumbs forward of the ankle bulge, along the line between the ankle bulge and little toe).

For Symptomatic Relief

1. Make compresses out of tea made with cloves, use black tea bags soaked in water (tannic acid is an anesthetic) or take sitz baths with uva-ursi (also known as kinnikinnick or bearberry).

2. Apply peppermint or clove oil, Vitamin E oil, A and D Ointment, baking soda, cornstarch or witch hazel to the sores. (Some people believe that keeping the sores moist may make them feel better but last longer.) Before applying any salve, some people suggest you rub the area with mouthwash containing thymol.

3. Make poultices using pulverized calcium tablets, powdered slippery elm, goldenseal, myrrh, comfrey root or cold milk. Make a paste using any of these and apply to the sores. After applying, keep the paste moistened with warm water.

4. Aloe vera gel soothes and helps to dry out sores and promote healing.

Herpes and Pregnancy

Studies show that women with herpes have an increased risk of miscarriage and premature delivery. Equally important, when a mother has active sores at the time of delivery, herpes can be transmitted to the baby during passage through the birth canal, causing brain damage, blindness and death in 60 to 70 percent of cases. Scary as this sounds, it is important to know that this is rare, occurring only in one out of every 7,000 normal births. The risk is much higher when mothers have a primary outbreak at the time of delivery; when they have open sores, their babies have a 50 percent chance of contracting herpes during a vaginal birth. For a mother with recurrent sores, the risk goes down to about 4 percent because she has passed antibodies on to the baby through the amniotic fluid and the baby's blood.¹⁹

Pregnant women who don't have herpes should avoid unprotected sex during the last six weeks with partners who have herpes. If you are pregnant and have recurrent herpes, get a Pap smear or viral culture done regularly from thirty-two weeks of pregnancy to delivery. If you have prodromal symptoms or active sores at the time of delivery, you will usually have a Cesarean section within four to six hours of the time the waters break. Some studies suggest that women who have negative cultures within three days of birth can and should deliver vaginally. After birth, take care not to infect the infant. After about three weeks, babies usually do not develop serious infections.

*Information adapted from "Herpes," Santa Cruz Women's Health Center; "Her Pease," Women's Health Services, Santa Fe, NM; and "Herpes, Something Can Be Done About It," by N. Sampsidis. To order copies of these booklets, see Resources.

Cytomegalovirus (CMV), another virus related to herpes which may be an STD, seldom causes symptoms in the mother but is also thought to be a major cause of birth defects.

Herpes and Cancer

Studies show that women with genital herpes have a five times' greater risk than others of getting cervical cancer. This does not mean that just because you have herpes you will get cancer, but it is advisable to get a Pap smear every six months. It is possible that the factors that make us susceptible to herpes are similar to those which make us susceptible to cancer.

Prevention

A herpes vaccine is being tested on people now, but it will be at least 1986 and probably later before we know how effective it will be. Only then will the FDA approve it for general use. Because there is no cure for herpes, it seems especially worthwhile to protect yourself from getting it. That does *not* mean that you should never have sex with someone who has the virus in a latent stage; it simply means using your common sense in evaluating the risk and taking simple precautions when possible. The following suggestions (along with the general methods outlined on p. 266) may also reduce your chances of getting herpes.

1. You will be less susceptible to herpes when you are in good health, eating well and have ways of dealing with stress in your life (such as yoga, deep breathing, meditation—whatever works for you).

2. Avoid sex with someone who has active sores. If you decide to go ahead anyway and your partner is male, use condoms and/or a diaphragm with spermicide containing Nonoxynol 9, which may possibly be effective against the herpes virus.

3. Because herpes can be spread by skin contact from one part of the body to another, try to avoid touching an open sore. Wash your hands after examining yourself or touching the genital area. Always wash your hands before inserting contact lenses.

Protecting Others (If You Have Herpes)

1. If you have active sores, you might try to keep towels separate and wear cotton underpants in bed at night, since herpes may be transmitted through shared towels or linen.

2. Do not donate blood during an initial outbreak.

3. Some people recommend avoiding swimming pools, hot tubs and saunas during an initial outbreak.

Preventing Recurrences

1. Herpes attacks seem to be triggered by stress. If possible, figure out what precipitated your attacks and try to eliminate or reduce tension in your life.

2. Limit the use of stimulants such as coffee, tea, colas and chocolate.

3. Increase your intake of Vitamins A, B, C and pantothenic acid as well as zinc, iron and calcium to help prevent recurrences.²⁰

4. Avoid foods which have a lot of arginine (such as nuts, chocolate, cola, rice and cottonseed meal).²¹ Instead, eat foods high in lysine: potatoes, meats, milk, brewers' yeast, fish, liver and eggs.

Living with Herpes

Accepting herpes as a permanent part of your life may be difficult. You may feel shocked when you discover you have herpes, and then frantically search for a cure. You may feel isolated, lonely and angry, especially toward the person who gave you the infection. You may become anxious about staying in long-term relationships, having children or getting cervical cancer. Not everybody experiences herpes in these ways, nor do these responses necessarily last forever.

After the first big episode of herpes, I felt distant from my body. When we began lovemaking again, I had a hard time having orgasms or trusting the rhythm of my responses. I shed some tears over that. I felt my body had been invaded. My body feels riddled with it; I'm somehow contaminated. And there is always that lingering anxiety: is my baby okay? It's unjust that the birth of my child may be affected.

If you are in a close relationship with someone who doesn't have herpes, it can affect you both in subtle ways.

Sometimes it bullies both of us. When my lover feels she has to protect me from stress because I'm about to get herpes, she doesn't always ask for attention, time or comfort when she needs them.

How much herpes affects your relationships can depend a lot on how much you trust each other and how comfortable you feel about sharing your concerns.

My lover really trusts me when I say the episode has passed and it's okay to have oral sex. She doesn't second-guess me and say, "Let's wait a few days so I won't get it." What a blessing.

The way we experience herpes may have a lot to do with our attitude about disease. For example, people who see herpes as a symptom of stress, illness or other problems rather than as a medical disaster seem to have a much easier time finding their own ways of coping with it.

Herpes is an inconvenience and a pain, but it's something you learn to live with. I think of it as an imbalance.

SEXUALLY TRANSMITTED DISEASES

Since I know it's related to stress, I keep myself in as good physical condition as possible and try not to get too upset about it.

The one good thing I can say about herpes is that it keeps me honest in taking care of myself. When I feel my vulva start to tingle and ache, it's immediately a reminder to me to slow down. I take long, hot baths. I try to think relaxing, releasing thoughts and send healing, calming energy to that area. Sometimes I meditate.

Humor is the best way of coping with herpes. There is so much serious, scary stuff about it. You've got to recognize that it's just one of the bad tricks people have to live with.

Herpes may be easier to cope with if you feel comfortable enough to talk about it openly. Some people manage to talk themselves out of recurrences.

What turns out to be really useful is when my family and I talk about the viruses. We say things like, "They don't want to come down now. It's much cozier up by the spinal cord where they are. The weather is pretty bad out here and everyone's too busy to pay them much attention." I think what it probably does is calm me and ease whatever is bothering me. Who knows? Maybe they hear! All I know is that sometimes after I get the warning aches we sit at dinner having those discussions about how my little herpes viruses should stay where they are, and they don't come!

The Herpes Resource Center (HRC), an organization with local chapters throughout the country, provides support, information and self-help groups for people with herpes. It also publishes an informative newsletter called *HELPER*. You can join by sending five dollars and a stamped, self-addressed envelope to HRC (see Resources).

Syphilis

Syphilis is caused by a small spiral-shaped bacterium called a spirochete. You can get syphilis through sexual or skin contact with someone who is in an infectious (primary or secondary and possibly the beginning of the latent) stage. A pregnant woman with syphilis can also pass the disease to her unborn child.

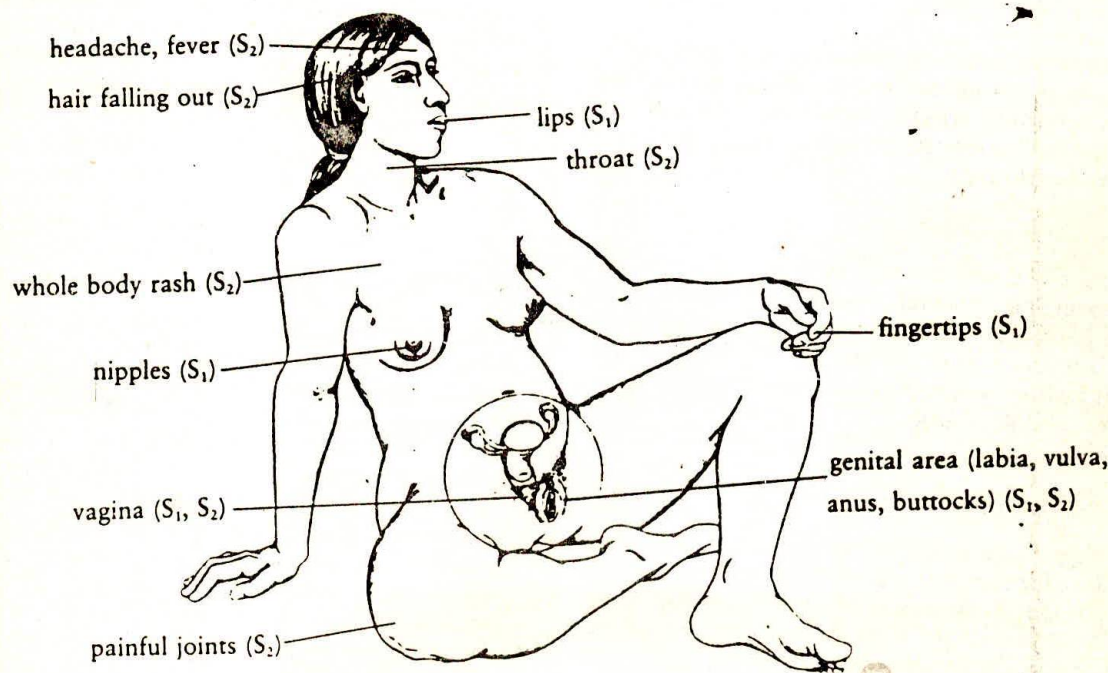
Syphilis spreads via open sores or rashes containing bacteria which can penetrate the mucous membranes of the genitals, mouth and anus as well as broken skin on other parts of the body.

Symptoms

Once the bacteria have entered the body, the disease goes through four stages.

Primary

The first sign is usually a painless sore called a chancre (pronounced "shanker") which may look like a pimple, a blister or an open sore, and shows up from nine to ninety days after the bacteria enter the body. The



SYPHILIS (S₁ = primary stage: chancre)

(S₂ = secondary stage: red, sore area; rash)

Christine Bondante

sore usually appears on the genitals at or near the place where the bacteria entered the body. However, it may appear on the fingertips, lips, breast, anus or mouth. Sometimes the chancre never develops or is hidden inside the vagina or folds of the labia, giving no evidence of the disease. Only about 10 percent of women who get these chancres notice them. If you examine yourself regularly with a speculum, you are more likely to see one if it develops. At the primary stage, the chancre is very infectious. The preventive methods outlined on p. 266 work only if the chemical or physical barrier covers the infectious sore. With or without treatment, the sore will disappear, usually in one to five weeks, but the bacteria, still in the body, increase and spread.

Secondary

The next stage occurs anywhere from a week to six months later. By this time the bacteria have spread all through the body. This stage usually lasts weeks or months, but symptoms can come and go for several years. They may include a rash (over the entire body or just on the palms of the hands and soles of the feet); a sore in the mouth; swollen, painful joints or aching bones; a sore throat; a mild fever or headache (all flu symptoms). You may lose some hair or discover a raised area around the genitals and anus. During the secondary stage the disease can be spread by simple physical contact, including kissing, because bacteria are present in the open syphilitic sores which may appear on any part of the body.

Latent

During this stage, which may last ten to twenty years, there are no outward signs. However, the bacteria may be invading the inner organs, including the heart and brain. The disease is not infectious after the first few years of the latent stage.

Late

In this stage the serious effects of the latent stage appear. Depending on which organs the bacteria have attacked, a person may develop serious heart disease, crippling, blindness and/or mental incapacity. With our present ability to diagnose and treat syphilis, no one should reach this stage.

Men's Symptoms

Men's symptoms are similar to women's. The most common place for the chancre to appear is on the penis and scrotum. It may be hidden in the folds under the foreskin, under the scrotum or where the penis meets the rest of the body. In the primary stages, men are more likely than women to develop swollen lymph nodes in the groin.

Diagnosis and Treatment

Syphilis can be diagnosed and treated at any time. However, because syphilis is less common now than in the past, medical care workers may confuse early symptoms with several other STDs, including chancroid, herpes and LGV (lymphogranuloma venereum).

Early in the primary stages a practitioner can look for subtle symptoms like swollen lymph glands around the groin, and examine some of the discharge from the chancre, if one has developed, under a microscope (a dark-field test). Do not put any kind of medication, cream or ointment on the sore until a doctor examines it. (The syphilis bacteria on the surface are likely to be killed, making the test less accurate.) Spirochetes will be in the bloodstream a week or two after the chancre has formed. They will then show up in a blood test, which from then on, through all the stages, will reveal the infection. If you suspect that you have been exposed to syphilis and have been recently treated for gonorrhea with medication other than penicillin, you should have four tests one month apart to cover the possible incubation period. (Some drugs used to treat gonorrhea do not cure syphilis.) Remember, incubation can be as long as ninety days. A good description of the different blood tests used can be found in "A Book About Sexually Transmitted Diseases" (see Resources). If you are sexually active with more than one partner or if your sexual partner is, request a syphilis blood test during regular health checkups.

Penicillin by injection or a substitute such as tetracycline pills for those allergic to penicillin is the treatment for syphilis. Since people sometimes have relapses or mistakes are made, it is important to have at least two follow-up blood tests to be sure the treatment is complete. You should not have sexual intercourse for one month after receiving treatment. The first three stages of syphilis can be completely cured with no permanent damage, and even in late syphilis the destructive effects can be stopped from going any further.

Syphilis and Pregnancy

A pregnant woman with syphilis can pass the bacteria on to her fetus, especially during the first few years of the disease. The bacteria attack the fetus just as they do an adult, and the child may be born dead or with important tissues deformed or diseased. But if the mother gets her syphilis treated before the sixteenth week of pregnancy, the fetus will probably not be affected. (Even after the fetus has gotten syphilis, penicillin will stop the disease, although it cannot repair damage already done.) Every pregnant woman should get a blood test for syphilis as soon as she knows she is pregnant and any time she thinks she may have been exposed. If she has the disease, she can be treated for it before she gives it to her fetus.

Genital Warts and Human Papillomavirus Infections*

Genital warts are caused by the human papillomavirus, or HPV, similar to the type which causes common skin warts. The same virus causes invisible warts or flat lesions on the cervix. HPV usually spreads during sexual intercourse with an infected partner. While HPV-caused infections have not been associated with serious complications in the past, studies now show that women with HPV-caused lesions on the cervix probably have a higher-than-normal risk for developing cervical cancer. Unfortunately, these invisible cervical lesions are not easily detected by either the health care practitioner or the woman with the infection.

Men's symptoms

Warts usually occur toward the tip of the penis, sometimes under the foreskin and occasionally on the shaft of the penis or scrotum. Using a condom can help prevent the spread of warts.

Diagnosis and Treatment

Diagnosis of warts is usually made by direct eye exam. An abnormal Pap smear may indicate the presence of cervical lesions, but a colposcopy is usually necessary to confirm this. Occasionally you will need a biopsy to check for unusual cell growth, especially if there are ulcerations (open sores) or a discharge, but these are rare. If you have cervical warts or lesions, get a Pap smear every six months for early detection of unusual cell changes.

There are several treatments for warts:

1. Practitioners most often prescribe podophyllin solution (some say ointment is better). Apply it to the warts and wash it off two to four hours later to avoid chemical burns. Protect the surrounding skin with petroleum jelly (eg., Vaseline). Sometimes several treatments are necessary, and they are not always successful.

2. Trichloroacetic acid (TCA) is currently used by only a small percentage of practitioners but appears to be better than podophyllin in several respects. It is usually equally effective and yet causes fewer problems than podophyllin. The strength of TCA is more easily controlled; it works on first contact with the skin and then stops in about five minutes, reducing the danger of scarring. It does not seem to provoke severe reactions as podophyllin occasionally does. Some doctors use TCA during pregnancy, although no studies have been done to verify its safety at that time.

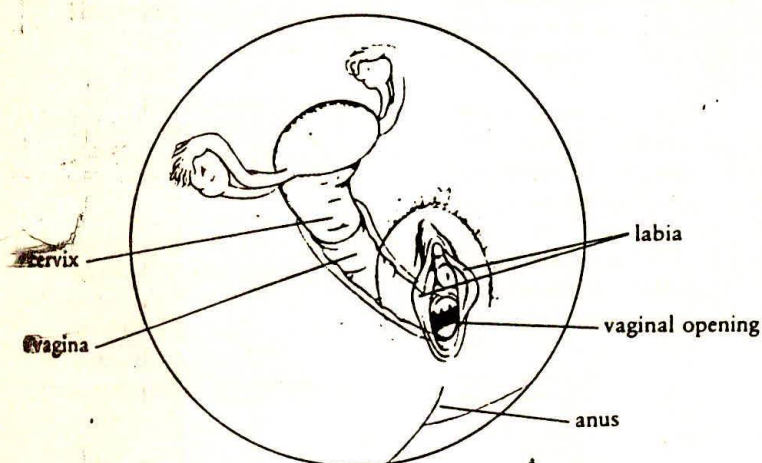
3. Cryotherapy (dry ice treatment) or acid can freeze or burn off small warts. This hurts briefly and sometimes causes scarring. You may want a local anesthetic.

4. You can apply 5-fluorouracil cream. It may cause irritation and discomfort.

5. Surgery or electrodesiccation (using an electric current to destroy tissue) becomes necessary for very large warts which fail to respond to other treatments. This procedure requires an anesthetic. If you have a cardiac pacemaker, the electric current may disturb it, so be sure to tell your practitioner.

6. Recent studies suggest that laser beams applied to warts is an effective treatment that does not affect normal tissue or cause scarring. Some practitioners recommend it particularly for HPV infections of the cervix (warts and lesions). Local or general anesthesia may be necessary, depending on the number and size of the warts. Only physicians specially trained to do laser therapy should perform this treatment.

No matter what treatment you get, it is important



GENITAL WARTS

Christine Bondante

Symptoms of genital warts usually appear from three weeks to three months after exposure. During the pre-symptomatic period (as well as while they are present), warts can be very contagious, so it is advisable for your male partners to use condoms if any of you have been exposed to the virus. The visible genital warts look like regular warts, starting as small, painless, hard spots which usually appear on the bottom of the vaginal opening. Warts also occur on the vaginal lips, inside the vagina, on the cervix or around the anus, where they can be mistaken for hemorrhoids. Warmth and moisture encourage the growth of warts, which often develop a cauliflowerlike appearance as they grow larger. Cervical lesions, though more prevalent than the visible warts, cannot be seen by the naked eye and have no symptoms.

*See "Who Is at Risk of CIN or Cervical Cancer," p. 487.

CONTROLLING OUR FERTILITY

to remove all warts, even those inside the vagina and on the cervix, to keep the virus from spreading. Sexual partners also should be treated.

Genital Warts and Pregnancy

Warts tend to grow larger during pregnancy, probably due to the increasing levels of progesterone. If the warts are located on the vaginal wall and become very large or numerous, the vagina may become less elastic, making delivery difficult. Do *not* use podophyllin to remove warts, as it is absorbed by the skin and can cause birth defects or fetal death.

Other Sexually Transmitted Diseases

There are many more STDs than we can cover in this chapter. See Chapter 23, which deals with common medical and health problems, for information on common infections which can be transmitted nonsexually as well as sexually. Other STDs which are rare or tend to affect men more than women (such as chancroid, lymphogranuloma venereum [LGV], granuloma inguinale, intestinal STDs and hepatitis B) are discussed in the newly revised "A Book About Sexually Transmitted Diseases" (see Resources).

Acquired immune deficiency syndrome (AIDS) is another recently identified STD. It is primarily a disease of homosexual men; however, some women and a few very young children have gotten it (probably while in the uterus or from breastfeeding). The total number of cases is a very tiny percentage of the general population, but a very high percentage of those who have gotten it have died. A person loses her or his ability to fight off common organisms that cause disease when a person is run down, and sometimes the victim develops a rare cancer called Kaposi's sarcoma. Researchers are working on a vaccine for AIDS, but developing this will take years.

Women who have gotten AIDS generally have had sex with bisexual men and/or use intravenous drugs. A few people have gotten it from blood transfusions.* There is no evidence that AIDS can spread in any way other than in the transfer of body fluids. This normally requires close, intimate contact between people. The warning signs of AIDS are not very distinctive; if you have any of the following problems you could have any of several illnesses other than AIDS. Symptoms include a serious form of pneumonia; rapid weight loss; persistent fatigue; fevers; drenching night sweats; diarrhea; dry cough not otherwise explainable; enlarged, painful lymph nodes in the neck and/or armpits; and/or purplish nodules on or under the skin.

*The recent discovery of a virus that is probably the cause of AIDS makes it possible to develop a test to screen blood collected for transfusions.

What to Do If You Think You Have an STD

Get a diagnosis as early as possible. Most STDs are easy to cure, though it can be difficult to wade through the medical system to get care. Women who think they may have an STD have several choices when it comes to medical treatment. Some of the advantages and disadvantages of each are listed below.

Private Physicians, Gynecology Clinics and Hospital Emergency Rooms (Varying Fees)

Many private doctors' offices, gyn clinics and hospital emergency rooms lack the equipment necessary to do a routine gonorrhea culture (GC), much less test for chlamydia or herpes. In addition, many practitioners in these places tend not to test readily enough if a patient is white and middle-class.

The first time I asked a gynecologist for a routine gonorrhea culture, he smiled with a comradely look in his eye. "But I'm sure no man you'd be involved with would have gonorrhea."

On the other hand, they may be overly suspicious about the possibility of STD in patients who are black and poor.

Public Health Clinics (Usually Free or of Nominal Cost)

Public health departments run STD clinics throughout the country (sometimes located in hospitals) which are called "L" or "skin" clinics. Because they deal with STD on a daily basis, most clinics have personnel experienced in diagnosing STDs and good diagnostic equipment for major diseases. They also offer the services of a public health adviser who answers questions about STD. Most of the clinics do not test for hepatitis or the intestinal STDs, and some of the smaller ones may only be equipped to deal with gonorrhea, syphilis and common complications like PID.

Women who use public health clinics on a regular basis sometimes say they feel a definite stigma attached to them (as opposed to the experiences of patients at a hospital or neighborhood or private clinic).

Everyone looks at you when you're sitting in the Health Department clinic as if you're dirty or something. Then there are so many people reading your file: secretary, nurse, doctor. It's like they all know about you. It's very embarrassing.

Because clinics tend to be overcrowded, you may have a long wait before being seen by a hurried doctor

Women and AIDS

While enumerating the cautionary steps necessary for women to safeguard against the AIDS virus, Dr. P.N. SEGHAL raises important points of concern for the infected woman, especially during pregnancy, childbirth and postnatal care



Acquired Immunodeficiency Syndrome (AIDS) is caused by Human Immunodeficiency Virus (HIV) which attacks and destroys certain white blood cells in a process that can take many years and as a result of which the infected person develops an immune deficiency and becomes susceptible to a wide range of opportunistic infections and cancers. In addition, at some point and in some people, HIV may attack cells in the brain, causing neurological and psychiatric problems.

People infected with HIV are both infected and infective for life. Even when they have no symptoms or outward signs, they can transmit the virus to others. Transmission of HIV virus happens only by three modes: sexual intercourse or donated semen; exposure to blood, blood products or transplanted organs or tissues; mother to foetus/infant infection.

The HIV infection is spreading rapidly throughout the world. According to WHO estimates, about eight million people were infected with HIV worldwide resulting in 700,000 AIDS cases in early 1990. HIV affects women, men and children around the world, a third or 2.5 million cases being women.

Susceptibility and safeguards
AIDS has a profound impact on

women, both as an illness and as a social and economic challenge. Women's lack of status within the family and society heightens their vulnerability to infection and other consequences of the disease. The stigma attached to AIDS can subject women to discrimination, social rejection and other forms of violation of their rights. Women who are based in the home usually do not have access to information about how HIV is and is not transmitted. Even informed women may have difficulties in protecting themselves against infection. Ideally, a woman needs to be confident and assertive to ensure that her sexual partner uses a condom. But in practice, many women are dependent on their male partners for financial or other support and so may be forced to engage in unsafe sexual intercourse where the alternative is having financial and social support cut off.

Safe sexual practices reduce the risk of passing HIV from one person to another. The best protection is to choose sexual activities that do not allow semen, vaginal fluid or blood (including menstrual blood) to enter the vagina, anus or mouth or to touch the skin where there is an open cut or sore as these fluids can carry HIV. Specific safer sex practices include: (i) a mutually faithful relationship between two uninfected persons (ii) using a condom for all types of intercourse

- vaginal, anal and oral (iii) non penetrative sex practices such as hugging, kissing, rubbing and masturbating (iv) reducing the number of sexual partners (v) avoiding sex when you have open sores or any sexually transmitted disease (STD) and (vi) avoiding sex with partners who have the same. While some practices are obviously safer than others, more people will change their behaviour if they have a range of choices and can choose the approach that suits them best.

HIV and childbirth

All pregnant women or those who wish to have children in the future should be informed about HIV infection/AIDS. They should be educated on how the virus gets transmitted and encouraged to consider whether they risk infection. Pregnant women should be told the following facts:

- If the mother is infected, there is a chance (between 20 and 40 per cent) that her unborn baby may be infected.
- The risk of transmission is probably highest if the mother becomes infected with HIV during pregnancy or is already showing signs of AIDS.
- An infected infant may die within the first few years of life.

Where mothers are to be confidentially tested for HIV, they must also be counselled so that they fully understand the implications of HIV testing. Testing should be both voluntary and confidential. Choosing to have a test could influence a pregnant woman suspected to be HIV infected to review her decision to continue with the pregnancy. There is at present no firm evidence to suggest that pregnancy adversely affects the health of an HIV-infected woman or accelerates the progression of the disease.

Antibody testing of a new born

WOMEN MORE LIKELY TO BECOME INFECTED

Women are three times as likely as men to become HIV-infected through sexual intercourse according to a review of studies conducted in Great Britain and the United States by the Lifeshield Foundation and AIDS Prevention Charity.

The study concludes that daily intercourse with a seropositive man will, on an average, cause a woman to become infected within a year. However, a man having daily intercourse with an infected woman would become infected after an average of two years and nine months - CDC, AIDS Weekly, January 15, 1990.

infant should only be done where it is clearly indicated for the clinical care of the child. As such testing more reliably establishes the HIV infection status of the mother rather than of the infant, it could be misused for indirect testing of the mother without her informed consent. Newborns at risk of HIV infection must be provided with adequate monitoring and care.

If found to be infected with HIV, both men and women of reproductive age need to decide whether or not to have a child and how to protect their sexual partner from HIV if he/she is not already infected. Detailed below are some likely situations that couples might face:

- If a woman is uninfected with HIV but her male sexual partner is not, it is impossible for her to become pregnant by her partner's sperm without running a high risk of becoming infected with HIV as there is no way of eliminating the virus from the infected man's sperm. However, the woman could be artificially inseminated with a non-infected donor sperm in countries where this is available. The woman should, however, carefully consider whether she could look after the child adequately in the event of her infected sexual partner facing grievous illness or death.
- If a woman is infected with HIV but her male sexual partner is not, the couple could

still choose to have a child, even knowing that the baby may be infected. However, the woman must be artificially inseminated with the sperm of her partner since penetrative sexual intercourse without the protection of a condom could result in HIV infection in the man.

HIV-infected women who become pregnant should be advised about the risks of having an infected child. Termination of pregnancy should be offered as an option in countries where this is legal and safe but the final decision must be made by the pregnant woman. Whatever her decision, she will need both special emotional support and practical advice on how to prevent others becoming infected with the virus. All health care workers, particularly traditional birth attendants and midwives, should be trained to ensure continuing care and support whilst ensuring privacy and confidentiality for the infected mother and her child.

Transmission from mother to child

Transmission of HIV from an infected mother to her foetus or infant is thought to occur in 20-40- per cent of cases. Data collected so far suggests that women who reveal symptoms of this disease are more likely to transmit the virus to their child (before or during birth) than women who are asymptomatic i.e. they have the virus but do not show signs of

illness. Asymptomatic infection can last eight or more years. It is also possible that women in the first few days or weeks of infection are more infectious than at a later stage when the infection could be asymptomatic. This means that if a woman is pregnant or breastfeeding at the time of infection, there may be a higher chance of HIV transmission to her foetus or infant. Transmission can take place before birth (prepartum), during birth (intrapartum) and after birth (post natal).

Prepartum

HIV transmission, via the placenta, occurs even in the first three months of pregnancy. In studies, HIV has been found in foetuses aborted within the first three months with evidence to suggest that women who have AIDS have a higher than average rate of spontaneous abortions.

Intrapartum

Transmission of HIV from an infected mother to her baby can occur during birth, probably because the newborn is exposed to a large amount of HIV infected maternal blood and secretions during delivery. Nevertheless, studies comparing the rate of perinatal HIV transmission appear to show no difference in transmission according to the mode of delivery, that is, whether the infant is delivered vaginally or by caesarian section.

Postnatal

Handling and cuddling of her baby by a mother with HIV infection does not transmit HIV to the baby. The risk of transmission via breast milk is apparently very low except if the mother is infected after birth and sero-converts (become HIV antibody positive) while breastfeeding. Risk from this source is considerably lower when compared to transmission in utero or during delivery.



Interavenous drugs and AIDS

WORLD HEALTH, AUGUST 1983

The immunological, nutritional, psychosocial and child spacing benefits of breastfeeding are well recognised. Breastmilk is also important in preventing infections which could accelerate the progression of HIV-related disease in already infected infants. In situations where the mother is considered to be HIV-infected, and recognising the difficulties in assessing the infection status of the new born, the known benefits of breast feeding should be compared to the theoretical but apparently small risk to the infant of becoming infected through breast feeding. In many circumstances, particularly where the safe use of alternatives is not possible,

breast feeding should continue irrespective of the mother's HIV infection status.

Confidentiality

While it may be generally understood that HIV cannot be spread by casual contact, the specific and individual instance of an HIV-infected child or adult can unveil deep-seated prejudices. It has also been observed that the lack of confidentiality in HIV testing causes decreased participation in voluntary testing for HIV.

In 1988, the World Health Assembly urged Member states "to protect the human rights and

dignity of HIV-infected people and people with AIDS, to ensure the confidentiality of HIV testing and to promote the availability of confidential counselling and other support services to HIV-infected people and people with AIDS".

The prevention and control of AIDS ultimately relies on the responsibility of individuals not to put themselves or others at risk of HIV infection. This cannot be achieved in a situation where lack of confidentiality may expose individuals to stigmatization and discrimination.

The service providers must be fully aware of this need for confidentiality in their contacts with women who are pregnant or contemplating pregnancy and who may be HIV infected or at risk of such infection or who are seropositive for HIV.

HIV positive and AIDS cases have been denied access to health care which constitutes discrimination and an inequality of treatment amounting to a denial of human rights.

In the absence of an effective vaccine or cure for HIV infection, education on how HIV is transmitted and how exposure to it can be minimized is the most important means of reducing its spread especially among people whose habits make them prone to such risk. Education must be provided for the entire population so as to reach all those at risk with programmes specially designed to help people understand the implications of HIV infection.

Prevention of HIV infection in women of reproductive age and voluntary contraception made available to HIV-infected women are two important means of preventing mother to foetus/infant transmission.

— Dr. P.N. Sehgal, Former Director, National Institute of Communicable Diseases Delhi, is currently Consultant with VHAI.

Punishing the Victims

Officials help the spread of AIDS epidemic

by
Shyamala Natarajan



In July 1990, the Madras high court ordered the release of four HIV positive women who had been illegally detained at the remand home in the city. These women along with several others had been originally detained under the Prevention of Immoral Traffic Act (PITA) and sentenced to between one and three years of detention in a remand home. While under detention, they along with about twenty other women similarly detained, tested positive for the Human Immunodeficiency Virus (HIV). After it was determined that they were infected with the possible precursor to AIDS (Acquired Immune Deficiency Syndrome), a court order was issued requiring the continued detention of these women, even after their sentences were served. The rationale was that the best way to prevent the spread of the infection to others and to provide medical help to these women would be to isolate them in detention for an indefinite period.

I first met these women in the remand home at Madras in May 1989 when I was doing research on discrimination against HIV positive people and possible methods of rehabilitation. All of them had originally been

sentenced under PITA and most had completed their periods of sentence. Access to them was difficult. The press was totally banned, a decision influenced no doubt by the superficial sensationalist reports that had appeared about the women. The superintendent of the home was a kind, cordial lady who nevertheless made it abundantly clear that any meeting with HIV positive women could be arranged only with the consent of her superior, who eventually did agree, but refused to make it official. She claimed that both the letters of request I had forwarded to the department had been misplaced. Finally, after more than a month of repeated visits and requests, I was allowed to meet them. "No cameras, no tape recorders, all interviews only in the presence of the superintendent," I was warned.

I waited that sunny morning in the superintendent's office. An *ayah* went out into the verandah calling, "AIDS girls, hey you AIDS, come here." From my seat near the entrance I could see curious knots of girls forming quickly beside the path to the office as a straggly line of ostensibly infected women walked past. They didn't look at any-

body in particular, just talked to each other in whispers with occasional bursts of defiant laughter. Some looked rigidly ahead, their heads held high. They all seemed completely normal, there was nothing to distinguish them from the others except the behaviour of the others themselves, who would quickly press back if any of the women got close. In the office, they had just been lined up against a wall, when one of them, 25 or 26 years old, tall and strikingly attractive, suddenly started shouting, "What do you mean by locking us up here like this? Are we sheep or cows to be paraded around, to be poked and pried into, to be stared at? Look at me—see my hands and legs, do I look like I am ill? How dare you lock me up like this after I have finished my sentence? Let me go I say, let me go or I'll kill myself." Turning to me she cried, "Amma, what is the use of all of you coming here? Why don't you help me get out? I have a little son I haven't seen for 3 years now." Suddenly, her energy spent, she started sobbing, wheeled from the room and ran right down the way she had come. Emboldened by her outburst, several of the other women also demanded

One reason for this anomaly is clear. Though prostitution is legal, soliciting (in a public place) is not. The police-pimp nexus uses this clause to its advantage. The police pick up a woman on the pretext of soliciting even if she is only shopping for vegetables—and the pimp holds the threat of conviction over her to demand total obedience. If soliciting were to be decriminalized, it is unlikely that the women would solicit in a truly public place (they are much more desirous of anonymity than their clients). On the other hand, the law can then truly be applied to the traffickers while actually providing the women themselves with more leverage.

Discussion about AIDS as an issue and of the vulnerability of prostitutes in particular was something no official was willing to talk about. One even told me that the AIDS file was closed. I wrote to the public prosecutor in November 1989, pointing out the facts of the case and requesting a meeting. I also sent copies of the letter to other officials. The letter was ignored. Nobody was listening. Though it was becoming more and more obvious that the magnitude of the problem would defy any quick solutions, the general tendency was to close the debate on HIV and AIDS.

In March 1990, I filed a writ of habeas corpus in the Madras high court seeking the release of five of the women, whose particulars I had. Though the specific purpose was to obtain their release, it was actually an attempt to stimulate discussion on an issue that screamed for attention. A supporting affidavit was filed by Dr. S. Sunderarajan, a psychiatrist who has been working unceasingly with prostitutes to promote awareness on sexually transmitted diseases (STDs) and AIDS. The petition argued that:

1) The detention of the women beyond their period of sentence was without the authority of law and amounted to a violation of their rights under Article 19 (i) (d) and Article 21 of the Constitution.

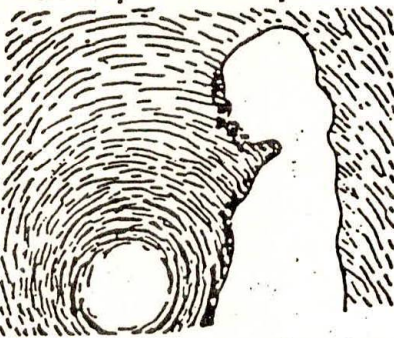
2) The detained women had not been

afforded the minimum procedural safeguards of the adversarial system or the rules of natural justice because they had not been furnished with copies of medical reports. Neither did they have the opportunity to challenge the accuracy of the same, thus violating their rights under Article 14 and Article 21 of the Constitution.

3) Blood tests had been done without the consent of the detained persons with no precautions to protect their confidentiality.

4) There had been invidious discrimination against the women because not all women arrested under PITA and testing positive for HIV are detained. In many cases the women are released on bail before the results of the blood tests are known.

5) Similarly, no attempts have been made to confine and isolate blood donors whose samples were HIV positive.



6) For every infected prostitute there was at least one man infected—the man who infected her—and possibly other men who were infected by her. No attempt had been made to identify and confine these men.

7) There was thus gender discrimination and prostitutes who were already sociological victims were being doubly victimised, while many men, including their clients and infected professional blood donors, were not being confined or isolated.

The authorities' reply merely submitted that the women were being held at the remand home on their written request for medical treatment; that the women posed a danger to society; and that, in the absence of any agency willing to rehabilitate them, the home had a responsibility towards society to

keep them there.

The court then appointed an advocate commissioner to meet the women to check if their stay was voluntary. In her report the commissioner pointed out that all the women said that they wished to go home, and that, in spite of having been at the home for five years, they were ignorant of why they had been detained and were under the impression that they were now cured. Citing the report, the Madras high court ruled on 17 July 1990 that the women be released as "it appears to us that there is no justification for keeping (these four) in the home."

After the ruling, I approached the authorities to let me meet with the women so that I could counsel them and offer help or rehabilitation if they so desired. But my request was ignored. I had no way of knowing whether the women had actually been released till I approached the Legal Aid Board for help. Through them I heard that they had indeed been freed. However there was no way of tracing them.

The story, unfortunately, doesn't have the traditional happy ending. The women are out, probably back to selling sex. Not only are other people at risk of infection, they themselves are soon likely to require medical and psychological attention which may not be available. Though these questions plague me, I still think it is wrong to set such a dangerous precedent— isolation in this case—that can only be self-defeating. On the other hand, I feel that in the years to come a good support system needs to be built around the needs of such people. I believe advocacy has a limited role in the context of a complete absence of social support. Realising this, several non-government organisations in the state are now looking at education, counselling and care projects in the area of HIV and AIDS.

However, the larger issue of prostitution and helping women engaged in commercial sex to be able to protect themselves from infections remains unresolved.

their release asking to be returned to their families. They were obviously unaware of the illegal nature of their detention and reported that they hadn't been allowed to talk to lawyers. "Help me please," whispered a young girl, certainly not a day over sixteen, possibly younger. Her huge eyes swam in unshed tears, her childish plump face constantly threatened to erupt into sobs. "They say there is something wrong in my blood because I slept with different men. Every night I pray to God that he will clean my blood soon so I can go back home. I just want to be with my mother. She will take care of me." The mother of another detained girl whom I met outside asked, "Now that they have served their sentence periods, why can't they be freed? Leave them to us. We can look after our children best."

Acknowledging the illegal nature of the detention, the authorities however pointed out that it was their responsibility to detain the women since they would otherwise be a threat to society. To be fair, it was obvious that the women's physical needs were adequately looked after. All of them were on a special diet and received regular medical attention. Though they were housed separately, they sat along with the uninfected girls in the classroom and ate their meals together as well. But it was easy to see that neither the infected women nor the others in the home, including the staff, had any clear idea of the nature of HIV and AIDS, the ways in which it was spread and the effects it could have on people. The women were constantly referred to as "pools of infection" and "threats to society" without any consideration whatsoever of the fact that they had originally been infected through some man who himself was continuing to spread it to every other woman he slept with, and sometimes through her to her unborn child. Besides, many of the men were likely professional donors of blood as well and the infection could spread through that route too.

It is fairly certain that all these women were infected by men already

infected with the disease who paid to have sex with them but did not use a condom during intercourse. It is not possible to tell from a person's appearance if they are HIV positive. Appropriate use of a condom is at present the best precaution to adopt to keep from getting infected during sexual intercourse with someone of either sex who might be infected.

Many of the infected women I met told me that the men never use a condom. When I asked them the reason, there were two main responses:

1. They weren't aware that they were at risk of falling ill with an incurable disease. Since they go to a doctor once or twice a month they thought that this visit took care of whatever risk there was in getting treatment for any sexually transmitted disease; they weren't aware that there is no treatment for AIDS, that all those who become HIV positive eventually get AIDS, and that it has proven so far to be invariably fatal.

2. They felt they didn't have a choice. In the brothels where they worked if they said they wouldn't have sexual intercourse with a man unless he used a condom, they would be beaten to force them into it. In addition, they might not be fed.

The brothel owners I spoke with



didn't seem to care. One madam screamed at me: "What condoms? We'll lose our business! Just go away and leave us alone. Don't come nosing around here. I take my girls to the doctor regularly...a private doctor, not all these government chaps...If any girl falls ill we'll replace her. Mine is a clean place. No man will pick up any disease here." Obviously, the notion that the client could be the cause of the infection hadn't occurred to her. Or if it had, she didn't seem to take it into account.

The mortal danger to women having unprotected sex with HIV positive men wasn't a salient issue for the brothel owners, nor did they make any efforts to devise means whereby the women might acquire more power to negotiate safer sex with clients.

The women talked about other issues. They told me that the only thing that would give them more security and help them negotiate directly with the client was to get the police off their backs. Asked the girl who had threatened to kill herself: "When my husband beat me every night, did the government help me? When my child had to go to school, did the government pay for his uniform or books or all the other things that even a so-called free school asks? If you people can't give me a good job so I can earn enough to eat well and educate my children, what right do you have to lock me up for doing the only thing I know to do to survive? Why don't you lock up the man who came to sleep with me, why don't you lock up the pimp who hired me into this, why do you people keep harassing poor girls like me who don't know anything?"

Indeed, even a cursory examination of court records in any state will reveal that there are almost no cases of conviction of brothel owners or pimps despite the fact that PITA is aimed primarily at stopping trafficking in women. Though prostitution is legal, it is invariably the women who are threatened, bullied and arrested by the police and subsequently convicted by the courts.

Women's vulnerability

PREMA RAMACHANDRAN

THE second half of the 20th century witnessed tremendous improvement in maternal and child health. Improved diagnostic tests, anaesthetic and operative techniques, availability of banked blood, antibiotics and other drugs gave physicians an unparalleled opportunity to tackle the health problems of women and children. Efforts to reach services to the needy through the primary health care approach were making headway. Everyone optimistically assumed that since progressive global improvement in health status is inevitable, health for all in India would be achieved, if not by 2000 AD, at least a couple of decades later.

With hindsight, one can see that the widespread availability of contraceptives to prevent pregnancy and antibiotics for the treatment of STDs led to behavioural changes in the population. The increased sexual promiscuity which resulted set the stage for a potentially explosive STD epidemic. Looked at from this perspective, the AIDS pandemic has all the inevitability of a Greek tragedy. It nevertheless came as a rude shock to us.

By mid-1980s it was realized that women and children are among the worst affected segments of the population. A rapid assessment of the

impact followed and today we have global data on the epidemiology, pathophysiology and clinical manifestations of AIDS in these two vulnerable segments of the population. Based on this data, measures to minimize the adverse impact have been defined, which include provision for care of AIDS cases and seropositive persons, strengthening of MCH care and supportive services and health education.

Of the three major modes of HIV transmission world-wide, sexual transmission has proved to be the most inefficient method of spreading HIV infection; the risk of infection has been estimated to range from 1/1000 to 1/100 exposures. However, because of the large size of the population and frequency of the exposure, sexual transmission accounts for over 75% of infections. Women are more likely to get infected by, rather than infect, men. The presence of sexually transmitted diseases, especially ulcerative lesions of the genitalia, increase the risk of HIV transmission.

Parenteral transmission due to blood/blood product infusion is the most efficient method of transmission, with the estimated transmission rate being 90%. However, with improved coverage of screening of

blood/blood products, this mode is likely to become rare. The risk of parenteral transmission following the use of contaminated syringe needles is estimated to range from 1-5/1000 exposures. It accounts for the observed HIV infection in IVU users, and accidental infection in health care delivery. Parenteral transmission is currently estimated to account for 5-10% of HIV infections in different regions but is likely to become less common by 2000 AD.

Perinatal infection occurs in 20-50% of infants born to seropositive women. It is estimated that perinatal transmission accounts for 1-10% of all infections in different regions. The contribution of this mode of infection is likely to increase over the next decade when HIV infection becomes more prevalent in Asia.

It is estimated that the average duration of the asymptomatic period in HIV infected adults may last from 8 to 10 years. Once the symptoms develop, progression of the disease, especially in developing countries, is rapid: the majority of AIDS cases die within two years of diagnosis. The progression of HIV infection in infancy and childhood is also rapid: 50% of the infected infants die by the time they are two years old and over 90% do not survive five years.

The illness and eventual demise of the mother from HIV infection has a catastrophic impact on the well being of the entire family. The infected infants may succumb more rapidly in the absence of maternal care while the uninfected infants face the grim prospect of becoming orphans early in childhood, with all the attendant adverse consequences.

Using all the data available from different sources, WHO estimates that currently there are 8 to 10 million HIV infected persons in the world. Of these, more than 3 million are women; and a million are children. Over two-thirds of all the infected persons live in a developing country and have little access to health care. In the USA and Europe, the HIV epidemic curve appears to be plateauing. In Africa and Asia, however, the steep rise continues. Currently 2 million HIV infected persons live in the US; 5 million in Western

Europe; 6 million in Sub-Saharan Africa and 1 million in Asia. Unless very effective intervention programmes are implemented, the number of HIV infected persons in Asia is expected to cross those in Africa by the mid-1990s and by the year 2000, Asia might have the largest number of HIV infected persons in the world.

WHO estimates that by 2000 AD about 40 million men, women and children are likely to be infected by HIV, with the cumulative number of AIDS cases around 10 million. The heterosexual and perinatal will be the most common modes of HIV transmission, and over 75% of the infected persons will be living in developing countries. Providing health care for these is likely to further strain the already severely strained resources of these countries. By 1989 an estimated 1.5 million uninfected infants were born to HIV infected women. Most of them are likely to lose one or both their parents as a result of AIDS and become orphans. This figure is also likely to double by the year 1992. Providing appropriate support to these homeless waifs until they become adults is a task that is likely to tax the welfare departments to the utmost.

Prior to the advent of AIDS, UN had projected that the under-five mortality rate would decline from 164 per 1000 live births in 1988 to 130 per 1000 by 2000 AD. Current estimates indicate that under-five mortality was 166 per 1000 in 1988 and the figure is likely to rise to 185 by the year 2000. A similar trend is likely in maternal and adult mortality rates. HIV has thus wiped out the decline in mortality rate achieved by three decades of toil.

AIDS will result in the death of men and women in the reproductive age group, leaving the elderly without support. Women and children will become doubly vulnerable as AIDS casualties and AIDS survivors. The economic impact of the disease is likely to become very important in the long run. Hospitalization for HIV related diseases may overwhelm the health services resources and manpower by the mid-1990s. Available data show that in some African

countries 80% of hospital beds are filled with AIDS patients and that AIDS will claim up to half of all national expenditure for health in some countries.

There is no doubt that the direct costs of AIDS will be substantial, but the indirect cost of the pandemic will be even more prohibitive. There will be a decrease in workforce productivity due to HIV infection. Millions of young adult lives will be lost resulting in a dramatic loss of potential productive years to society. AIDS related sickness and deaths will affect the urban industrial sectors to begin with, but later, it is likely that agriculture, which remains the backbone of many areas, will be affected. Eventually the entire socio-economic system will be eroded resulting in a tremendous negative effect on national development.

India has the unique distinction of being the first country in the world to initiate systematic nationwide sero-surveillance among asymptomatic men and women belonging to high and low risk groups to obtain information on the magnitude and major modes of HIV transmission before AIDS cases were reported from the country. In 1986, ICMR organized a national sero-surveillance programme in close collaboration with Directorate General of Health Services (DGHS) and the state health services. The programme utilized the existing health care infrastructure with minimum essential additional inputs.

The data collected by the national network of reference and surveillance centres during the first six months showed that HIV infection was present in different parts of the country, and that heterosexual promiscuity was the major mode of transmission in India. Although the next 18 months of the survey indicated that the magnitude of infection in India was low, it became obvious that the infection is not confined to promiscuous men and women. HIV infection was detected among blood donors, spouses of promiscuous persons, children born to seropositive women and persons receiving blood/blood product infusions. It was also clear that the seropositivity rates among promiscuous men and women

and blood donors had shown a steep rise between 1986 and 1991.

Right from the inception of the programme, ICMR investigated not only the so-called high risk groups—promiscuous men and women, recipients of blood/blood products, IV drug users—but also low risk groups like pregnant women. Detection of asymptomatic seropositive persons in the low risk group had to a large extent contributed to the realization in the country that HIV can affect all segments of the population, leading to a consequent reduction in the tendency to discriminate against HIV positive persons.

Based on the available data, ICMR estimates that there are between 0.4 million to a million HIV infected persons in India. Estimates on the magnitude of the silent epidemic of HIV in India based on data collected by the ICMR sero-surveillance, together with the data from Thailand, led to the upward revision of WHO's estimates of HIV infection load in Asia. This, in turn, has led to the shift in the focus of global AIDS control programmes to Asia in an effort to slow down the epidemic, so that the Sub-Saharan tragedy is not repeated again.

The first seropositive persons detected in India were sex workers in Tamil Nadu. Since then, centres in different states undertook the screening of a substantial number of sex workers. Data from these studies indicate that there had been a slow but steady increase in the seropositivity rate from 10% in 1986 to 30% in 1991. Intervention programmes are currently underway in Bombay and several other cities to reduce HIV transmission to and from commercial sex workers.

Seropositive pregnant women (detected by screening during pregnancy) and pregnancy in known seropositive women were reported by sero-surveillance centres in as early as 1986-87. Data from the ICMR sero-surveillance indicate that between one-third to a half of the HIV seropositive persons in India are women. Most of them had been infected by heterosexual transmission; many do not belong to high risk groups. The majority are in the asymptomatic

phase and do not know that they are infected.

It has been variously estimated that between 100,000 and 400,000 women in India are infected by HIV. Every year, approximately 20,000 out of the 24 million deliveries in India are likely to occur in seropositive women. Prior to the HIV epidemic, India and Sub-Saharan Africa had similar MCH profiles. The modes of HIV transmission in these two areas are also similar. The major difference is that apparently HIV entered India a decade later. Effective implementation of intervention programmes can avert the re-enactment of the Sub-Saharan tragedy in India.

Contrary to initial reports, pregnancy does not have any adverse impact on the course of HIV infection. Immunodepression associated with pregnancy does not accelerate the progression from the asymptomatic phase to AIDS and death. HIV infection per se does not appear to have any adverse effect either on the health of pregnant women, the course of pregnancy, labour, puerperium or lactation. It readily crosses the transplacental barrier. Available data indicate that intrauterine infection occurs in 25 to 50% of pregnant women. There is some evidence that the risk of IU infection is lower in asymptomatic women, especially those who have a higher antibody titre. The risk of intrauterine infection is higher in women who are viraemic—these include women who have very recently acquired the infection and those with AIDS. Infection risk is reported to be higher in women who had earlier delivered an infected offspring.

In the last two years, there has been speculation about whether the use of drugs that reduce viraemia, such as azidothymidine and CD4, during pregnancy would increase foetal salvage. However, to do this, one would have to weigh the possible adverse effect of these drugs on pregnant women and the foetus against potential benefits. There may also be major ethical problems in conducting even clinical trials to test the hypothesis. HIV infection is associated with a higher rate of premature delivery and intrauterine growth retardation. It is possible that at least

part of this association might be attributable to coexistent risk factors like smoking, drug addictions and anaemia in HIV infected women.

The fate of the unborn child is the major reason for concern in the context of HIV infection in pregnancy. To prevent these potential calamities, medical termination of pregnancy (MTP) may be done in the first trimester, if the patient wishes it. Women who want to continue pregnancy should be provided with adequate and appropriate antenatal, intrapartum and postnatal care. Intensive neonatal care facilities should be available for looking after the low birth weight neonates. Every effort should be made to counsel the mother to adopt appropriate contraception soon after delivery and teach her the importance of correct and consistent use of condoms. Stringent precautions should be taken to prevent the accidental spread of HIV infection while providing health care, especially during delivery.

Screening for HIV during pregnancy along the lines of screening for syphilis during pregnancy has many ardent advocates. The major reason for screening for STDs like syphilis in pregnancy is to provide therapeutic intervention to prevent IU infection. This justification does not exist for HIV. Counselling for MTP in early pregnancy in seropositive pregnant women may provide the rationale in our country, but there are several practical problems that come in the way of the proposed HIV screening in India: (a) most infected women do not belong to any recognizable risk groups; (b) screening of all pregnant women is impossible because the majority do not attend antenatal clinics; and (c) screening facilities are neither available nor affordable. Most infected women will thus continue to remain undetected.

There is, nevertheless, a need to screen all pregnant women. The advantages of undergoing HIV testing are many and should be clearly explained. In India, the majority of the people, even those in high risk groups, are not seropositive. Screening would therefore provide these women with proof that they are uninfected, relieve them of their anxiety and possibly ensure that they

do not encounter any future risk of HIV infection.

For those with HIV infection, there are now drugs to prolong the asymptomatic period and alleviate their suffering. These women could take steps to ensure that they do not spread the infection to their partners/family. Identification of seropositive pregnant women and follow-up of their children is the only method by which children requiring special care in the future could be identified long before the need arises. The time available could be utilized in identifying the uninfected children who require societal support for their upbringing, so that they do not suffer the severe adverse effects of being 'AIDS orphans'.

It is imperative that safe and effective contraceptive care is provided for all seropositive women because of the known adverse consequences of HIV infection during pregnancy. In developed countries, condoms and spermicides containing monoxynol-9 have been advocated because they afford protection not only against pregnancy but also against HIV infection. In India, the current acceptability and use effectiveness of condoms is very low. Incorrect and inconsistent use of condoms could lead to a false sense of security and consequent increase in HIV infection rates. It could also result in unwanted pregnancies with all the attendant hazards to the mother-child dyad. In view of this, it is essential that health education regarding the advantages of condom use, the correct method of use and the need for its consistent use be initiated to improve acceptability and effectiveness. Subsequently, condom promotion for the prevention of AIDS could be taken up.

So far, no adverse interactions between any of the currently used contraceptives and HIV infection have been reported. In view of the known adverse consequences of pregnancy in HIV infected persons, it is essential to provide safe, effective and suitable contraceptive care to all HIV infected individuals. The choice of contraceptive for individuals should take into account the risks and benefits of the method, life-style and contraceptive preferences of the individual, avail-

ability of the contraceptive and existing health care facilities. However, in addition to the use of contraception of their choice, all seropositive persons should be taught to correctly and consistently use condoms for reducing the risk of HIV transmission. It is essential to ensure that needles, syringes and other equipment needed for fertility regulation are properly sterilized before use.

Due to limited laboratory facilities, lack of infrastructure and the prohibitive cost, it is not possible to screen all contraceptive advice seekers for HIV infection in India. Thus, in the majority of cases, contraceptive care will have to be provided without any knowledge of the HIV infection status of the individual. The WHO expert group on contraception and HIV infection has recommended that under these circumstances, contraceptive care can continue to be provided according to the existing guidelines, even though the HIV status of the person is not known.

HIV has been isolated from breast milk. Intense research efforts over the last four years have resulted in documentation of a few instances where the infant *might* have been infected through breast milk, but this mode of HIV transmission is very rare. All available data suggest that breast feeding will protect the HIV infected from other infections and may even prolong their survival period. In India, this advantage will by far outweigh the small potential risk of HIV infection through breast feeding. Therefore, breast feeding is desirable in children born to seropositive mothers.

In India very few of the infected mothers can be detected because universal HIV testing is not possible. Breast feeding is essential for infant survival and growth especially among poorer segments of the population, because infant food formulae are neither affordable nor safe. Hence breast feeding by the biological mothers should continue irrespective of the HIV infection status of the mother or infant, known or unknown. Promotion of breast feeding should continue to be the national policy.

The increasing prevalence and awareness of HIV infection has led

to concern about the efficacy and safety of immunization of HIV infected infants and children. Experience with live and inactivated vaccines in HIV infected children suggests that the immunization is free from major short-term side effects. Risks and known consequences of natural infection are likely to be graver than the risks associated with vaccination, even with live attenuated vaccines. Taking all these factors into consideration, WHO has recommended that all asymptomatic HIV infected children receive all standard vaccines, both live and inactivated; and that those with ARC/AIDS symptoms should receive all other vaccines except BCG.

Since extensive HIV testing of pregnant women is not possible in developing countries like India, the majority of seropositive infants remain undetected. At present there are no tests for detecting infected infants. Under these circumstances, WHO has recommended that all asymptomatic infants receive all standard vaccines irrespective of their HIV status, known or unknown. The existing immunization programmes in the country should therefore be vigorously pursued.

The advent of HIV infection in the community is yet another reason to intensify efforts to provide optimal MCH care. Providing appropriate contraceptive care to all eligible women would substantially reduce the birth of infected infants. It is essential that all aseptic precautions are meticulously adhered to during the provision of antenatal, intrapartum and contraceptive care, so that accidental HIV infection is prevented. Breast feeding, which is the best form of infant feeding, should be encouraged as the method of ensuring infant survival and growth and birth spacing. Irrespective of HIV infection status, all apparently healthy infants should continue to receive immunization against the six major vaccine-preventable diseases. With the introduction of mandatory screening of blood/blood products, the risk of HIV infection in children through parenteral transmission is likely to be minimized.

Public concern regarding AIDS stems from the knowledge that there

is no curative therapy or prophylactic vaccine for this infection. HIV per se does not kill; it is infections and malignancies that occur in the immuno-compromised persons that are responsible for the ensuing suffering and death. The available meagre data from India indicate that tuberculosis and amoebiasis are two common infections in immuno-compromised HIV infected persons. However, safe and effective drugs for the treatment of these two infections are now available. Also global research efforts have resulted in better diagnostic tests and effective drugs (though many do have severe side effects) for the treatment of several opportunistic infections seen in AIDS patients.

AIDS patients require hospitalization for the treatment of acute pathogenic or opportunistic infections and life-threatening emergencies. Many require emergency or elective surgical intervention. Malignancies occurring in AIDS patients also require appropriate management. Facilities for all necessary investigations and therapeutic procedures should thus be made available in the nodal hospitals. Every effort should be made to provide optimal care for AIDS patients, especially during acute infections and life-threatening emergencies, even though this effort is likely to strain the already meagre monetary and manpower resources available for health care in India.

During the chronic and terminal phases of their illness, AIDS patients require symptomatic treatment. These patients have to be provided with care in hospices so that they can spend the last days of their life in comfort and with dignity. Special efforts must be made to explore the feasibility of involving non-governmental/voluntary agencies for providing this type of care.

The AIDS pandemic caught the world in its most complacent decade when all seemed well on the surface and progressive improvement in health and prosperity appeared to be inevitable. With startling suddenness the HIV pandemic ripped this surface veneer exposing the ugly realities, shortcomings, weaknesses

and prejudices not only in the health system but in the entire social structure. The initial reaction was predictably panic, passionate protests and aggressive postures or depression and desperation.

But soon the challenge brought forth the best in mankind—the organization of a truly global systematic effort to define the problem and evolve and implement effective measures to alleviate the suffering and control the infection. Never before had so much been done in so short a time. Very high priority is accorded to research efforts directed at finding a drug to cure or a vaccine to prevent AIDS. If one is found soon, the social and ethical problems may vanish overnight and AIDS will become yet another remediable STD.

It is however, unlikely that during this decade there will be a vaccine or drug for the prevention or treatment of AIDS. Hence our efforts should be focused on prevention of HIV infection. Its spread can readily be prevented by mutually faithful monogamous sexual relationships. In persons who cannot follow this golden norm, the correct and consistent use of barrier methods such as the condom could minimize the risk of HIV infection. Massive health education campaigns of the kind never before attempted in the health sector are underway, using all channels of communications to spread information about AIDS so that every individual can take steps to prevent the spread of HIV.

Women have a very special role to play in the containment and control of HIV epidemic. They have to protect themselves, their spouses and their children (born and unborn). They have to provide care and compassion to those who are already infected so that they spend their life in comfort and die with dignity. If the breadwinner of the family dies, they have to take on the additional role of the wage earner so that their family does not suffer economic deprivation. Last but not least, the majority of MCH care providers and health educationists in India are women: it is possible that they may succeed in providing appropriate counselling and care through interpersonal channels.

Sexuality

MIRA SAVARA

ABOUT four years ago, an official for the Indian Council of Medical Research, New Delhi, spoke at the International AIDS conference in Montreal. He maintained that 'AIDS cannot, will not be a problem in India because we are a traditional society,' because we are unlike the decadent West, where the pill brought about a sexual revolution, with promiscuity and homosexuality.

Hardly five years later, and world authorities believe that India will probably be the epicentre for AIDS in Asia. Estimates about the number of HIV infected persons in India are many: ranging from 40,000 (in a WHO publication) to 0.5 million (accepted by the International Development Agency and many aid organizations) to 2.5 million (attributed to T. Jacob John of the Christian Medical College, Vellore, the first doctor to report of the presence of HIV in India). The estimate of the number of full blown AIDS cases was about 115 in March 1992.¹ But it is commonly agreed that the official numbers of HIV infected are grossly under-reported because of our inadequate medical infrastructure.

These figures have caused serious concern, and a massive amount of money is pouring in for AIDS-related work. Estimates keep changing, with the official government amount just for the state of Maharashtra, where the most AIDS cases have been detected, often being quoted as over Rs. 300 crores. This does not include the aid given by private agencies to NGOs.

In this article I shall argue that much of the AIDS-related educational

work currently being undertaken in India is irrelevant because there has been no attempt to understand and put sexuality into the Indian context. Prostitution, generally considered to be the hot-bed of infection, has been targetted for a massive onslaught. But since prostitutes are the wrong audience, the messages fail to make the desired impact. Moreover, the messages themselves are culturally irrelevant since Indian understanding of the causes of disease and health differ. I shall therefore attempt to put sexuality in a socio-historical context by examining the conditions under which the homosexual community developed in the US. The socio-economic scenario in India and the implications for sexuality will then be discussed.

It is widely believed that AIDS is caused by the HIV virus. Recently, however, a controversy has developed about this, with several top medical researchers, including Luc Montagnier who discovered HIV in 1983, and Peter Duesberg who first mapped the genetic structure of such viruses, believing that AIDS is not caused exclusively by HIV. They argue that the virus does not kill the cells of the immune system, but that the disease occurs when the immune system gets mis-programmed and begins to commit suicide in the presence of certain co-factors. Duesberg also maintains that AIDS is not infectious and is the result of other factors that damage the immune system including 'recreational drugs such as cocaine'.²

The reason for mentioning this detail is that all current educational intervention programmes are based

1. Lal, Shiv, 'AIDS/HIV Infection in India—National Programme and Future Strategies/Policies', *CARC Calling*, Vol. 5, No. 1, January-March 1992.

2. Bidwai, Praful, 'AIDS: Panic More Widespread than HIV', *Times of India*, 11 May 1992.

on the fact that HIV causes AIDS. And HIV is transmitted through body fluids, one avenue being the exchange of sexual fluids. It is therefore important to keep in mind the ongoing controversy about the HIV-AIDS connection. There is, after all, a large, world-wide AIDS bureaucracy and a multi-million dollar industry which exists on the belief that HIV and AIDS are connected. Any research that could topple this belief might therefore be prevented from reaching the public.

From the Indian point of view, this new development is extremely interesting. Western medical understanding of the causes of disease has been based on the germ theory. Eastern and more holistic methods of understanding health have stressed that it is the basic balance and health of the body which determines whether a person succumbs to a disease. The new developments fit a holistic system far better. However, since this article concentrates on AIDS and sexuality, we will assume for now, that HIV causes AIDS, and that HIV is passed through an exchange of body fluids. Blood is one. But another, which is more relevant here, is sexual fluids. Chances of infection increase with multiple sex contacts, which occurs through affairs (unpaid sex), paid sex and homosexuality.

It has finally been accepted that there are no 'natural' sexualities; and that sexual behaviour is socially constructed; that the rates and forms of sexual expression vary across time and space, and that they differ for different classes and social groups. In each society and sub-culture, the social meanings of sex differ, as does its place in the life of men and women. In order to concretize this social construction of sexuality, we will examine the conditions under which the 'homosexual community' developed in the US.

AIDS literature often talks about two different patterns of transmission—that of the West, where it starts in the homosexual community, and then filters into the heterosexual. The other is the African (also applicable to India), which is primarily heterosexual. However, rather than viewing them as two differing modes

of transmission, it is possible to see them as being related to the differing historical and social conditions. In the West, societal changes were such that there emerged a sub-group and culture which could clearly be perceived as homosexual, making it possible to identify AIDS with a particular social group and thus be seen as the Gay Plague. Such conditions did not occur elsewhere. This is not to say that homosexual activity in Asia and Africa did not exist, but that the social context and expression of such behaviour are different in these societies.

It was in the middle decades of the 20th century that a gay sub-culture took root in American cities. The war years pulled millions of American men and women from their families and small towns and deposited them in a variety of sex segregated, non-familial institutions. For men, it was the armed forces; for women it meant migrating to the cities and often lodging and working in virtually all-female environments. For a generation of young Americans, the war created a setting in which to experience same-sex love, affection and sexuality.³ At the same time, the pill and birth control movement was breaking the connection of sex with reproduction. A new philosophy was emerging: sex was for pleasure.

The standard of living was also rising, together with the number and reach of consumer products. This allowed individuals to actually live a life dedicated to only pleasure. With growing consumerism, the advertising industry increasingly started to indulge in a not very subtle use of the erotic and sensual to sell their products. The entire society became sensualized, as it were, with lips, breasts, cleavages, and skin spilling out of every paper, magazine and TV programme.

The changes set in motion by the war continued after demobilization. As male homosexuals and lesbians came to associate more freely, they created institutions to bolster their sense of identity. The sub-culture that evolved took a different shape

3. D'Emilio and Estelle B. Freedman, *Intimate Matters: A History of Sexuality in America*, Harper and Row, USA, 1988.

for men and women. With a long historical tradition of greater access to public space as well as gender socialization that encouraged sexual expression, gay men could meet more openly in bars, parks, bath houses. Boston, for example, had about 24 bars for gay men, as against one which served only women.

The expanding possibilities for gay men and lesbians to meet did not pass without a response. The post-war years bred fear about the ability of American institutions to withstand subversion from real and imagined enemies. Politicians first latched on to the issue of homosexuality in February 1950, the same month that Senator Joseph McCarthy initially charged that the Department of State was riddled with communists. A Congressional hearing was told that thousands of sexual deviants worked for government. In June 1950, a formal enquiry was commissioned. The ensuing reports charged that homosexuals lacked emotional stability, and that they have a corrosive influence on other employees. The cold war against communism made the problem of homosexuality even more threatening, with the charge that homosexuals could easily become spies because their deviance made them prime targets for blackmail.

There was a remarkable increase in the annual number of dismissals from government service, the number of discharges doubling with each passing year. One study in the mid-1950s estimated that over 12.6 million workers, i.e. more than 20% of the workforce, faced loyalty/security investigations as a condition of employment. This labelling encouraged local police forces to harass homosexuals by openly attacking them in parks, clubs and bath houses. New York, New Orleans, Miami, San Francisco, Baltimore and Dallas—all experienced police raids on bars and a large number of arrests.

On 27 June 1969, a group of police officers raided Stonewall Inn, a bar in the heart of Greenwich village. The act became cause for a riot. Thus began the 'Gay Power' movement, a social movement giving

political visibility to the gay community. In time they were able to chip away some of the institutional structures, public policies and cultural attitudes that sustained a system of oppression. In the 1970s, half the states eliminated the sodomy statute from the penal code. In 1974, homosexuality was removed from the list of mental disorders. Several cities incorporated sexual preference into their municipal civil rights law. In Congress, the movement found sponsors for a federal civil rights law. Thus, though homosexuals have always existed in the US, for the first time they acquired political and social visibility as a rather powerful group.

Since AIDS is also a sexually transmitted disease, the chances of it being communicated in the homosexual community are as high as anywhere else. Easier in fact, since in the West it has been established that while male to female transmission occurs easily, female to male is rare, except if the male has genital lesions so that absorption of female sexual fluids is possible. Given the higher access of males to the medical system, and given the fact that it was possible to identify the sub-group, AIDS was initially associated with gay men's sex.

This history was quite unique to America, and perhaps to other countries of Western Europe. It did not occur in India. However, a look at the trends in India indicates that there are changes taking place which point to growing sexual promiscuity, and hence a growing susceptibility to all STDs, including AIDS. Nevertheless, it is difficult to talk about sex in India, given the vast varieties of groups that the country encompasses. We still have groups practising polygamy and polyandry. There are still areas where matrilineal systems exist, and areas where adolescent girls and boys live together in hostels as part of their growing up process. There has been so little work done on sexuality that to draw a real picture of Indian sexuality, taking into account the many regional and sub-group differences, is

difficult. However, we can discuss how the changing socio-economic conditions are related to sexuality and hence make some predictions regarding possible trends.

Based on our discussion of the growth of the homosexual community in the US, we can identify some parameters which affect the nature and types of sexual interactions and the social expression of sexuality. Some of these are: type of urbanization, women workers, changes in family structure, migration, the availability of birth control, the standard of living, and the type of consumerism and advertising.

The past few decades have seen a phenomenal growth in urbanization, the total urban population according to the 1991 Census reportedly being 217 million residing in 291 cities and towns all over India, 23 of which are million-plus cities. Urbanization has always been accompanied with a break-up of close extended family ties and with the growth of individualism in society. The nature of industrialization was also such that to a large extent, cities have had an excess of males. In 1931, for example, Bombay had 554 females for 1,000 men. This was because in the early stages of industrialization, it was common for men to migrate alone to the cities to work in factories, leaving the women and children behind in the rural areas to tend the small plots of land. This meant that the cities had a large number of single men without their families.

The most common living arrangement for those employed in the textile industry were all-male boarding houses. These provided a new opportunity for the expression of male-male sex, and for the growth in the number of prostitutes. Earlier, paid sex was usually associated with the other exclusively male setting, the armed forces. Now, millions of workers were potential customers. Prostitution in industrializing cities expanded. In Bombay, tens of thousands of prostitutes could be found in the infamous cages of Kamati-pura.

Besides this internal Indian migration, there has been a phenomenal growth in the export of labour from

India. Lakhs have migrated to the Gulf and returned with different experiences and rising aspirations, matched with a surplus income which they could not have imagined, let alone seen before. The number of women in the working force has also been showing an upswing, with a declining proportion of women working in household industry. In urban areas, the share of non-household industry increased from 12.9% to 14.3%. More and more women were leaving their homes for work, thus acquiring greater independence in their lives.

In addition, the tradition of the extended joint family has broken down, giving rise to a mushrooming of nuclear families. The pressures of industrialization and the erosion of traditional modes of living have also led to an increase in single women, and it is estimated that at least 20% of Indian households are headed by women. This again means that there are a large number of women who live independent lives, with little male supervision.

Indian women have never had to fight for birth control. It has been literally thrust upon us from every nook and corner. The government advertizes condoms, abortions, sterilizations, pills. Even though there is resistance to the forced nature of the family planning programmes, the overall effect is the awareness that it is now possible to separate sex from reproduction. One reason why women prefer to get sterilized themselves is that if the men do so, and the women become pregnant, it could lead to problems. This gives us some idea of what is actually happening.

All this has been taking place at a time when there has been a rise in the living standards of a large section of the people. With the help of unions, industrial workers, once part of the oppressed poor, now earn comparatively more, so that they have risen to join the ranks of the middle class. The level of income earned by the middle class has also been rising, as have the numbers of the nouveau riche. With this have come a growing number of consumer durables being manufactured by a large number of competing

industrial groups: fridges, TVs, music systems, mixers, air conditioners, ovens, microwaves, convenience foods, vacuum cleaners, washing machines, motor cycles, mopeds, cars. Once the exclusive preserve of the rich, these are now middle class household gadgets.

And all these durables are accompanied by advertising. Erotic images, as in the West, have become an everyday affair. Be it the Kamasutra ad for condoms or MRF tyres, showing the male body almost to perfection, or be it the sensuousness of Garden Vareili or the soft lips of Lakme, pretty girls are used to sell just about anything, from tractors to computers. All these factors point to a situation where there is a growing tendency towards freer social relationships outside of immediate family, village or caste control. With the increasing independence of women, one would expect a larger number of affairs contracted, not on the basis of force or money, but for mutual satisfaction. Prostitution would possibly grow in new areas, and specially in large towns where the first generation of villagers are leaving the confines of tradition. We could also expect a more open form of homosexuality.

There are some indications affirming the growth of a more open form of sexuality. The number of cases coming to the government STD clinics, which only records the tip of the iceberg, is increasing: from 479,000 in 1978-79 to 919,000 in 1984-85. The number of abortions done in government clinics has also risen from 317,000 in 1978-79 to 573,000 in 1984-85.⁵ Last year, Bombay Dost, the first magazine devoted exclusively to those practising an alternative sexuality, was launched.

Studies on sexual behaviour patterns would give us an idea of these changing trends. Unfortunately, in India, there has been no study of actual behaviour patterns, of what people actually do, as opposed to what people think people should be doing. It has long been assumed that virginity and monogamy were the

general rule. Deviant forms, like hijras, existed, but they were on the fringes—little noticed, of little concern.

Recently, however, a magazine conducted a small survey on the actual behaviour patterns of urban, educated men. The sample consisted of 1500 men, and the results broke several myths about the nature of Indian sexual behaviour.⁶ Over four-fifths of the men had had sexual intercourse, 41% of them before they had reached the age of 20. Only 22% had their first sexual experience with their wives; 29% had it with a friend, 21% with a paid person. 13% had their first experience with a relative, while for 10%, it was with a person of the same sex.

Among married men, 55% claimed to have had extra-marital affairs with a non-paid person of the opposite sex. 25% of these affairs took place with relatives, 18% occurred in the workplace, and 53% with friends. Thirty-seven per cent (414 men) claimed to have had homosexual experience. It was usually at a young age, 80% having had it before they were 20. 220 of these men were married, and a third of them said their wives knew about their homosexual activities. A fifth of the men said they had had over 10 persons. The main reasons given by respondents (30%) who claimed to have gone in for paid sex were because they felt like it, and because they were on tour. Of them, 43% had been to 1 to 5 women, 23% to over 10. Only 19% of this highly educated group used a condom on such occasions. Anal intercourse, considered by many to be the act of homosexuals, is not so. Among the married men, 20% said that they had had anal intercourse with their wives.

This is a small sample, based on a self-administered questionnaire published in an English magazine. It points to the urgent necessity of carrying out more extended research on sexual behaviour patterns. However, this small survey indicates that there is much sexual activity going on

outside marriage, which is not confined to prostitutes or paid sex.

The current emphasis of AIDS education work has been on the prostitutes, with free and subsidized condoms being distributed and their being 'motivated' to educate their customers to use them. Here, it is crucial to understand the basis on which the exchange between prostitute and client occurs, and to what extent she is capable of negotiating the terms of that exchange. This determines whether she has any bargaining power over the usage of the condom. In India, supply far outstrips demand, and in many cases women are totally dependent on only sexual exchange to make their livelihood. In such a situation, it is unlikely that she would insist on condom usage.

Increased bargaining power is a precondition for the prostitute to be able to negotiate the terms of her contract. In the absence of this, all propaganda, like free condoms, get thrown in the garbage. Not eating today is far more real than the possibility of getting a disease from an act which she has been performing for years, without too serious a problem. For an AIDS intervention to make sense, it needs to be linked with empowerment, which can only occur if other means of making an income exist. AIDS education for prostitutes has to be linked with income generation.

But prostitutes, as a distinct group, are not the only ones concerned with sex. As the survey indicates, a relatively high number of affairs are with relatives and with co-workers. In the absence of data, it is difficult to conclude that these are totally voluntary. Since there is an unequal social relation, it is possible that women in such a situation have little control over the conditions of sexual exchange. The focus on usage of condoms with prostitutes denies the need for clients to use condoms in their other sexual encounters.

As the above statistics show, the extent and nature of sexual contacts is far wider and the range encompassed similar to the other social contacts a person is likely to have. Hence, the emphasis on educating

5. Department of Social Welfare, *Handbook of Social Welfare Statistics*, Government of India, 1986.

6. Savara, Mira and C.R. Sridhar, 'Sexual Behaviour of Urban, Educated Indian Men: Results of a Survey', *Journal of Family Welfare*, Bombay, April 1992.

prostitutes about AIDS creates the illusion that it is a disease which is primarily transmitted by this group.

Little of the educational work addresses itself to homosexuals. This is because at some level there is denial that homosexuality exists here, particularly since its social expression differs from that in the West. In India, homosexuality is not perceived as providing an exclusive social identity. However, the survey mentioned earlier does indicate the prevalence of such behaviour, although most men do not engage exclusively in male-male sex. Hence the social matrix of the possibilities of AIDS transmission in India differs substantially from the West. And it is evident that if the current focus on prostitutes continues, it will fail to contain the infection.

There have been some attempts to educate the public through ads and TV. The lesson most often given is that AIDS is a killer disease. The picture of a skull with AIDS written over it has become commonplace. It carries the message that sex could equal death, a message which would probably jibe well with the West, given its Christian sub-culture that sex equals sin. However, the usual understanding is that the Indian conception of sex is quite different. Our myths talk of creation as a joyous act of intercourse: our gods are always male and female together; control of sexual energy can be a means of spiritual enlightenment in Tantra: the erotic sculptures, or what remains of them after all the invasions and breaking of temples, are one indication.

In the West, there has been a growing separation of sex from other kinds of relationships. The advice contained in sex manuals seems to be directed towards machines, to be touched here, tickled there. Compare it to the Kamasutra, which laid down complicated ethics of behaviour and gave hints on how to approach others' wives and courtesans. Romancing, and the art of seduction, of pleasing the other, is what is important. Sensuousness. Not this obsessional preoccupation with the orgasm. It is a more total experience, entwined into the texture of life, with smell, taste and feeling.

The current educational campaigns on AIDS treats sex in the abstract manner of the West. 'If you go with another woman....you could get AIDS.' The ads for Kamasutra condoms show a much better understanding of the Indian feeling for sexuality, including it as part of the skill in making love. The view of sex as dehumanized and impersonal, as something which could cause death is currently being supported by a multi-dollar campaign funded primarily by the West. Local NGOs working on AIDS have been drawing attention to the West's ideological control of the way we approach our problems. For example, already the World Bank has stipulated that the AIDS project must be run by an independent body, outside government control and with free access to WHO, which will monitor and evaluate the project.

Local NGOs also allege that the national AIDS project is being hijacked by foreigners and India could soon become a playground for foreign AIDS researchers, just as Africa was in the 1980s. This is a real possibility, given the fact that the international AIDS programme has reached the stage where they want to test possible cures.⁷

The current AIDS campaign is based on an understanding of sex, individuals and society which has essentially come from the West. Sex is referred to entirely in the abstract, as an act which exists apart from the individuals concerned: a medico-technological impersonal act, to which we have to apply our scientific, men as object, gaze. The purpose of this article has been to indicate that sexuality is a social construct, and that its construction in India differs from that of the West. Our current educational campaigns are based on a lack of information, or information that we are incorrectly transposing from the West. And this has serious implications. Finally, it is only with an open recognition of the need to understand sexuality and disease within our own culture that any adequate and effective educational campaign can be developed.

7. 'IBRD Funding of AIDS Project Flayed', *Economic Times*, 8 April 1992.

Hapless victims

S. SUNDARARAMAN, SURESH PURUSHOTHAMAN and A. K. GANESH

THE Human Immunodeficiency Virus (HIV) first made its official appearance in India in Madras in 1986. The first few cases of HIV infection were reported amongst women engaged in prostitution (prostitutes are hereinafter referred to as the CSWs or commercial sex workers). Not surprisingly, a great deal of frenzy was whipped up in the media and the popular feeling was that if you do away with these women, you've killed the problem.

This is not being realistic even if prostitution provides an imminent threat of transmitting the virus. A whole gamut of issues need to be looked into for us to develop a more understanding and mature outlook towards those segments of societies which are sought to be marginalized further as a result of this epidemic, and overall, towards the very import

of HIV and AIDS in our society. This article attempts to explore a few of these. It should be noted, however, that the scope of the article confines itself to the women operating in the lower socio-economic category and does not apply to those operating in higher economic levels.

The CSWs are predominantly from the economically weaker sections and operate from diverse locales like rail/bus stations, cinema theatres, other public places and highways. Their lower levels of income per sexual encounter necessitates them to have the maximum number of clients possible within the day. The high number of sexual contacts increases their risk of contracting HIV from an infected partner. Consequently, this large client turnover, intrinsic to sex work, also magnifies the risk of infection from

HIV through clients who are already HIV infected.

CSWs though, are not the only dimension to the whole problem. The clients of these sex workers, who belong to all sections of society, have a greater chance of transmitting the virus across the general community. The social and cultural factors that govern our societies respond in a manner that is at variance with this reality. Marginalization of the sex workers under the premise that they are the real and only vectors of transmission is taking place, and the chances of orchestrating detection to fix the blame on them therefore become higher, all the while clients being the unseen partners of HIV transmission.

The problem of HIV and the vulnerability of the commercial sex workers to its transmission is further compounded by several factors that have hindered the prospects of their being able to lead a healthy and full life.

A majority of the sex workers are illiterate. This renders preventive education campaigns in the media hard to reach this community. Outreach based, community level intervention strategies are the only viable and credible option.

Because of the high turnover of clients they have to ensure to meet their economic needs, and because of the fact that both medical treatment and the time spent on it constrains their earning a great deal, CSWs accord health the lowest priority. Their genital hygiene being poor, they are subject to repeated vaginal trauma. As is the case in even the general population, any occurrence of Sexually Transmitted Diseases (STDs) is often neglected and left untreated. Since the danger of HIV transmission is much higher in the event of an STD, the sex workers are at greater exposure to the virus.

Protective devices i.e. condoms are rarely used within the ambit of commercial sex. Many workers hardly possess the knowledge nor do they have access to the information that use of condoms minimizes risk of transmission. Granting that HIV/AIDS prevention and education cam-

paigns do offer a credible and correct source of information to the sex workers, what are the factors that deter assimilation of this information and subsequent shift to protective sexual behaviour based on this knowledge?

Traditionally, since the man-woman relationship in our country has always been loaded in favour of the male, women are often always left without any decision-making powers. Both within the confines of a family, a marital relationship or outside of it, men have always had their say in all matters. This socio-cultural factor extends itself to commercial sex work as well.

Women sex workers, faced as they are with competition and economic pressures, are left with very few options to enforce or ensure condom use. This feeling of absolute powerlessness negates any positive effect that HIV/AIDS education or knowledge aimed at the commercial sex workers would otherwise have.

Clearly, the pattern of HIV transmission across the country is heterosexual, multi-partner sex. The taboo that clouds and inhibits open discussion of sex and sexuality in India constricts any reasonable knowledge of the magnitude of sexual interaction that takes place outside of commercial sex. It, therefore, becomes all the more easier to fix the blame for spreading HIV on the CSWs, which is grossly unfair.

Moreover, in view of the lack of any policy framework for the testing and surveillance of HIV, forcible testing of the CSWs and thus coercive detection of infection among these women leads to a more greater distancing of the problem. The popular perception that the sex workers are responsible for infecting others, ignoring the fact that clients infected them in the first place, has led to all strategies centering around this community. Reality demands otherwise.

Like the rest of the world, the Indian government also initially adopted a cavalier attitude towards HIV/AIDS. The epidemic was sought to be controlled by merely marginalizing and isolating the commercial

sex workers. With each passing day, with more and more cases of infection being reported from amongst the general population, the centre awoke to the haunting reality that here was something that necessitated more than disease control measures.

Yet, precious little has been done apart from drawing up elaborate plans and strategies. The time lost in the implementation of these, however myopic they may be, is proving to be costly. Information and education campaigns focusing on prevention have still not been taken up by the government. AIDS, however, is high on the priority list, even found to be deserving the formulation of a medium-term plan.

Few state governments, notably, Maharashtra, Manipur and Tamilnadu, have initiated any action. These states are then considered to be epicentres of HIV infection in India. The thrust of these strategies is predominantly on minimizing HIV spread, with not much being done about STD prevention which could hold one of the keys to the successful combatting of the epidemic.

India boasts of an extensive network of non-government, community-based organizations that are dedicated to serving society on social, economic and health/medical fronts. NGOs working exclusively on AIDS have been few and far. However, many other grassroots organizations have now started to concentrate their energies on HIV prevention.

The major stumbling block for NGOs working on AIDS seems to be the acute sensitivity attached to discussing issues relating to sex. Many of the NGOs themselves are not comfortable while talking about these issues and STDs, as also in working with or among the CSWs. Quite a few have adopted retrograde, regressive policies with a reformist stance aimed at the abolition of the practice of prostitution. The ground reality that it will take a social and economic revolution to end this profession, which is unforeseeable even in the long-term future, has escaped these NGOs and they work at cross-purposes to the whole effort.

However, there have been a few interventions aimed at sex workers that have adopted a more humane, non-judgemental approach to the whole issue of prostitution and HIV/AIDS. Notable among them are the Indian Health Organization; Population Services International; and the Bombay Municipal Corporation, all of whom work in the red light district of Kamatipura in Bombay. As is apparent, much of the focus and effort has been concentrated in one geographic area i.e. Bombay, where a modest measure of success has been documented.

The need of the hour is therefore to look at successful projects and adopt these to suit the socio-cultural needs of particular geographic areas, and quickly and efficiently replicate successful projects/programmes addressing STD/HIV transmission throughout the country.

As discussed earlier, a shift in focus from interventions aimed toward the commercial sex workers to the clients, is imperative. During the course of a one-year pilot project conducted among the commercial sex workers by the AIDS Research Foundation of India in Madras, several observations were made, which have been discussed earlier: absolute lack of information/knowledge on HIV/AIDS due to illiteracy, lack of negotiating skills and power to enforce/ensure condom use etcetera among the CSWs.

It was then decided that it was futile to aim all interventions at the CSWs alone, without creating an environment that is conducive to the adoption of prevention mechanisms while selling sex. More gains would follow by shifting the focus of interventions to the clients of these sex workers. Since the presence of STDs is a fairly good parameter of the vulnerability to HIV infection, a study was done at three STD clinics in Madras city which revealed distinct profiles of people reporting infections. Correlated with the information culled from the CSWs about client patterns, these were seen essentially as people who were migrant or living outside of their home towns/villages. Few of the client profiles were of long-distance truck drivers and other transport

drivers, blue collar industrial workers, construction workers, port employees etcetera.

The clients came from diverse segments of society and as such, exhibited diverse socio-cultural behaviour that was peculiar to their individual communities. For example, it was found that the long-distance truck drivers were familiar with condoms on a day-to-day level, though for a different purpose: they used it to plug radiator leaks. Their constant sex seeking was born out of a felt notion that they had to dispel the heat assimilated in their body due to being exposed to the engine heat during their long journeys. This notion was passed down among their community by generations of truckers.

It was also observed that the construction workers took to commercial sex seeking due to the fact that they were mostly migrants living away from their families, and that the port employees patronized CSWs mostly on Fridays, their weekly pay day. Such factors need to be carefully analyzed and used to develop and implement interventions that are appropriate to the different segments of the people involved.

In the light of the current projections of HIV infection that portray a very grim picture for the coming years, HIV control programmes have to immediately assume a much more broad-based canvas that ensures that prevention messages reach everybody and consented safe sexual practices become the norm of the day. The immediate need for integrating STD prevention with the HIV prevention programme should also be addressed.

The CSWs do require particular attention due to their specific vulnerability to the infection. But, before interventions repeatedly target these people, an atmosphere that is conducive to their negotiating and selling safe sex must be fostered. It is for this reason that the focus now needs to be shifted towards the clients and that a positive change from unsafe sexual behaviour to safe sexual behaviour that promotes a bi-directional process is brought about within them.

INFERTILITY AND PREGNANCY LOSS

Rewritten by
JILL RAKUSEN

INFERTILITY

Infertility is a life crisis. It is usually unexpected; often we don't know how to cope with the feelings raised by the experience of discovering we are infertile. There is an initial reaction of shock and denial.

I, like every other woman in this society, always believed that I would have children without any problems – as many as I wished, and when I decided it was the right time. Unfortunately, after four years of trial and error, tests, operations, etcetera, my husband and I are realizing that life does not always happen the way we plan it. I have found it quite hard dealing not only with our infertility problem but also with the reactions of people around me.

I'm sick of people telling me to 'relax', 'stop thinking about it', 'adopt and you'll get pregnant', and all the other wonderful clichés that, although said to be comforting, ring of insensitivity. Friends and family can never possibly know the pain that I feel inside, the anger and resentment I feel every time I see a woman walking down the street with a big belly. How could they understand? How could anyone capable of having children understand?

Often you find yourself putting off making decisions, or changes, because 'six months from now you will be pregnant'.

I stopped teaching five years ago to become pregnant. When that did not happen, everyone wanted to know what I could possibly be doing at home all day if I didn't have kids. Neither a mother nor a career woman, I stayed in limbo because I kept thinking, Maybe it will happen this month! I was drifting, and it is hard to believe so much time has gone by with just this single purpose in mind.

When women you know have children, it may be hard for you to relate to them. Feelings of envy, jealousy and 'why them and not me?' are common. Because holidays are so child-centred, they can become stressful, lonely and depressing times for you. You may feel isolated from friends or your partner.

My husband is disappointed with our failure to conceive, but he could easily accept a child-free life. He says he understands my feelings and sympathizes, but doesn't care to hear any more about the subject. His view is 'Play the cards dealt you' – you go on about your business no matter what. His disappointment is mitigated by involvement in a job he likes and other alternatives. I have not found a satisfactory alternative.

Infertility is not only a problem for childless women. Difficulty in conceiving a second or subsequent baby is not uncommon.

I didn't feel I had the same right to grieve as a woman who had no children. Yet the loss seemed particularly intense because I knew what it was that I was losing. I was being denied the pleasure of holding my own baby in my arms again. I could feel what it felt like but I couldn't have it. All I had learned about mothering would be wasted. For fifteen months my life seemed to have been suspended while I waited to fill the hole inside me.

Anger is a common feeling, but it is hard to know where and towards whom to direct it. We tend to look for a reason for our infertility. We may feel that something we did in the past caused our present inability to conceive. Some people irrationally think that masturbation, unusual sex practices, etc., have caused this form of 'punishment'. They do not cause infertility, but our minds can trick us into believing it and make us feel terribly guilty. Or we may feel that we are

to blame because we had an abortion. As we discuss in the abortion chapter, while abortion can result in infertility, this is very rare, unless the abortion was badly performed or wasn't carefully followed up.

Depression, sadness and despair are common.

I grew up surrounded by the idea that if you were willing to work or study hard and always did your best, nothing was beyond your grasp. Generally I have found this to be true. The theory fell apart when I began to deal with my infertility problems. Not only did I become very depressed, but without the help of a friend of mine who shares the same problem I seriously doubt whether my marriage would have remained intact.

It is only through a great deal of pain and anguish that I have begun to accept the idea that I may never have children. After the initial shock wore off, my husband and I became closer than ever.

I wish that more doctors dealing with infertility would address themselves to the feelings of their patients instead of leaving them floundering, looking for their own resources.

I'm tired, I'm tired of an empty, longing, aching heart that yearns to hold a little baby of my own. Oh, I've tried everything. I've tried praying, relaxing, furthering my education, working hard at my career, social clubs, church work, service work, slimnastics, cross-stitch – you name it, I've tried it. And I still cannot get rid of that aching, yearning, longing emptiness that can only be known by barren women.

Infertility is defined by most doctors as the inability to conceive after a year or more of sexual intercourse without contraception. The category includes women who conceive but can't maintain a pregnancy long enough for the fetus to become viable (able to live outside the mother). You have the right to seek help or advice whenever you begin to feel concerned about your failure to become pregnant. Infertility may be a temporary or permanent state, depending on your problem and on the available treatments. Many people are surprised to learn that infertility is not unusual. Commonly quoted figures are that between 15 and 20 per cent of couples are infertile, although there are no reliable data on the subject (see Pfeffer and Quick in Resources).

CAUSES OF INFERTILITY

Infertility involves complex physiological events, some of which are poorly understood.

Male infertility may be connected with:

1. Problems of production and maturation of sperm, e.g. because of previous infection, such as mumps; undescended testicles; environmental factors (including chemicals in the workplace and drugs – both prescription

and otherwise).^{*} Extremely intensive exercise – e.g. marathon running – has been found to lower sperm count too; infertility has been recorded in some male Olympic marathon runners according to Professor Rose Frisch of Harvard Medical School. The effect is reversed when exercise is reduced.

2. Problems with sperm movement ('motility') – but little is known about what causes this.

3. Blocked tubes through which the sperm travel, possibly caused by untreated infections. (Vasectomy involves blocking these tubes deliberately.) Varicoceles (swelling of the veins from the testis) may also affect some men's fertility.¹

4. Inability to deposit sperm sufficiently near the cervix, because of disability, impotence, premature ejaculation or malformation of the penis (e.g. when the opening is either on the top or underside of the penis instead of the tip).

5. Poor nutrition and poor general health. See Diet p. 425.

6. It is possible that psychosomatic causes may also play a part (see p. 425).

Female infertility may be connected with:

1. Hormone problems: failure to ovulate regularly or irregular menstrual periods may be due to a problem in the ovaries, pituitary, hypothalamus, thyroid or adrenal glands, or to the normal ageing process – as we approach menopause (see p. 454), we ovulate less frequently.^{*} Women often develop amenorrhoea (absence of periods) following use of the Pill or Depo Provera (DP). While there is as yet no clear evidence that Pill-use can result in permanent infertility, it can certainly cause infertility for many, many months and for several years in women who are in their thirties and have never had a baby. Prolonged Pill-use seems to increase this risk in older women. Women who have irregular periods or who are older when they begin menstruating also seem to be more prone to this 'post-Pill syndrome'.² We do not know enough about DP to be specific about its effect on fertility. Sometimes fertilization does occur but low progesterone levels may mean that implantation does not occur, or the pregnancy is lost in the first twelve weeks.

2. Scarring on tubes or ovaries from endometriosis (see p. 485) or untreated infection due to STD (see p. 503), gynaecological procedures such as a D&C or abortion, or

^{*} See Chapter 9, p. 151 for certain environmental factors; for information about drugs known to affect the male reproductive system, see *Out of Our Hands* by Jill Rakusen and Nick Davidson.

¹ Schwartz et al. found that older women tend to take a little longer to get pregnant than younger women. ² Although they did not establish what proportion, if any, of women over thirty-five failed to get pregnant at all, this study has been widely referred to as indicating that women should get pregnant in their twenties or face infertility. This is not only groundless on the basis of the evidence cited, it also fails to take into account the negative effects of having a child early – see for example Danich and Wengarten, who found that, without exception, couples who had their first child in their early twenties later wished they had delayed parenthood until they had developed as individuals and as a partnership.

the use of an IUD (see p. 287). Even infection following childbirth can cause infertility.

3. *Abdominal surgery*: it is possible that some medical emergencies in childhood, in particular a perforated appendix, could be responsible for subsequent infertility, particularly if the emergency was not treated with this in mind. But there is more evidence that poorly conducted abdominal surgery (e.g. that is rough or unnecessarily damaging) is a cause. Dr Robert Winston, whose research has highlighted this problem, has found that a considerable proportion of infertility cases he sees are iatrogenic (i.e. caused by medical treatment). See *Out of Our Hands* for further discussion.

4. *A badly done abortion*, or as a result of an *untreated infection* after abortion (see Chapter 17). Abortion is widely believed to be a cause of infertility; while this was indeed the case when abortion was illegal, the risk of infertility with a legal abortion, particularly early abortion, is minimal, and with late abortion the risk is mainly due to cervical damage if the doctor is not careful.

5. *Structural problems in the uterus*, due to congenital problems or exposure to certain drugs such as DES and other hormones while being carried in their mothers' womb, can cause infertility in some women (by preventing conception or affecting the ability of the uterus to sustain a pregnancy).

6. *Other factors*, such as genetic abnormalities, fibroids, extreme weight loss or weight gain, excessive exercise (see Chapter 6), poor nutrition, stress and chemicals at work or in the environment at large may affect a woman's fertility (see Chapter 9). So, too, may subconscious feelings of fear or anger (see p. 425).

A couple may have a combination of problems which results in infertility. For example:

1. Sperm being unable to penetrate the cervical mucus; this problem tends to be defined solely as the woman's problem – the woman having 'hostile mucus' (which may be due to an infection like chlamydia or T mycoplasma – the treatment of which can often result in pregnancy). However, as Hull et al. conclude: "The usual terms 'cervical infertility' and 'mucus hostility' are . . . inappropriate', except in unusual circumstances. They found that 'defective sperm function' is a frequent hidden cause of so-called hostile mucus."

2. They may not know when the woman is fertile, how often to have intercourse during this time or what to do to make pregnancy more likely (see Self-help below).

It is thought that the causes of infertility are roughly equally divided between male factors, female factors and joint factors. However, in around 10 per cent of cases, it is not always possible as yet to diagnose the cause of infertility; when the cause is not understood (which may sometimes be because of inappropriate sequencing of tests) it is referred to as 'idiopathic infertility'. We must press for more research about the causes and prevention of infertility, and for recognition and application of future and existing know-

ledge. In particular, the effect of 'environmental' factors on both sexes' fertility, including stress, drugs, chemicals present in the working or home environment, or in the environment at large, is largely unknown, but all are thought to be relevant, at least to some extent (see *Out of Our Hands*). We do know about certain drugs (e.g. people of both sexes who as fetuses were exposed to DES in the womb have an increased risk of fertility problems) and this can teach us lessons about other drugs and chemicals, many of which are used with little thought about long-term effects. Effects on fertility, for example, can take more than one generation to show up, but they'll only show up at all if they are looked for, and to do that accurate records must be kept and the will to look at them must exist.

SELF-HELP

Learning about Our Fertility

This can help a lot. Masters and Johnson stated that one out of five couples who attended their infertility clinic over a twenty-four-year period conceived within three months with no treatment other than use of this basic information: if your menstrual cycle is regular, whether it be long or short, you will probably ovulate fourteen days (give or take twenty-four hours either way) before the beginning of your next period. In other words, you should try to become pregnant on the thirteenth, fourteenth and fifteenth days before your next period. During these three days, spacing your love-making is important (see *Fertility Awareness*, p. 37). A man's sperm production decreases if he makes love too often, so you should have intercourse no more than once every thirty or thirty-six hours to keep active sperm in your genital tract during that period of time. Infertility clinics suggest a four- or five-day 'abstinence' period in order to get a high sperm count.

Use no artificial lubricant when having intercourse and never douche afterwards. If lubrication is necessary, saliva is the safest choice. Your partner's penis should remain inside you until it has gone limp. Approximately 60 to 70 per cent of the sperm are contained in the first part of the ejaculate. Since it usually takes about twenty minutes for sperm to reach the uterus and fallopian tubes, it is a good idea to lie on your back with your knees elevated for about thirty minutes.* If your uterus is not tilted back, your chances of conception may be increased by having intercourse with your partner above and facing you, and a folded pillow under your hips to raise them.

You can also get a good indication of whether or when you are ovulating by using a basal temperature chart, and monitoring the type and amount of your cervical mucus (see *Fertility Awareness*, p. 37 for how to do this). You can then time intercourse to coincide with your fertile time.

Planned sex can really affect your sexual life. You have to plan intercourse around your menstrual cycle; it becomes

*Some women recommend douching with baking soda thirty minutes before intercourse to change the consistency of cervical mucus and make it less viscous, so that sperm encounter less resistance.

less an act of loving and pleasure and more a medically necessary response. Recording the times of your intercourse on a temperature chart may make you feel that nothing is private or sacred in your life any more!

I started with the temperature charts. This was quite taxing for me, and mentally depressing. I felt very regulated and calculating, both with my own body and in my relationship with my husband. I need not say what it did to our natural sexual impulses. But a child at all cost – this was how we felt. My husband woke me every morning at six A.M. so that I could take my temperature. Afterwards he charted it. I needed his involvement.

Learning about Ourselves

There is some evidence that subconscious feelings – e.g. fear, at some level, of having a child – may be responsible for infertility. Dr Paul Entwistle has had considerable success in enabling such feelings to surface and be resolved through hypnosis – with ensuing pregnancies⁶ – and it is possible that therapy, self-therapy or co-counselling (see Chapter 8) may be helpful in this area, as well as hypnosis.

Learning Relaxation and Similar Techniques

The link between stress and infertility in women with no 'structural' reasons for their infertility may sometimes be due to increased prolactin secretion. Although little research has been done on this, there is evidence to suggest that reducing prolactin levels by reducing stress alone may indeed help such women get pregnant, or doing this in combination with hormone drugs where appropriate (see p. 428).^{*} Of course, the whole process of trying to get pregnant can be extremely stressful. Anything you and your partner can do at this time to find ways of experiencing inner peace and calm on a regular basis is likely to be helpful generally; it will help you cope with the pain and turmoil, and may even increase your chances of getting pregnant. *Self-healing techniques* such as visualization may also help. See Chapter 7 for further information.

Diet

Poor diet contributes to your stress too. There is also evidence that women who live on refined foods appear to secrete smaller quantities of the hormone responsible for ovulation than women who have a diet rich in unrefined cereals and fresh vegetables.⁸ Indeed, a naturopathic approach has reportedly been successful. This approach assumes, for example, that the vaginal secretions can be affected by diet, and if the secretions are too acid, sperm can be destroyed. To ensure alkaline secretions, we need to eat a lot of vegetables (preferably raw) and fruit. Alkaline pessaries or solutions can also be used. If you have a constant, heavy discharge (leucorrhoea), diet can also deal with this. Kelso's *Women's Ailments* (see Resources, p.

^{*}In an as yet unpublished paper, Mona and Rory O'Moore of Dublin studied thirteen infertile couples who were taught autogenic training – a form of relaxation. It reduced prolactin levels and 'anxiety scores', and three of the women got pregnant.

441) recommends a specific diet along the lines suggested above, as well as other naturopathic ideas.

Women who are underweight may also find that weight gain increases their chances of conceiving.⁹ In addition, it has been suggested that deficiency in 'essential fatty acids' can lead to infertility, especially in men. As their name suggests, these fatty acids are essential nutrients. For information about them, see Chapter 4. Some researchers also recommend that men with infertility problems increase their intake of zinc, Vitamin C and Vitamin E, as reported by the Boston Women's Health Book Collective. There is certainly evidence of male cases of subfertility responding to zinc supplementation.¹⁰ At the very least, men, like women, should pay careful attention to their diet.

'Social' Drugs

If we take 'social' drugs, we can try cutting down on these, or eliminating them altogether. Drinks containing *caffeine* are associated with decreased fertility. *Alcohol* and *tobacco* are potentially harmful to sperm production, as is heavy use of *cannabis*, which also seems to be associated with irregular ovulation in women. Smoking in women decreases fertility – the greater number of cigarettes smoked, the greater appears to be the risk.¹¹ (Ex-smokers do not appear to be unduly at risk from infertility problems.) Heavy alcohol consumption may also impair fertility in women, although the evidence is mixed. (For more about drugs, see Chapter 5.)

SEEKING MEDICAL HELP

Ideally, ask your GP to refer you to a clinic which specializes in infertility and where the same doctor sees both you and your partner. Many family planning clinics run infertility sessions; you can refer yourself to these. You usually have to wait for an appointment at a fertility clinic – but it should not be more than three months. Clinics do not always offer help to all women; sometimes, for example, they will only see married women. If you feel obliged to go outside the NHS, bear in mind that private treatment does not mean better treatment, but it may mean getting help more quickly. The charitable, non-profit-making organization BPAS (see p. 442) is a good bet for single or lesbian women, and in general provides a model service, which the NHS would do well to emulate. For more on where to go for help, see Pfeffer and Woollett, and Pfeffer and Quick, listed in Resources.

Since, overall, the causes of infertility are equally distributed between women and men, it is obvious that in any couple the man and the woman should be diagnosed and treated together. If the man has the problem, then tests and treatment involving the woman alone have no value. A man, because of his anatomy, is easier to diagnose: semen analysis is one of the logical tests to perform first.

Everyone seeking help for infertility needs support – from partners (if we have them), close friends, family or an infertility support group. The experience of infertility can be very isolating. If at all possible, take someone with you to your appointments.

DIAGNOSIS

British clinics vary a lot in the type and quality of diagnostic tests they do. In some clinics the man is not even examined. This is an unacceptable way to investigate infertility. Make sure that both of you are examined and that full medical histories are taken.*

Though a sequence of diagnostic studies will vary with both doctors and individuals, it should include the following:

1. *A general physical examination and medical history of both man and woman.*

2. *A pelvic examination of the woman.* Your reproductive tract, breasts and general development will be checked for hormone balance. Tell your doctor about your menstrual history, its onset and pattern; about any previous pregnancies, STD episodes or abdominal operations; about your birth control history; about your sexual relations (e.g. frequency of sexual intercourse); about where you live and what contact you and your partner have (had) with chemicals, and about drugs either of you are taking.

3. *A basal temperature chart.* You may be instructed in the use of a special thermometer and chart, and taught how to record your temperature to see if and when you are ovulating (see Self-help above).

4. *Semen analysis.* Your partner ejaculates a sample of semen into a clean container. It must be kept at body temperature and examined as soon as possible under a microscope to determine the sperm count and motility. A count over 20 million sperm per cc is considered in the normal range; below 10 million per cc is considered poor. Yet doctors disagree about how to assess fertile sperm and men with low sperm counts can impregnate. If the sperm count is zero the man will be examined for blockage in his tube.

Ask to repeat the semen analysis at least one more time: the test is notoriously unreliable, not least because of ignorance in some clinics, and a man's sperm can fluctuate in count and motility for many reasons, including stress.¹² If the semen analysis continues to be worrying, your partner should pursue his own diagnosis and self-help strategy (see above) before you have further tests.†

Any diagnosis of infertility can make things difficult for both man and woman.

My husband's sperm count was very low; we were both crushed. I don't think my husband believed it was actually happening. In fact, he often talked in the third person, not truly accepting the results. I didn't know what to say. I couldn't say the typical 'Oh, it's all right' because we both knew it really wasn't all right. For some reason, I found I could

handle a problem with myself but found it very difficult to handle my reaction to his problem. I was even more concerned that he couldn't handle his problem.

5. *Blood levels of the hormones* oestrogen, progesterone and prolactin as well as urine tests to determine your hormone levels and whether ovulation has occurred. Hormone tests are also done following treatment with certain drugs (see p. 428).

6. *STD tests*, particularly for chlamydia, which can cause infertility in both men and women. Make sure you both are tested for this (you may have to go to an STD clinic, see p. 488).

If all male factors are normal, you may have:

7. *Post-coital test (Sims-Hühner test).* Just before you expect to ovulate you have intercourse and visit the clinic within several hours without washing or douching. The doctor takes a small amount of mucus from your vagina and cervix to study whether, and how many, sperm have survived in the cervical mucus.

We were supposed to make love at seven o'clock in the morning and then I had to run to my doctor's for the post-coital test. Who feels like making love at seven in the morning during a busy week anyway?

I had to make two appointments for the post-coital because the first time he couldn't do it. They were very nice about it and said it happens all the time.¹³

Thankfully, this test is now becoming less common with the advent of a similar test – a *sperm/mucus cross-hostility* test – which can be done in a laboratory without one having to provide a sample following intercourse.

8. *Hysterosalpingogram (HSG)*, which allows for direct visualization of the tubes and provides a permanent record that can be used for comparison if future X-rays are needed. Doctors usually perform this procedure in the first part of the cycle, before ovulation, to prevent possible X-ray exposure of a fertilized egg if conception has occurred.* It involves injecting a dye into the vagina and uterus which should pass up through the uterus to the tubes and out into the abdominal cavity. If it doesn't, it means that the tube is blocked, and that an egg is probably unable to pass through it. A series of X-rays are taken during this process. The dye then passes out into the surrounding cavity and your body reabsorbs it. This test can be painful, and it's a good idea to be prepared for this. Take someone who can take you home; learn some relaxation techniques to help you through it. It's also worth discussing pain relief with the

*See 'The Trouble with Infertility Testing' in Rakusen and Davidson, *Out of Our Hands*.

†It may be possible for the man's blood to be tested for anti-sperm antibodies, although this is a new area of research; antibodies can be suppressed by large doses of corticosteroids.

*But since all X-rays in the region of the ovary are potentially harmful to unfertilized eggs too, you may want to bear this in mind before considering this test.

doctor beforehand (it can be done under a general anaesthetic).

9. *Tubal insufflation (Rubin test)*. This is much less common than the HSG test. Carbon dioxide gas is blown under carefully monitored pressure into your uterus through the cervix. Normally it will escape out of the tubes into the surrounding cavity, causing shoulder pain when you sit up. (It is eventually absorbed into your body.) If the results are abnormal, it may be repeated or confirmed by X-ray studies. The Rubin test can indicate blockages but can't tell where they are located and can lead to pelvic infection.

10. *Laparoscopy* (a hospital procedure) which allows direct visualization of the exterior tubes, ovaries, exterior of the uterus and the surrounding cavities (see p. 596) and can yield a great deal of information, such as whether you have small pieces of endometriosis at critical sites; treatment for this may lead to pregnancy. Sometimes a dye is pumped into the uterus during laparoscopy, to see if it can pass through the tubes and out into the pelvic cavity (see HSG above).

Feelings about Going for Tests

Clinics tend to be very pressured and you may rarely see the same doctor twice. Some tests can be painful, and they can also leave us feeling undignified and emotionally exhausted and depressed. It takes a lot of strength to go through some or all of the above tests. A good, supportive doctor makes a difference; try to change your GP if yours isn't. Relatives may not be too helpful either:

My parents and parents-in-law want grandchildren and make me feel a failure because I'm not producing them. My husband wants children very badly and sometimes reminds me that other women could provide him with them. I always feel guilty about my jealousy whenever any of my friends becomes pregnant.

Jane and Ann had very similar experiences and feelings, and derived much support from each other when they discovered that they were not alone.

Jane: Just decided we'd like kids and thought we ought to go ahead straight away, as I was twenty-eight. As the months went by, the worry and tension mounted. I was worried anyway as I'd always taken lots of risks and nothing had ever happened, and I'd had gonorrhoea and knew this could cause infertility. The doctor wouldn't help, as I wasn't married and he said my fellow would leave me, and if I had a baby it would grow up homosexual! The FPA told me I'd got to try for at least two years before they'd begin investigating although I was worried about my age. I kept getting ill with other things, and eventually saw a partner of my doctor who was sympathetic and could see the worry was affecting my health and who referred me to the infertility clinic.

The tests were terrible and long drawn out – well over a year. Never once were the emotional problems referred to. Each new test was a major trauma.

Ann: My tests went on for the best part of two years. My overwhelming feeling was hoping something would be found – I couldn't even be treated if there was nothing wrong.

For both Jane and Ann, sex became very difficult.

Ann: This was one of the worst aspects, so dominated by the idea of reproduction it ceased to be an expression of anything for each other and became much more mechanical.

Jane: Quarrels assume enormous proportions when they mean you don't make love on the crucial day, or terrible bitterness is caused when your partner just doesn't feel like it on the crucial day.

Ann: The other side of it is quite as bad – if you don't feel sexy on the 'right' day – it becomes dominant enough to turn you off anyway. That causes huge problems with any other relationships too. I didn't know which came first: the totally unexpected feeling of jealousy or the idea that someone other than I might conceive by my husband. It totally squashed any ideas or practice we'd had of not being exclusive – I couldn't face using contraceptives (emotionally) at that time and couldn't do to him what I couldn't face and get pregnant by someone else. And the aftermath – it must have been nearly two years after the last tests before I felt really relaxed and spontaneous about sex again, which used to be good before it had to be functional.

Not all people feel the pain of living through this period with equal intensity. With luck we can call on help from our partners, and can find support from close friends, family or an infertility support group.* But we need to be prepared for investigations and/or treatment to go on for many years. Here, a woman GP who has herself had to come to terms with being infertile speaks:

It is easy to let the tests and procedures take over your life, and to lose your other interests. This is a pity even if you eventually succeed in having a child; if you don't, it can be a disaster. So while you are undergoing tests and treatment, it's a good idea to make a conscious effort to develop other

*The National Association for the Childless sees as one of its main functions the support of people going through tests and treatment for infertility. The WHRRIC can also put you in touch with support groups. For addresses see p. 442

sides of yourself – perhaps your career, perhaps a hobby, or a network of friendships. If you end up with a child, you'll have more to offer as a parent; if you don't, your life won't feel as empty.

TREATMENT

In this section we focus solely on 'orthodox' treatment. We cannot discuss 'alternative' approaches in any depth because so little research has been done in this area. This does not mean, of course, that any alternative practitioner's claims of success are necessarily bogus, but it is impossible to assess effectiveness without adequate research. Nevertheless, most 'alternative' systems and techniques, if practised well, aim to improve our general health and well-being – which can, theoretically at least, have spin-offs for our infertility and in any case are potentially worthwhile in their own terms.

I knew I couldn't cope with batteries of tests and medication. I felt the need to harmonize my body and allopathic treatment would do the opposite. I don't know whether it was the acupuncture that restored my fertility or whether the feeling of well-being simply made me feel relaxed enough to conceive. Maybe it was just a matter of time. But the treatment certainly made me feel better.

Most 'alternative' systems also have something to offer us in relation to stress (see Chapter 7).

Turning to orthodox medicine, we also have to report that no controlled studies have been done which would clearly establish its value with regard to infertility either.*

In general, male problems have so far responded poorly to medical treatment with drugs, though surgery is sometimes successful. Insemination with your partner's sperm is sometimes used if his sperm count is low, in the hope that with careful placement of sperm, the chances of conception will be increased. This procedure is called AIH (Artificial Insemination by Husband). A method of separating out fertile sperm from others and inserting them directly into the uterus or using them for 'in vitro fertilization' (see p. 429) is currently being tested; it is too early to know how successful it is. If infection is causing a decrease in sperm motility, it may be corrected by antibiotics. Otherwise, AI (Alternative Insemination) is the only hopeful solution for male infertility (see AI, p. 432).

For women, treatment of hormone disorders currently offers the highest degree of success, although the advent of microsurgery means that many more surgical problems can be tackled compared with in the past.

*Most infertility clinics appear to have a conception rate of 50–60 per cent. However, this is not necessarily due to treatment. One recent study found that over 60 per cent of infertile couples' pregnancies were completely unrelated to treatment.¹⁴

Drugs

The main drugs to induce ovulation are clomiphene citrate (clomid), HCG (human chorionic gonadotrophin – a hormone extracted from the human placenta), and HMG (human menopausal gonadotrophin – extracted from the urine of menopausal women, who have very high levels of the hormones LH and FSH that induce ovulation); HMG is also called menotrophin, and its trade name is Pergonal.

Clomiphene citrate was introduced in the 1960s and is commonly used. It appears to act directly upon the hypothalamus in the brain and causes it to produce more LH and FSH. About 80 per cent of women will ovulate with the help of this drug, and about 50 per cent will become pregnant, with a slightly higher risk of multiple pregnancies.*

Potential side-effects of clomiphene include visual disturbances, abdominal discomfort, a throbbing feeling in the ovaries at the time of ovulation, hot flushes, nausea, breast tenderness, depression, weight gain, skin rashes and hair loss. Clomiphene can over-stimulate the ovaries (which can damage them): for this and other reasons, the British National Formulary recommends that 'It should only be administered under specialist supervision in carefully selected patients.' You should have a check-up at the end of each cycle to check that the ovary is not being over-stimulated, but this is rarely done; you may wish to ask for it and also to make sure that it is an appropriate treatment in your case (Pfeffer and Quick discuss the inappropriate use of this drug – see Resources).

HCG may be combined with clomiphene. It acts like LH on the ovary and helps the egg ripen and release. Side-effects include headache, tiredness and mood changes.

HMG is used to induce ovulation. It is a very potent hormone and should only be prescribed when other hormone treatment has failed. It requires particularly careful monitoring to avoid over-stimulation of the ovaries, possible rupture, and multiple pregnancies. This means that you might have to travel some way to specialist centres. It involves frequent injections and often daily visits to a laboratory for blood and urine checks. This can play havoc with your life, and employers are not always understanding.† Some doctors use ultrasound to monitor the development of the ovarian follicle(s).**

Bromocriptine (trade name Parlodel), introduced in the 1970s, is used if levels of the hormone prolactin in the blood are high (this occurs in a small minority of infertile

*Publicity has centred on 'fertility drugs' because they sometimes cause multiple births. If clomiphene is used carefully and the woman is properly monitored, it only increases the incidence of twins – at most. Pergonal has a higher risk (up to a quarter of pregnancies result in more than one fetus, usually twins).

†Following pressure from infertile women, one trade union has managed to negotiate an agreement for infertility leave on a par with maternity leave.

**The effect of ultrasound on the ovary is virtually unknown. There is, however, evidence to suggest that the use of ultrasound on ovaries around the time of ovulation reduces fertility somewhat. With regard to other possible effects, we are unlikely to know about them until the second generation.¹⁵

women). It appears that high prolactin levels can disturb normal ovulatory patterns. Side-effects of bromocriptine may involve nausea, dizziness, headache, constipation or drowsiness.

The newest development involves *LHRH*, the hormone that enables LH to be released (*LHRH* stands for LH-releasing hormone). Until recently, use of *LHRH* was ineffective; then it was discovered that the key was to administer the hormone in short, tiny bursts – mimicking the way the body itself releases the hormone. Several studies have now shown this treatment to be extremely effective for women with certain types of amenorrhoea (in one study, out of twenty-eight women whose ovaries had not responded to clomiphene, all ovulated, and all conceived, nineteen of them within three months).¹⁶ In addition, the incidence of multiple pregnancies was low. Now that a convenient, portable pump has been designed, pulsatile *LHRH* administration appears far safer, simpler and, above all, more effective for suitable women, than gonadotrophins. Moreover, as *Out of Our Hands* concludes:

Because this treatment so closely mimics the natural bodily process, in theory it is less likely than most to have powerful side-effects.

Problems in the luteal phase of the menstrual cycle may be treated with clomiphene, HCG, and/or natural progesterone.

Progesterone is given either as vaginal pessaries or as injections. Side-effects include weight gain, gastrointestinal disturbances, breast discomfort and acne. Synthetic forms of progesterone (progestogens) are not advised as they can be harmful to fetal development.

Cervical mucus problems, depending on their cause, are treated with hormones or a form of steroid (not a common treatment; effects are fluid retention and masking of other infections). Special douches can help if the mucus is overly acid. Diet may help too (see p. 425).

Deciding on what treatment to go for, and for how long can be difficult.

Only you can decide where to draw the line . . . Properly administered and monitored drug treatment for female infertility can be extremely successful. However, as with all medical technology, some doctors are better at using it than others. If you are thinking about drug therapy you should be aware of the potential complications and side-effects and be prepared to stop if these get too serious. Drug treatment is something of a balancing act in which you need to weigh the desire to have a baby against the possible costs.¹⁷

Apart from the costs to you, you may also need to consider the possible costs to the baby. As with all drugs taken during pregnancy and around conception, there is the theoretical possibility of causing damage to the fetus:

With regard to embryos resulting from drug-induced ovulation, it is possible that many may have limited potential for continued development at all.¹⁸ In addition, there have been reports which suggest that clomiphene *might* be associated with fetal abnormalities.¹⁹

Surgery

Surgical techniques can often correct structural problems of the uterus. It is also possible that *dilating the cervix* may improve the chances of conception; this was discovered as a by-product of IVF (see below).

The development of *microsurgery* (involving the use of very fine instruments, guided by a microscope) has made it possible to try and repair blocked or damaged reproductive organs. Successful pregnancies following microsurgery are quite high at the Hammersmith Hospital in London (over 50 per cent for certain types of problem).^{*} However, they have pioneered and developed the techniques at the Hammersmith and success rates are unlikely to be as high where staff have less experience; nor is microsurgery generally available, because doctors have been slow to pursue it. Instead it appears that they much prefer IVF, partly because to do microsurgery well you need to be extremely skilled.

Gamete Intrafallopian Transfer (GIFT) is basically a surgical technique that has been developed recently, where eggs and sperm are placed in a fallopian tube together, under laparoscopy (see p. 596). Obviously it is impossible if both tubes are blocked, but it has already been used with egg donation (see p. 430), for example, where women have had a premature menopause or had their ovaries removed. Birth rates with GIFT have been quoted as one in four in a *Lancet* leader,²⁰ but no reference is given for this figure.

Laser surgery, for example to clear the fallopian tubes, could also be a possibility in the future – the first baby conceived following laser treatment was born in Glasgow in September 1988.

In Vitro Fertilization (IVF)

IVF involves a variety of procedures, so we are devoting quite a lot of space to explaining what is involved. By doing this, we do not mean to imply that IVF is a viable option for many women; indeed, there may be a case for pressing for the availability of more microsurgery than more IVF programmes.

In vitro is Latin for 'in glass'. At its simplest, *in vitro* fertilization involves extracting a ripe egg from the ovary, fertilizing it with sperm in a glass dish (not a test tube, as the media would have it) and replacing it in the womb. At the time of writing, it usually involves the following.

- Hormonal treatment with *gonadotrophins* (see HCG and HMG above) to get several eggs to mature so that more than one embryo may be implanted at the same

^{*}The success rate depends on the extent of the damage. It can be as low as 10 per cent. Possible adverse effects of surgery also need to be considered: from anaesthetics (see p. 596), reformation of scar tissue or post-operative infections.

time which increases the chances of a successful pregnancy – see below)

- *Ultrasound* examinations (see p. 368) and hormone level checks, in order to ascertain when ovulation is about to take place (the eggs have to be collected just before they would normally be released). Ultrasound is also being developed to enable collection of eggs on an outpatient basis via the vagina – as opposed to on an inpatient basis involving laparoscopy (see footnote on p. 428 about possible effects of this).
- Removal of ripened egg(s) from the follicle in the ovary by means of *laparoscopy* (see p. 596); (the extraction procedure is not dissimilar to the procedure involved in *amniocentesis* (see p. 370).
- Placement of egg(s) in a sterilized dish containing nutrient solution, to which semen is added; the dish is then placed in an incubator so that fertilized eggs can start to grow.
- Several embryos (technically still conceptuses at this stage) are transferred to the womb in the hope that one of them will attach itself and continue growing. (This can possibly lead to multiple pregnancy.) The transferal process involves a similar procedure to inserting an *IUD* (see p. 287). Other embryos (if any) may be frozen and stored if subsequent IVF attempts are required. The first child from such frozen beginnings was born in 1984.

As with the initial stages of most technological innovations – from X-rays onwards – doctors have argued that the risks are negligible. They have been proved wrong many times, including in relation to X-rays, the administration of certain hormones in pregnancy, and numerous other procedures. It is difficult to ascertain what effects if any there might be from IVF and all the procedures involved. Many of the procedures (such as hormone administration) have themselves been used as infertility treatments for far longer than IVF, and we know little about their effects either. Doctors argue that if an egg or embryo is damaged during IVF, it simply won't develop. But we don't know whether that's true until thousands of babies conceived in this way have had a chance to grow up, and possibly reproduce themselves. As far as freezing of embryos is concerned, even less is known about the risks.* However, set against any possible risks to the fetus are (1) the fact that the timing of embryo insertion can be chosen so that it is most favourable for implantation (the administration of hormones can throw off the cycle), and (2) the lessened risks to the woman, who in the long run won't have to have a series of operations each time IVF is attempted.

IVF is usually considered only for a woman whose ovaries and uterus appear to function normally, but whose fallopian tubes can't function, although it seems to be particularly unsuccessful for women with endometriosis.²¹

It could, however, be used for a lot more women, including those with 'unexplained' infertility;²² there have also been reports of some IVF successes where male infertility was the problem, for example because of inability of sperm to survive in the cervical mucus.²³

You don't necessarily have to be married, but a male partner is required, and we know of no cases where lesbians have had access to IVF using donor sperm.

IVF is being practised (with emphasis on the word 'practise') in relatively few clinics, and it has a low rate of success. We can be forgiven for assuming the success rate is good because of the media hype, and also because the doctors involved tend to restrict their programmes to healthy women, usually under thirty-five, and carefully avoid talking about the numbers of *births*, restricting themselves to the number of pregnancies – which sounds more impressive.²⁴

Usually it takes several attempts before implantation is achieved, let alone before it proceeds to a live birth, if at all, and the chances are lower for some women than others (so far, the success rate declines with increasing age). While many of us are prepared to come back if it is unsuccessful, clinics may limit the number of times a woman can try.

While IVF is arguably high-tech, it is certainly high cost at present,* and is mainly an option only for the well-off. It also causes tremendous upheaval, with daily, and sometimes more frequent, visits to hospital for tests.

IVF, though as yet possible only for a few, and successful for even fewer, opens up two more possibilities: *egg donation* which enables IVF to be performed using another woman's egg (the first such baby was born in Australia in 1984); *embryo donation*, likewise, is a possibility, where neither partner can produce *gametes* for the production of an embryo, or where to produce such an embryo would be genetically risky. (The use of a surrogate mother – see p. 436 – to carry an embryo conceived by another has been condemned by the Royal College of Obstetrics and Gynaecology Ethics Committee.)

These techniques mean that more than one man and woman can contribute to the many stages involved in creating a fertilized egg, carrying it in pregnancy and raising the resulting child. This brings up many social, emotional and legal questions. It is likely that pressure from religious, medical and political sources will aim to put tight controls on how this technology is allowed to be used.

INFERTILITY TREATMENTS: THE DILEMMAS THEY RAISE

The development of IVF, egg transfer, etcetera and future possibilities (see p. 613) has led to public concern and stimulated debate about the development of reproductive technology in general. As far as women are concerned, they

*The same applies to frozen eggs – if and when egg freezing is found to be successful (which may well be by the time you read this).

*However, as a leader article in the *British Medical Journal* (28 July 1984) suggests, eventually, IVF could be a cheaper way of treating infertility than current methods. Along the same lines, *The Lancet* (5 December 1981) suggested that IVF might eventually be possible on a day-care, outpatient basis.

herald the need to question afresh what the implications are when doctors – and possibly the state itself – intervene regarding decisions we can make about our own bodies (in the same way that both intervene now with regard to our right to choose abortion). While many of the Warnock Committee's recommendations are helpful,²⁵ they barely consider women's rights: for example, the committee felt the need to 'discourage' widows from using husbands' frozen sperm, and concluded that 'as a general rule', children should be born into two-parent families, with both father and mother. The report thus lends support to many current practices which are, by the time you read this, likely to be enshrined in law.

Yet despite the media hype about 'test-tube babies', the resources available for infertility treatment have been consistently very low, resulting in scandalously long waiting lists, and poorly coordinated research and treatment. Infertility is a low priority issue, and will remain so unless we make our voices heard – through organizations such as WHIRRIC and the National Association for the Childless. It is particularly important now, with medical interest in the newer technologies, that progress is clearly in the interests of women. There is much glory to be gained by the predominantly male medical elite which is jumping on the 'test-tube baby' bandwagon, and this search for glory (which may well be connected to a more unconscious search for the ability to give birth) can all too easily obscure the issues as women might see them.

Medical approaches to infertility, as currently practised, represent yet another example of how doctors are developing high technology 'solutions' to the exclusion of:

1. improving their all-round services and developing an understanding of preventive strategies which could serve many more of us. For example, they could emphasize and promote the importance of good gynaecological practices, less damaging forms of contraception, and sheer good nutrition. Indeed, it is possible that many of us who end up wanting infertility treatment would not need it if we had known about possible causes and preventive measures and if our doctors had been more careful;
2. considering the effects of their treatments when they are unsuccessful – which is the case for many women, and the vast majority of us when it comes to such procedures as IVF;
3. considering the overall effect of their activities in support of the ideology of motherhood. Perhaps we would feel less obliged to put ourselves through semi-permanent emotional turmoil and what are often extremely invasive and at times degrading medical manipulations if a woman's worth in our society were no longer measured in terms of her fertility.

Approaches to infertility treatment can represent a technological fix for something that has at least in part been socially created.* Sometimes the treatment works . . . or

we manage to have a child anyway. All the torment and treatment then seem worthwhile. But the very existence of sophisticated treatments, however slim their chances of success, can simply increase the pressure on us to try everything – with all the attendant pain and uncertainty that this process entails. It can make it all the more difficult to accept what may well have to be a fact of life for us.

I used to cling to every story I heard about people having babies against innumerable odds, as I wanted so much to believe there was hope. It made adjusting to the whole problem so much harder.²⁶

We also may suffer from the attitudes of other people, perhaps friends or family, if they see technology as the answer to our (and perhaps their) problems.

I feel trapped in other people's belief systems. It's like I'm not allowed to give up hope. But until I do I can't begin to really live again.

And as a psychotherapist says:

It's very problematic helping people come to terms with infertility if a baby is something they might be able to have, however remote the chances are, if, say, they undergo IVF.

Coping with living – as with dying – is painful. Technology can help. Sometimes. But if we look to it as the answer to our pain, we court disaster. It can create a prison for us, particularly if that technology fails us. Yet through our pain we can discover parts of ourselves, of others, of life, that enrich us beyond our wildest dreams. Maggie Jones ends her book *Trying to Have a Baby?* with the following quote.

I remember walking up the hill – it was a bright day in early summer – after having the final results of the tests and thinking, that's it, I shall never have children. The thought gave me a lot of pain, but as soon as I had thought it, I had the sensation of a huge weight being lifted off my shoulders. I no longer had to go on thinking, if, when, somehow, if only . . . it was all suddenly settled. I walked past the children's playground on the corner of the street and two small boys were playing on the swings. I stood and watched them for a while, and again, I was no longer thinking, if only, perhaps one day, and feeling that familiar stab of jealousy; instead I was standing in the warm sunlight and listening to their high, clear voices with something approaching joy. Suddenly I felt completely washed clean, and at peace – and freer than I had ever felt in my whole life.²⁷

We must try to ensure that any available medical help recognizes the problems that that very help creates for us. We need to ensure a more sophisticated understanding by

*This belies the question of how often we are told about the chances of success of any particular treatment.

the medical profession of the repercussions of infertility, and guard against their using their power (yet again) both to protect themselves from their own pain at being of such limited help and/or to exercise powerful control over us. We must guard against doctors playing god – not just in terms of wanting to produce babies themselves (consciously or unconsciously) but also in terms of deciding who 'deserves' their treatment. Doctors' 'power-tripping' over women is linked to all reproductive issues, not just infertility. The difference is that, with infertility, it can be harder to see what's happening because of the intensity and complexity of the emotional pain.

COPING WITH INFERTILITY

It is difficult and painful to acknowledge that our infertility is permanent. Particularly when there are no clear-cut medical reasons for infertility, it can be difficult to know when to stop the investigations and treatments, and to put away the thermometer. Feelings of hopefulness may give way to depression. We now have to begin to examine our lives. We may feel grief for the loss of a part of womanhood or manhood, for the parts of us that don't work or have been cut out of us. If we deny or repress this feeling of grief, we prolong the process of its resolution.* Somewhere inside we are dealing with the experience. We have the choice of living it as consciously and directly as we can or suppressing these very natural but painful emotions. The pain of infertility is never completely resolved but is accepted as a familiar ache which may recur, unpredictably, throughout life. Grieving often takes a long time.** The support of friends, family and other people who have experienced infertility can be helpful.

Last year I had a hysterectomy at the age of twenty-nine. Needless to say, I was crushed with grief. I never had the chance to have a baby and then all hope was snatched away. In my case it had to be done – fibroid tumours had practically destroyed my uterus (there were twenty-one, to be exact). I was very bitter for a while, but now I am healing. That is not to say I don't hurt sometimes; I think a pain this deep will always come back from time to time.

After learning of my untreatable infertility five years ago, I experienced the usual shock and denial. Unfortunately, I pushed down all other stages and feelings by submerging myself in work. Eventually we adopted a son and all seemed right with the world. I thought I had everything

*Since we often need to repress our feelings in order to cope with infertility tests and treatments, it is particularly important to allow ourselves to feel them at some point.

**Some people immediately block this feeling of grief by planning to adopt. The adoption is more likely to be happy and successful if you can 'work out' the grief.

together, as I rarely thought of my infertility and was very active.

Then, for no obvious apparent reason, my infertility again became a prominent concern, and all the feelings I had submerged five years ago resurfaced. After four unstable months I ended up in severe, crippling depression.

Only with the help of counselling have I been able to begin to work through the feelings and to come out of my depressed state.

I share this only in the hope of helping someone else not to fall into the trap of thinking they have worked through to resolution their infertility, when in reality they have only dealt with the problem on an intellectual level. The pain of the past four months has been as intense as when I first learned of the diagnosis of infertility. I feel that somehow I failed myself because five years ago I was too frightened of the pain to face it. The truth is, it has to be faced sooner or later, and hopefully all the way to resolution.

It was relieving to meet and talk openly with other couples experiencing infertility. Each of us had our own specific difficulties but our feelings and reactions were quite similar. After the initial nervousness that accompanied our first two meetings, I began to feel much more accepting and able to deal with the previous two and a half years that had given us two pregnancies and two miscarriages. My almost constant obsession with pregnancy was lifted. I began to feel in touch with myself and somewhat alive again.

ALTERNATIVE INSEMINATION (AI)*

This can be used by single or lesbian women who do not wish to have intercourse in order to become pregnant, and also by fertile women whose partners are infertile.

AI is a technically simple procedure that can be done in a clinic or at home. A fertile donor male masturbates into a container (clean, preferably boiled and then cooled). The sperm may be frozen and put in a sperm bank, or it may be used fresh – in which case it should be kept at body temperature and inserted into the woman's vagina as near to the cervix as possible; as sperm die fast, insertion should take place as soon as possible after thawing or masturbation, within two hours at the outside. AI should take place around ovulation, so you need to establish this in advance (see Fertility Awareness, p. 37).

A clean, needleless syringe is usually used to insert the semen but women doing self-insemination on their own have used anything from eye droppers to turkey basters. The woman lies flat on her back with her rear raised on a

*This is the term being increasingly used by feminists for what is described in medical circles as Artificial Insemination by Donor (AID).

pillow. Ideally she should stay like that for half-an-hour so that as little semen as possible leaks out of her vagina. AI may be repeated on successive days if frozen semen is used; or alternate days with fresh semen from one donor. On average, women who become pregnant from AI do so after trying for three to five cycles; at BPAS 40 to 50 per cent of couples achieve pregnancy within a year. If you aren't pregnant after having tried for six to eight months, you may want to explore the reasons at the clinic or hospital.

Getting AI can be much more problematic than the technique itself. Currently it is not widely available on the NHS, and there are long waiting lists; those clinics that do provide a service often restrict it to couples where the man's sperm production is very poor – as opposed to just averagely poor. They often decide who should receive AI on the basis of whether they consider you to be a suitable parent. And as a *Lancet* article on AI in 1982 concludes:

Some practitioners provide AID services for single women, for lesbian couples, and for people with psychosexual difficulties – when there is clear evidence that children brought up in such circumstances can be seriously disadvantaged.²⁸

It is worrying that such prejudiced and ill-informed attitudes can masquerade as scientific truth. (See chapters on relationships.) This attitude is reflected in the Warnock Report (though in a more circumspect manner), which in addition recommends that the provision of AI without a licence for the purpose should be an offence. While this recommendation, if enacted, should ensure a well-run service (something that is not necessarily the case at the moment), it does not augur well for those of us deemed 'unacceptable' either because of our colour, class, disability or sexual orientation, whose only recourse would be self-insemination.*

Until we are able to improve the NHS service, many women therefore consider seeking AI privately. Some clinics have been known to charge scandalously exorbitant sums (upwards of £1,000 per course of insemination). Others, like the charity BPAS (see Resources) are non-profit-making (BPAS currently charges a maximum of £40 for two inseminations per month; there are additional costs, e.g. for counselling and initial examination). If all AI clinics were regulated, they would at the very least be obliged to offer a suitable service – ensuring first the anonymity of both donor and recipient (which can forestall possible emotional and even legal complications) and secondly that all donors are properly screened for possible health problems, particularly HIV, the virus that leads to

AIDS (see p. 501). *Because of the risk of contracting HIV or other sexually transmitted infections from donors, it is important that all donors are adequately screened. High-risk men are advised not to donate sperm.* Current Department of Health recommendations are that, to allow for a valid test for HIV, all semen should be frozen and stored for three months. (Conception rates with frozen semen are slightly lower than with fresh, but this may be connected with busy clinics not defrosting semen carefully enough.)

All clinics should have access to sperm banks. This means you don't need a donor on call to produce semen when you ovulate; finally, although insemination often takes place in a clinical setting, some clinics send you home with special portable containers for the semen, so that you can do it in less stressful surroundings with a partner.²⁹

A big problem with AI is the shortage of men willing to be donors, particularly men who are from minority groups. If male readers and partners of women readers would consider becoming sperm donors, there might not be such a problem.

Deciding on whether to try for AI, and the process of trying, can both be very stressful.

I've never felt so isolated in my life. Despite comparatively few hassles and BPAS being very encouraging, I was going through it as a single woman. There was no one else as interested or as committed to this baby as I was. In the end, I just couldn't cope any more with watching to see if I'd got pregnant, getting false symptoms, not being able to concentrate on anything else. I was aware of every movement in my body. Then there were the emotional demands of going to the clinic each time. It all got too much and I decided I couldn't take any more after nine months of trying.

I never expected it not to work. But after three to four attempts, I began to worry. I started remembering all the women I knew who needed more than a year to get pregnant to try to make myself feel better.

Some women have said that AI made them feel they were committing adultery or being promiscuous. (The Roman Catholic and Orthodox Jewish religions consider AI adultery.) As you think about your situation, as well as about alternatives (including structuring your life without a child), you may find it helpful to talk with others who have used AI, and to read about other women's experiences. Listed in Resources are publications and organizations that may be helpful. There may also be an infertility support group in your area that could help.

If you decide to try for AI, it is important to consider what you will tell close friends and family and – most importantly – what you will tell your child. Many parents in the past have kept AI a secret, but it is gradually being recognized

*For more about self-insemination, see Resources or contact WHIRRIC. Since AI is such a simple procedure, as many doctors acknowledge, attempts to restrict its use illustrate perhaps even more clearly than the abortion issue the extent to which it is deemed that women's right to control our own bodies should not exist. However, at present at least, self-insemination remains legal.

that secretiveness can create problems for AI children, just as it creates problems for adoptees.*

Our daughter is really extraordinary – enormous energy, very strong-willed and totally different-looking from either of us. I am reminded constantly that her father was a stranger.

My husband and I had more than our share of doubts right up until the moment of our daughter's birth. When we saw our baby girl, all our doubts disappeared.³⁰

Francie Hornstein, discussing AI for lesbians, wrote in 1984:

My decision to conceive a child by donor insemination was a long time coming. It was nearly seven years between the time I first considered the possibility and when I began trying to get pregnant. The one recurring reservation in what had become a passionate desire to have children was my fear of how the children would cope with being from a different kind of family. I knew I would be sorry if I never had children; sorry not only for giving up a part of life I really wanted, but for not making a decision I believed was right. I felt I was as worthy of having children as any other person. To not have children simply because I was a lesbian would have been giving up on a goal that was very dear to me.³¹

Two lesbian partners, who plan to raise children together, told us about the bond it created between them for the one to help the other with her insemination. We need to assert the right of all women to AI. And as Francie Hornstein says:

We need to establish and protect the rights of partners of lesbians who may not be biological parents of the child, but who may be parents in every other sense of the word.³²

ADOPTION

After we had stopped trying to have a baby, I balked at the idea of adopting a child – bearing one, having the mixture of us had seemed important as well as living and changing with a child. I felt I had to really believe I would never produce children before I could even consider

adopting because if I had the slightest 'perhaps' in my head, I couldn't know I would totally accept an adopted child. That took a long time. But it gradually became clear that living through growing up with a child was far more important to me than producing one.

My sister-in-law hasn't been able to have children. It's been very frustrating for her. But, although it's still very rare in our Asian society, she's adopted two children. It's made her very happy.

While adoption may be an alternative to consider for many of us,* it is becoming increasingly difficult to adopt a baby unless s/he has a form of mental and/or physical disability.** Although it is impossible to be precise about waiting times, a wait of at least two years is not uncommon. For children with 'special needs' (i.e. any child over five or any child with a handicap), the waiting periods may be much shorter.

Organizations such as Parent to Parent Information on Adoption and Family Care (see p. 442) have originated the idea of holding group discussions for prospective adopters. It can be very helpful to talk over thoughts and feelings in an atmosphere free from the pressures of an interview with a social worker or with an adoption agency, where we are likely to feel under a great deal of pressure to appear 'perfect'.

Getting together with other would-be adopters of special needs children was very important and helpful to me. Socially I didn't know anybody who had adopted a special needs child, and it made me feel very sane and good about what I was doing. One of the best things about the adoption group was sharing experiences of loss people had experienced (infertility, miscarriages and children dying), and being able to acknowledge my own grief in losing potential children of my own was very important in the process of preparing to adopt a child. Somebody else's child isn't second best, neither is a special needs child less 'good' than a 'normal' child. It is about the resources you have to give and being able to fulfil your own needs in that giving that is important, and since most people who apply to adopt have experience of loss around children, it seems to me that help to grieve is an essential part of preparation for adoption.

*The National Association for the Childless has received letters from a group of grown AI children, angry at the secretiveness about their origins. To put AI in perspective, however, a by-product of some research on blood is the discovery that in one English town, at least 30 per cent of husbands could not possibly be the fathers of their children.

*Though bear in mind that adoption agencies have a 'ceiling' age limit on prospective adoptive parents (between thirty-five and forty years).

**This is partly because of the Abortion Act, and partly because societal attitudes have made it easier for women to bring up children as single parents, though as yet it is still very much harder to contemplate bringing up a child with a disability on your own.

THE PROCESS OF ADOPTION

If you try to adopt, the process *can* be long, difficult and painful, so be prepared. You may have to try a large number of agencies, particularly if you are trying to adopt an able-bodied baby. Some agencies close their lists if they know they will never be able to find enough children for prospective adopters. Most are choosy – though their criteria will vary. You will have to give up any infertility treatment.

Adopting a 'special needs' child can in theory be a lot easier. Parents for Children, an organization concerned solely with placing special needs children with adoptive parents, has opened its doors to less conventional would-be parents, and many other agencies have followed suit. As Parents for Children says, special children need special parents. Often people with unusual relationships, lifestyles or life experiences are more successful at parenting children with multiple problems.

To adopt a child, you will need to approach either your local authority (in which case, write to the Director of Social Services) or a registered voluntary adoption agency. It is illegal to adopt through any other third party, unless you are a relative of the child or you are 'acting in pursuance of an order of the High Court' (Children Act, section 28). You have to go through an approval process which might take a few months. It involves being allocated to a social worker with whom you will have several interviews. If you are in a couple, you are seen together and separately. You will also have another interview with a different social worker. Police records are looked into and you also need to go to your GP for a medical; your GP will be required to furnish a report to the social worker about your medical history.

I think I was lucky. My GP discussed with me what should go in his report. I had had a period of depression some years before and he was aware that the way he presented this information might make a difference to whether I was approved of or not.

Then your 'case' goes to an 'adoption panel', which may include professionals as well as adopting parents. The panel is the approving body, although in practice most seem to go almost entirely on the social worker's report. Social workers, therefore, have a lot of power (though they are at times overridden). If you don't feel you're getting on with your social worker, you can ask for another one. You can also check whether the particular adoption agency concerned has an appeals system in case your application fails. If it doesn't, all you can do is try another agency.*

*You can also try to adopt from abroad, though the issue of removing children from their culture and roots is very controversial. The least potentially exploitative approach is through a government agency. BAFA and Parent have lists of bona fide agencies abroad. Beware unscrupulous ones that kidnap children from Third World countries: in 1988 a conference of the International Bar Association was told by Margaret Bennett, a London solicitor, that approximately 16,000 newborn babies were likely to have been abducted from their mothers' bedsides each year in Brazil alone.

The adoption process raises many negative feelings, often surprisingly similar to the ones experienced during the first stages of coping with infertility. Feelings of powerlessness, anger and frustration are common, especially during the time of the approval process when the social worker is evaluating and 'testing' you on your potential as a parent. Families and friends may not be as supportive as you would like, and you may go through periods of anxiety and desperation.

My husband and I found out we might become prospective parents in April. That gave us about seven to eight weeks to think about this. I had many things going through my mind. So many things could happen in the interim. The natural mother could still change her mind. I wondered what the child would be like. The baby's looks, personality, health – everything is unknown . . .

I thought a lot about bonding. I wondered what I'd feel like when someone put an infant in my arms saying, 'Congratulations! You are a mother. This is your child.' Who is this stranger? How am I supposed to love someone I do not even know? How am I supposed to feel? I believe these are healthy feelings, but still it is frightening to think about . . .

I believe couples facing adoption go through the same feelings that biological parents go through – the fears, insecurities, the great change of lifestyle. The only problem is that you do not have nine months to work your feelings through. It is like being told you are eight months pregnant.

I have found most other people trying to adopt, feel desperate to have a child. I had all sorts of feelings of divine intervention stopping me from having my own.

It is quite normal to feel desperate in a society that tells you that having your own child is the only way you can have that particularly special relationship of responsibility with a child growing up. Also your dependence on the approval process can bring up all the previous powerless feelings of depending on fate as to whether you will ever be able to have a child or not. However, the process may in fact be very helpful. A single woman speaks:

My experience of the 'assessment' process was very positive. I was lucky in having a social worker who obviously had a lot of respect for me right from the start and so I felt safe to express all sorts of feelings. It gave me a chance to explore all the feelings and questions of why I wanted a child, what was it about a child that I wanted, and I found I did really want to be with a young person growing up and discovering the world and I would be quite happy to do that with a child with a physical handicap. Five months after this process

was begun, I was approved as a potential adopter, and have since adopted a child with 'special needs'.

Once you have been through this process, you are likely to experience all sorts of feelings resulting from your decision being officially approved. You are one step nearer the possibility of having a child. You will feel a mixture of excitement, anxiety, vulnerability and joy at the prospect of a child being placed in your home. But be prepared that things may still not be easy, and whether they are or not, you will still need the support of family and/or friends.

Usually there are several people who are informed about a child awaiting adoption. All of those are likely to want to be considered, and will therefore go through the process of mentally and emotionally adjusting their lives in anticipation. When the prospective parent(s) have been chosen, this can be emotionally devastating for the others. And this process may be repeated several times.

Adoption poses a number of problems which prospective adoptive parents need to think about in advance. In particular, when adopted children start to grow up they may have very powerful feelings about being adopted which they do not always express. The Children Act of 1975 also gives adopted people the right to see a copy of their birth certificate when they reach eighteen.

It is important to recognize the suffering of 'birth mothers' – as they are now called – who have had to give up their children for adoption. To do this is not an easy option, nor is it a decision that is possible to forget. Increasingly, birth mothers are beginning to speak about not being able to have contact with the children they have given up. Many birth mothers can never begin to heal from the 'surrender' experience until they have been reunited with their children.

The few studies concerning the adoption process which have been done demonstrate that the feelings and experiences of all those involved in the adoption process are often neglected. We need to challenge the assumptions and practices of social workers who label certain feelings and lifestyles 'abnormal' and distort the experiences and needs of adoptees, birth mothers and adoptive parents alike.

FOSTERING

Fostering is a way of providing a home for a child who cannot be with its own parents – although they are still the parents. Usually, but not always, the aim is to enable the child to return to the original family at some stage. Fostering can be short- or long-term, or 'fostering with a view to adoption'. Many people have successfully adopted after taking this latter fostering option, but securing the adoption can be a long and painful process, and there is always the chance that it won't go through.

The process of becoming a foster parent is easier than for adoption because it does not require the approval of the courts and is solely at the discretion of the local authority. This means that people with 'unconventional' lifestyles, including single women, are more likely to be able to foster.

However, fostering itself is by no means easy. Forming ties with a child can be very difficult if you don't know when s/he's going to be taken away, and children's responses to the situation are understandably confused.

ADOPTION AND FOSTERING FOR LESBIANS AND SINGLE WOMEN

The law now states that a single person or a married couple may adopt (an unmarried heterosexual couple cannot adopt as a couple). At least one local authority – Hackney in London – has changed its policies so that lesbians may adopt or foster children, and a few other authorities, such as Camden in London, are considering similar moves. Single women, including lesbians, have been fostering children for years. The only change in recent years is that this is now being acknowledged more publicly. We do not know how recent changes in attitude towards homosexuality, condoned and promoted by the present Thatcher Government, may affect lesbian parents of all kinds – either now or in the future.

SURROGATE MOTHERHOOD

Practised in its simplest way, this involves one woman – the surrogate – bearing a child that another woman raises as her own. Where a woman in a heterosexual relationship is infertile or unable to give birth herself, the possibility may appeal to use her partner's sperm to inseminate a surrogate, either through intercourse or AI.

Surrogate motherhood raises a host of social, legal and financial questions. Much discussion followed media coverage of the first known surrogate birth in the UK, with the result that it is now illegal to advertise for, or offer, surrogacy, and for all third-party intervention on a commercial basis. However, surrogacy arrangements on a non-profit-making basis are still legal according to the 1985 Surrogacy Arrangements Act. Nevertheless, it is another question whether such contracts would be enforceable by a court of law.

The Department of Health has recommended to all local authorities that any child of a surrogacy arrangement should be made a Ward of Court if there is any indication that the child might be at risk, thus endorsing what happened in the 'Baby Cotton' case, where the child was kept 'in care' (but actually deprived of parental care) for the first ten days of its life. Although it is still legal to make a

non-commercial surrogacy arrangement, the courts may well intervene where the people concerned were in dispute (e.g. if the surrogate decided she wished to keep the baby). At the time of writing, the possibility of further legislation is being considered which could confirm the unenforceability of all surrogacy contracts. Meanwhile, an additional and unforeseen legal issue has emerged following the enactment of the Family Law Reform Act 1987, whose effect is that if a married woman plans to become a surrogate mother by means of artificial insemination, and with her husband's consent, her husband will become the legal father of the child.* (In Scotland, where the Act does not apply, the child would be regarded as illegitimate.)

It is possible that a form of surrogacy involving IVF might be enforceable, whereby the fertilized egg of another woman is implanted in the womb of a surrogate – a curious commentary on how the intervention of doctors via technology appears more acceptable even than loving and non-commercial arrangements between people.** The first such recorded gestures are documented in the Old Testament of the Bible: Hagar bore Abraham's child, so that he and his 'barren' wife Sarah could have one; Rachel and Jacob brought up a child whose surrogate mother was Bilhah (though in this latter case Bilhah may or may not have been willing – to have intercourse or a baby). Surrogacy is indeed a traditional practice among families in many parts of the world, particularly between relatives, including parts of the UK.³³ The legal status of all such children, however, is illegitimate.

There has been a recent outcry against surrogacy. It has to an extent been echoed by some feminist opinion – although the outcry has been dominated by precisely the sorts of people who seek to curtail women making decisions about our own bodies in other spheres. Aside from the legal issues, there are immense social, political and psychological issues surrounding surrogate motherhood, and feminists have only begun to get to grips with them. For the debate so far, see Rita Arditti et al, *Test Tube Women* and the WHIRRIC newsletter (see Resources).

MISCARRIAGE (NATURAL ABORTION)†

It is a surprising statistic that in women who know they are

pregnant, about one in six pregnancies ends in miscarriage. About 75 per cent of these occur before twelve weeks. Miscarriage, then, is a fairly common event. We need to be at least minimally prepared to know how it feels and what to expect. Miscarriage is both a physical event for a woman and a serious emotional crisis which may be shared or experienced in very different ways.

When I found out I was pregnant, I danced around the house. My pregnancy was an easy one. . . . My body was slowly and pleasantly changing. Because it was a conscious and well-thought-out decision to have a child, I felt free to revel in my pregnancy and motherhood. It was a special time. I mention all of this because having a miscarriage has to do with the loss of something so deeply ingrained for so long that it is partially by understanding the depth of the joy that one can understand the depth of the loss.

The medical term for miscarriage before twenty-six weeks is *spontaneous abortion*. You may experience a *threatened abortion* beforehand, with cramps and bleeding or staining. Often bed rest is advised (though there is very little evidence that it makes any difference, apart from calming you down), and your doctor may order specific blood tests to check your hormone levels. In *inevitable abortion*, bleeding becomes heavy, cramps increase and the cervix may begin to dilate. The fetus, amniotic sac and placenta, along with a lot of blood, may be expelled completely intact. You'll probably know when this is happening. If you are not in hospital, you must do the difficult task of collecting fetus and afterbirth, putting them in a clean container and taking them to your doctor or hospital so that they can be examined. Some doctors do not consider doing an examination, or only if you've had several miscarriages. Since an examination may yield important information as to why you miscarried, you may want to press for this. Ask that specialized as well as routine tests be done, such as cultures for infection and genetic examination of tissues. If tests show you have lost a 'blighted pregnancy' (where egg and sperm together have failed to divide correctly) then you can try to be more at ease, knowing that this has been a random event and that the chances of it happening again are small. If a study of the fetal tissue shows genetic abnormalities or suggests that you had an illness or infection, you can work with your doctor on how to proceed. If the fetal tissue is normal, you may learn that your hormone levels were insufficient or that a weak cervix was the problem. Both of these conditions may be treatable.

An *incomplete abortion* means that only part of the 'products of conception' has been passed. Part remains within, and bleeding will continue. Usually a doctor will do a dilatation and curettage (D & C) to clean out your uterus so that it will heal. A *complete abortion* means that everything in your uterus has been expelled. You will continue to bleed, but less and less. If you think you are

*If she becomes pregnant under different circumstances – e.g. by intercourse – then the Act does not apply.

**At the time of writing, WHIRRIC has been contacted by several women interested in acting as surrogates out of love for friends or relatives unable to have babies themselves.

†A miscarriage is often referred to as an abortion – thus confusingly, and sometimes distressingly, implying that the miscarriage was deliberately induced. We prefer the term miscarriage, but we do have to use the technical term on occasions.

bleeding too long, consult your doctor. (Perhaps a D & C may be necessary after all.)

During a miscarriage, you may not believe what is happening. Feelings of helplessness may develop as cramping and bleeding increase. Many women fear that they may bleed to death. Having to go to hospital may intensify your anxiety and fear.

We went home from the hospital dazed and tired. I was weak and enormously sad. I don't know that I've ever experienced such deep emotional pain. The loss was so great and so complete in the way that only death is. For the first few days I couldn't talk to anyone, but at the same time it was painful to be alone. I would just cry and cry without stopping. One of the clearest reminders that I was no longer pregnant were all the speedy changes my body went through. Within two days my breasts, which had grown quite swollen, were back to their normal size. My stomach, which had grown hard, was now soft again. My body was no longer preparing for the birth of a child. It was simple and blatant. Tiredness was replaced with weakness. And then there was the bleeding. My body would not let me forget. I knew things would improve once we could make love again and would be even better when we were full of hope. But it seemed so far away.

You may also experience a missed abortion. In this case, a fetus dies in the uterus but is not expelled. It can remain within for several months. Signs are lack of menstrual periods coupled with cessation of signs of pregnancy; sometimes there is spotting. If it is not eventually expelled spontaneously, the fetus must be removed with a D & C or induced labour – a procedure which will be very hard to accept emotionally.

Some possible causes for miscarriage are structural problems of the uterus, infection, weak cervical muscles, hormonal imbalances, environmental and industrial toxins. According to Dr Ian Murray-Lyon of Charing Cross Hospital, drinking alcohol during pregnancy (more than ten units a week) has been shown to increase the risk of miscarriage. Genetic error is associated with a high number of early miscarriages, and blood incompatibility between a mother who is Rh negative and the fetus who is Rh positive can also lead to miscarriage. If you are Rh negative, it is very important to ensure that the drug Anti D is given if you bleed at all during pregnancy to prevent this reaction and safeguard future pregnancies. Some doctors recommend Anti D daily throughout the period of bleeding (see Chapter 18, p. 343).

Try to learn why you had a miscarriage. Some of the diagnostic procedures outlined above for infertility will be useful here. Ask to see the pathology report, and ask that all terminology be explained fully. If you are not satisfied with the explanation, ask if there are other tests that can be done.

It is your right to learn as much as possible about your miscarriage.

One miscarriage does not mean you are infertile. There is a 70 per cent chance that you will have a successful pregnancy even after two miscarriages. However, if you have two or more in a row you may want to begin investigating. Try to find a doctor who specializes, or is interested, in the problem (the Miscarriage Association may be able to help). Plan with your doctor to check out each detail of your next pregnancy as it progresses, including possible reasons for any spotting or cramps, definite ways to deal with contingencies, tests to be made as they become necessary and so forth. You will need encouragement in this project from your partner (if you have one), family, friends and/or a support group, possibly one geared to childbearing problems.

The time following a miscarriage is difficult. Physically, your body may still feel pregnant for a while, your breasts full and tender, your stomach enlarged. You may continue spotting for several weeks. If you have increased flow or odd- or foul-smelling discharge or a high temperature, contact your doctor, as you may have an infection which should be treated immediately. It is usually safe to have sexual intercourse after four to six weeks when your cervix is closed and there is less risk of infection.

You will almost always feel grief and anger. You will need family and/or friends.

Most people didn't know how to give me support, and perhaps I didn't really know how to ask for it. People were more comfortable talking about the physical and not the emotional side of miscarriage. I needed to talk about both. It was also difficult for my husband, because people could at least ask how my body was doing. Unfortunately, he would sometimes be completely bypassed when someone called to talk with us, despite the fact that he, too, was in deep emotional pain.

Feelings of grief are often complicated by guilt. This can cause tension between partners. You may wonder if either of you did something 'wrong' (too much activity, too much sex, but neither is known to cause miscarriage, so blame is inappropriate). Dispelling the tension will take a while, longer for some than for others. It is best if you acknowledge and talk out your feelings. The effects of the miscarriage can last for months. On the date when the baby would have been born, there is usually a resurgence of grief.

If you experience more than one miscarriage, you will need compassion and understanding of the losses you have experienced, and of how very precious these pregnancies were to you. Unfortunately, doctors who can offer this are rare. Your helplessness and hopelessness may increase if you begin or return to treatments for your infertility and start working on becoming pregnant again.

For further help and support, see Resources.

FEELINGS WHEN THE BABY DIES

The death of your baby – either at birth or soon afterwards – is utterly devastating. As well as the emotional pain is the physical pain – a constant reminder of the loss. In fact, your body knows nothing about the baby's death; your breasts are filled with milk, never to be used. You will require help and care on every level at this time: physical, emotional, practical and spiritual.

If the baby's death takes place before delivery, maximum pain relief and delivery in the quickest and least hazardous way are desirable. You should have the chance to decide if and when you want to go into labour spontaneously. Your partner if you have one should be present as long as either of you wish. Once the baby is delivered, many women find it helpful to spend time with it, touching and holding it.

That was all I saw of him; the soles of his feet when he was born and then the top of his head. They brought him to me all wrapped up, even his face was covered. I didn't know if I could unwrap him or not. If I'd known he was only going to live two hours, I'd have unwrapped him and held him next to me all that time. They tell me he had arms and legs, but I don't really know because I didn't see.

I was gently coaxed into holding him, and my initial revulsion disappeared. Time passed all too quickly and allowing him to be taken away to the mortuary was the hardest thing I had to do.

Many hospitals now provide photographs, which can be a godsend later.

The photographs and slides have been a great source of comfort to us, and to our parents.

You should be put in a room away from the nursery and hospital personnel should be told that you have lost your baby. Above all, you and your family must be allowed your grief, in privacy if you need and want it.

You might need to withdraw at first and not confront the reality which may be too much to bear. There might be a period of numbness. If you ask for help in grieving, we hope it will be intelligently and humanely extended. Platitudes such as, 'You'll have another baby before you know it', or, 'Think of your wonderful children at home', have no place. The death of this particular child is being experienced – no other actual or potential children have any relevance to the situation. Perhaps the best help others can offer is sympathetic listening and close physical comforting. And we can often need a lot of listening to, even for months afterwards.

I developed an irresistible urge to describe our ordeal in minute detail to anyone who would listen

and have since discovered that this is a common reaction.

Since the last edition of this book, hospitals have begun to improve in terms of their ability to respond to the death of a baby. But maternity units are geared to producing life, and unless staff are given help to cope with their own feelings about the death of a baby, they can be of little help to us. They may have a strong tendency to prescribe routine sedatives, yet such drugs can interfere with our ability to grieve – and grieving at this time is as necessary as breathing.

While procedures for registering stillbirths have been made easier, there are more improvements we can press for: more sensitivity during the time we have to make decisions about burial, and more care to ensure for example that we are not put near mothers and/or their babies.

It is important to understand if possible why the baby died. Most likely whatever happened was totally beyond anyone's control, but if you suspect negligence, you should seek legal advice quickly so that the facts can be analysed. AIMS could probably help you with this (see p. 442).

It can take a long time to get over the death of a child. Feelings of guilt or shame are not uncommon. Be prepared for this and, if possible, make contact with people who will understand the problems you are facing. Compassionate Friends (see p. 442) is a national network of people who have lost a child. It is a non-religious society. By contacting them we can give and/or receive much-needed help. The society acts as a twenty-four-hour service for bereaved parents, however long ago the death occurred, as well as a pressure group to urge research into children's diseases.

Nobody wants to deal with death, especially when your friends are at the childbearing age themselves and can't help being afraid of you for what you stand for. I found that my friends wanted me to pretend nothing had happened. I don't think it was just my particular friends – it's natural to want to avoid those things. And so my fantastic pregnancy, in which a lot of things went on in my head and body that helped me to change and get myself together, had to be buried. Even now, after a year, I can see their pain and fear for me as I start into my eighth month of pregnancy with my second child. I have to be the one who keeps them calm, and I especially must assure everyone that this one will be OK.

ECTOPIC (MISPLACED) PREGNANCY

Whether we intend to get pregnant or not, it is always possible to develop an ectopic pregnancy. Such a pregnancy is dangerous. There is a danger of severe blood loss, shock, and even death unless appropriate medical attention is

given (see below). If your blood group is Rhesus negative, you will need injections of Anti D, as for miscarriage (see p. 343).

Fertilization of the egg by the sperm almost always occurs in the fallopian tube. If the function of the tube is impaired in any way, for example by pelvic inflammatory disease, then it is possible that the fertilized egg might attach itself to part of the tube instead of proceeding on into the uterus. This results in an ectopic pregnancy; more rarely an ectopic pregnancy can begin to grow in the abdominal cavity, the ovary or the cervix.

Between 5 and 10 per cent of women who have had previous tubal surgery may experience ectopic pregnancy, but it can happen to any woman. Ectopic pregnancies are on the rise because of the increased incidence of PID and use of IUDs, which can result in scar formation on the tubes or inflammation of the uterine lining, which then 'resists' implantation of the fertilized egg. *If you're of childbearing age, have had intercourse and feel constant abdominal pains you don't understand, it's possible you have an ectopic pregnancy.*

Because all the hormonal changes are similar to those of a normal early pregnancy, you can have all the early signs of pregnancy, such as fatigue, nausea, missed period and breast tenderness. As the pregnancy progresses, causing pressure in the tube, symptoms such as stabbing pain, cramps or a dull ache may become severe. In addition, you may or may not have menstrual-type bleeding. To diagnose an ectopic pregnancy, an ultrasound is needed, and/or a beta blood test can be done to pick up levels of HCG in the blood. If levels are low, an ectopic pregnancy should be suspected.

If an ectopic pregnancy is misdiagnosed and the tube ruptures, you will need emergency treatment in a hospital. If you have severe pain, it may be better to go straight to a casualty department than wait to go through your GP. You may need an emergency operation.

It should be stressed that an ectopic pregnancy can be very hard to diagnose. You may need to be persistent.

I kept on going to my GP with various symptoms and was told it's an early miscarriage, all in my mind, etc. This went on for a month, until I was

admitted to hospital with severe pain, and even then was only operated on four days later!

Ectopic pregnancy is sometimes misdiagnosed as an early spontaneous abortion. It is essential that any tissue passed from the uterus be checked for developing fetal tissue.

If the doctor detects an ectopic pregnancy early enough, s/he may be able to remove the pregnancy and save the tube. In some cases it is necessary to remove the whole tube and/or the adjacent ovary. Careful surgical technique is important; the less bleeding and consequent adhesions and scar tissue, the better the chance for a normal pregnancy later. In any case, if you have already had a tubal pregnancy, there is a higher risk of having another.

The outlook for future pregnancies is somewhat changed by this experience: you may feel depressed and frightened by the possibility that this could happen again. In addition, if the pregnancy was wanted, you are likely to feel all the feelings that result from a miscarriage. In a future pregnancy it may be worth asking for a very early scan.

POSTSCRIPT

We hope that this chapter provides help and support for women who have experienced infertility or pregnancy loss. Yet while medical approaches may develop and change, we can never assume that they can solve all our problems. This is an uncomfortable fact of life that we are not helped to face by medical professionals who so often fail to disabuse us of the myths that they themselves have created. In fact, the medical profession can neither cure life's problems, nor can it cure many medical ones. By stimulating awareness on this point, we can contribute to creating a more hopeful approach to infertility and pregnancy loss, to life and death. If we tackle this issue alongside the fundamental issue of women's role in society, then women in the future will be better equipped to face infertility and pregnancy loss, and other devastating events in our lives, unclouded by the belief that only medicine can heal the pain with which we have been confronted.

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23. J.L. Yovich et al. 'Treatment of Male Infertility by In-vitro Fertilisation', *The Lancet*, 21 July 1984, p. 169; J. Cohen et al. 'Application of In-vitro Fertilisation in Cases of a Poor Post-coital Test', *The Lancet*, 8 September 1984, p. 583.

24. For example, R.G. Edwards and P.C. Steptoe. 'Current Status of In-vitro Fertilisation and Implantation of Human Embryos', *The Lancet*, 3 December 1983, p. 1265; and C. Wood et al. 'Clinical Implications of Developments of In-vitro Fertilisation', *British Medical Journal*, 13 October 1984, p. 978. In an unusual reference to actual birth-rates, a *Lancet* leader, op. cit., note 20, suggests that at best, birth-rates of only one in five or six per treatment cycle can be expected. Since no reference is given for these figures, even these should probably be treated with scepticism. And in a recent editorial in *Fertility and Sterility* authors were actually asked to 'be honest with one another' (M.R. Soules. 'The In Vitro Fertilization Pregnancy Rate: Let's Be Honest with One Another', *Fertility and Sterility*, vol. 43, 1985, p. 511.)

25. Report of the Committee of Inquiry into Human Fertilisation and Embryology (the Warnock Report), Cmd 9314, London: HMSO, 1984.

26. From Maggie Jones. *Trying to Have a Baby? Overcoming Infertility and Child Loss*. London: Sheldon Press, 1984.

27. Ibid.

28. 'Whither Human Donor Insemination in Britain?' *The Lancet*, 6 March 1982.

29. E.A. McLaughlin et al. 'Use of Home Insemination in Programmes of Artificial Insemination with Donor Semen', *British Medical Journal*, 15 October 1983, p. 1110.

30. From Barbara E. Menning. 'Donor Insemination: the Psychosocial Issues', *Contemporary Ob/Gyn*, October 1981.

31. Francie Hornstein. 'Children by Donor Insemination: a New Choice for Lesbians', in Rita Arditti et al. (eds), *Test Tube Women: What Future Motherhood?* London: Pandora Press, 1984.

32. Ibid.

33. As a Royal Society of Medicine meeting was told recently, 'It happens every day in Rochdale.'

RESOURCES

PUBLICATIONS

GENERAL

Arditti, Rita et al. (eds). *Test Tube Women: What Future Motherhood?* London: Pandora Press, 1984. An international collection of feminist writings, mostly very critical of technological development.

Dowrick, Stephanie and Sybil Grindberg (eds). *Why Children?* London: Women's Press, 1980. Invaluable collection of writings by eighteen women, each talking about her feelings/decisions/non-decisions.

Holmes, Helen B. et al. (eds). *The Custom Made Child: Women Centered Perspectives*. Chilton, NJ: Humana Press, 1981. Part of a two volume collection that came out of a meeting in which community workers, doctors, scientists, ethicists and government planners – most of

them women and feminists – spent several days discussing women's reproductive health issues.

Houghton, Diane and Peter. *Coping with Childlessness*. London: Unwin, 1984. By the funders of NAC (see Organizations, below). Includes chapters on 'Assisting the healing process' and 'Being childless in later life'.

Jones, Maggie. *Trying to Have a Baby? – Overcoming Infertility and Child Loss*. London: Sheldon Press, 1984.

Overall, Christine. *Ethics and Human Reproduction: A Feminist Analysis*. London: Allen & Unwin, 1987.

Piercy, Marge. *Woman on the Edge of Time*. A feminist novel that envisions a world where reproductive technology exists for the benefit of women. London: Women's Press, 1979.

Rich, Adrienne. *Of Woman Born*. London: Virago Press, 1977. A moving and inspiring book that recognizes patriarchal control of our reproductive capacity and of our attitudes to it.

Stanworth, Michelle (ed.). *Reproductive Technologies – Gender, Motherhood and Medicine*. Oxford: Polity Press, 1988. A collection of feminist writings taking a different view from Arditti et al.

INFERTILITY (see also GENERAL, above)

First Report of the Voluntary Licensing Authority for Human In Vitro Fertilisation and Embryology. London: MRC, 1986.

Harrison, R.F. et al. 'Stress in Infertile Couples', in R. F. Harrison et al. (eds), *Fertility and Sterility*. Lancaster: MTP Press, 1984.

Hull, M.G.R. et al. 'Population Study of Causes, Treatment and Outcome of Infertility', *British Medical Journal*, 14 December 1985, p. 1693.

Kelso, Isa Anderson. *Women's Ailments*. Wellingborough, Northants: Thorsons, 1973.

Pfeffer, Naomi and Anne Woollett. *The Experience of Infertility*. London: Virago Press, 1983. A very thoughtful and helpful guide; a must.

Pfeffer, Naomi and Allison Quick. *Infertility Services – A Desperate Case*. London: Greater London Association of Community Health Councils, 1988.

Rakusen, Jill and Nick Davidson. *Out of Our Hands: What Technology Does to Pregnancy*. London: Pan, 1982. Contains chapters on infertility testing and treatments, plus information on the effects of drugs.

Winston, Robert. *Infertility: A Sympathetic Approach*. London: Martin Dunitz, 1986. Useful on the subject of surgery among other things.

ALTERNATIVE INSEMINATION

Berer, Marge. *Donor Insemination*, available from WHRRIC.

'Case Conference, "Lesbian Couples: Should Help Extend to AID?"', *Journal of Medical Ethics*, vol. 4, 1978, pp. 91–5.

Feminist Self Insemination Group. *Self Insemination* (1980): no longer in print, but on file at WHRRIC and Feminist Library.

Hornstein, Francie. 'Children by Donor Insemination: a New Choice for Lesbians', in Arditti, *Test Tube Women* – see General, above.

Klein, Renata Duelli. 'Doing it Ourselves: Self Insemination', in Arditti, *Test Tube Women* – see General, above.

Saffron, Lisa. *Getting Pregnant Our Own Way – a Guide to Alternative Insemination*, 1986 (available from WHRRIC).

Snowden, Robert and G.D. Mitchell. *The Artificial Family – a Consideration of Artificial Insemination by Donor*. London: Allen and Unwin, 1981. Considers social and legal issues prior to any changes in the current law. Attempts to be liberal. See also *The Experience of Infertility* and *Out of Our Hands* in General, above, both of which contain sections on AID.

FOSTERING AND ADOPTION

Adopting a Child, 1984–5 (booklet available from BAAF, see Organizations).

Argent, Hedi. *Find me a Family – the Story of Parents for Children*. London: Souvenir Press, 1984. A must for people considering adopting 'special needs' children.

Rowe, Jane. *Fostering in the Eighties*. London: BAAF, 1983.

Rowe, Jane. *Yours by Choice*. London: Routledge and Kegan Paul, 1982. A guide to the adoption process.

MISCARRIAGE AND STILLBIRTH

Borg, Susan and Judith Lasker. *When Pregnancy Fails: Families Coping with Miscarriage, Stillbirth and Infant Death*. London: Routledge and Kegan Paul, 1982. A sensitive and helpful book, though American, for anyone who has been through the tragedy of their child's death.

Leroy, Margaret. *Miscarriage*. London: Optima, 1987. Based on the experiences of the Miscarriage Association.

National Childbirth Trust. *Miscarriage* (leaflet available from the NCT, see Organizations).

Oakley, Ann, Ann McPherson and Helen Roberts. *Miscarriage*. London: Fontana, 1983. A helpful book that looks at causes and treatment and women's experiences.

Standish, Liz. 'The Loss of a Baby', *The Lancet*, 13 March 1982, p. 611.

ORGANIZATIONS

GENERAL

Association for Improvements in the Maternity Services (AIMS), 40 Kingswood Avenue, London NW6 6LS

British Organization of Non-parents (BON), BM Box 5866, London WC1N 3XX. Support group for those who believe that being child-free should be a seriously respected option in society.

British Pregnancy Advisory Service, head office: Austy Manor, Wootton Wawen, Solihull, West Midlands B95 6BX. Tel: 05642-3225. Has branches in many parts of the country - see Resources in Chapter 16 or your local phone book. A charity that can help with AI, infertility testing, etc.

Child, 367 Wandsworth Road, London SW8 2JJ. Tel: 01-486 4289. Supports infertile people through support groups, telephone counselling, etc.

National Association for the Childless, Birmingham Settlement, 318 Summer Lane, Birmingham B19 3RL. A self-help organization, registered as a charity, offering advice, information and support to people experiencing infertility. Tends to be orientated towards heterosexual couples, but has about 100 contacts throughout Britain, and many support groups. Produces factsheets and an invaluable newsletter, all of which are free to members. Also holds seminars, e.g. on inter-country adoption. NAC also aims to improve NHS infertility treatment.

Single and Infertile, 293 Meadgate Avenue, Chelmsford, Essex. For both single men and women who are infertile.

Women's Health and Reproductive Rights Information Centre (WHRRIC), 52-5 Featherstone Street, London EC1Y 8RT. Tel: 01-251 6580/6332. Provides information about self-help groups generally and infertility support groups in particular, as well as general information, including about AI.

ALTERNATIVE INSEMINATION

BPAS (British Pregnancy Advisory Service) provides AID (AI) in many parts of the country and does not limit their service to heterosexuals or to couples. Also offers counselling and other services, such as sperm testing and sperm storage facilities. See General Organizations above for address, and for other organizations which can advise on availability of AID.

FOSTERING AND ADOPTION

British Agencies for Adoption and Fostering (BAAF), 11 Southwark Street, London SE1 1RQ. Tel: 01-407 8800; Scottish Centre: 23 Castle Street, Edinburgh EH12 3DM. Tel: 031-225 9285. Has useful leaflets for prospective adopters, adoptees, stepchildren and on issues such as 'a child from the past'. Very helpful on adoption altogether.

Contact-a-Family, 16 Strutton Ground, London SW1 2HP. Tel: 01-222 2695. Contact Line 01-222 2211. Links parents of children with special needs. Runs local groups: national telephone link-up service, Contact Line.

Family Care, 21 Castle Street, Edinburgh EH12 3DM. Tel: 031-225 6441. Information and counselling service on all aspects of adoption and on childlessness; also provides social work service for single-parent families and a befriending scheme.

Jewish Association for Fostering, Adoption and Infertility (JAFI), headquarters: PO Box 20, Prestwich, Manchester M25 5BY. Tel: 061-773 3148/776-3199. Provides support, advice and assistance, and has branches nation-wide.

Lesbian and Gay Fostering and Adoption Network, c/o London Friend, 86 Caledonian Road, London N1. Tel: 01-837 3337.

National Foster-Care Association, Francis House, Francis Street, London SW1P 1DE. Tel: 01-828 6266. Exists to encourage high standards of foster care and increased opportunities of a foster home for children 'in care'.

NORCAP (National Organization for the Reunion of Children and Parents), 3 New High Street, Headington, Oxford OX3 7AJ. Helps adult adopted people who are trying to get in touch with their birth parents, and parents who have given up their children for adoption, as well as adopters. Send see for information.

Parents for Children, 222 Camden High Street, London NW1 8QR. Tel: 01-485 7256/7548. Specializes in especially difficult to place children and also 'unusual' parents and families. (see Hedi Argent's book above).

Parent to Parent Information on Adoption Services, c/o Lower Bodington, Daventry, Northamptonshire NN11 6YB. Tel: 0327-60295. A self-help support and information service for prospective and existing adoptive families.

MISCARRIAGE AND STILLBIRTH

The Compassionate Friends, 6 Denmark Street, Bristol BS1 5DQ. Tel: 0272-292778. Helps bereaved parents.

Foundation for the Study of Infant Deaths, 15 Belgrave Square, London SW1 8PS. Tel: 01-235 1721.

Miscarriage Association, PO Box 24, Ossett, West Yorkshire WF5 9XC. Tel: 0924-264579.

National Childbirth Trust, Alexandra House, Oldham Terrace, London W3. Tel: 01-221 3833. Can also put women in touch with others who have experienced miscarriage and who hold regular meetings.

The Stillbirth and Neonatal Death Society (SANDS), 28 Portland Place, Argyle House, London W1N 4DE. Tel: 01-436 5881. Helps bereaved parents.

Twins and Multiple Births Association (TAMBRA), Secretary: 41 Fortuna Way, Aylesbury Park, Grimsby, South Humberside, DN37 9SJ. Tel: 0472-883182. Support networks for people who have experienced death of one or more babies.

लुप्त वेद

बहुत पुरानी बात है, ब्रह्मलोक में उन दिनों काफी उत्साह था। ब्रह्मा के बेटे अथर्वन की शादी देवी से हो रही थी।
तीन साल बाद देवी के पाँव भारी हुए। अब वह बाप बनेगा सुनकर अथर्वन बहुत खुश हुआ। “मुझे बेटा देना, जिससे हमारे परिवार का नाम आगे बढ़ाने वाला कोई हो।” मुस्कराते हुए उसने अपनी पत्नी से कहा।
देवी ने शर्माकर सिर झुका लिया। पर देवी को चिन्ता खा रही थी। “मैं किस तरह से तुम्हें लड़का होने का वादा करूँ?” उसने अथर्वन से पूछा।
अथर्वन अपने पिता ब्रह्मा के पास गया और बोला, “आपने तो सारी दुनिया बनायी है। देवी को कह दीजिए कि वह मुझे बेटा ही दे।”



ब्रह्मा मुस्कराये। “पुत्र अथर्वन!” उन्होंने कहा, “एक बार गर्भ रह जाए तो मैं भी यह नहीं बतला सकता कि किसी माँ के गर्भ में पलता हुआ बच्चा लड़का हो या लड़की। तो देवी क्या करें?”
“उसी के गर्भ में बच्चा है”, अथर्वन जिद करता हुआ बोला।

चित्रांकन : शुद्धसत्त्व बासु



“बेटे, तुम्हें वृहद् वेद की जानकारी चाहिए।”
ब्रह्मा ने प्यार से कहा, “इधर आओ, तुम्हें
ब्रह्मचक्र में ले जाता हूँ।”

अथर्वन और देवी ने ब्रह्मचक्र में सहमते हुए पाँव रखा। इसमें ऐसी-ऐसी चीजें
दीखती थीं जिसे कोई भी इंसान जादूई दृष्टि के बिना न देख पाता। उन्होंने वहाँ
इंसान के शरीर के भीतर की चलती-फिरती तस्वीर देखी।

बिना माइक्रोस्कोप
के आप सैल नहीं
देख सकते !

यह एक माइक्रोस्कोप है।
यह बहुत छोटी चीजों को
देखने लायक बड़ा बनाती है।

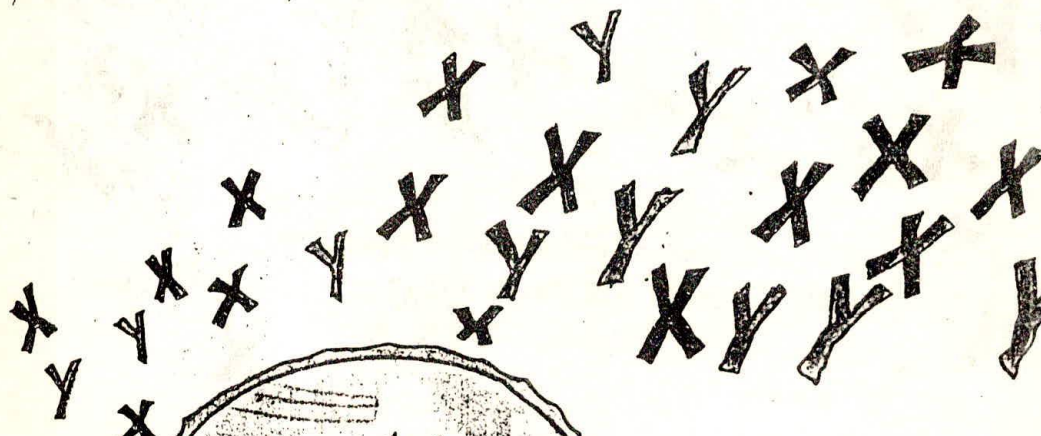
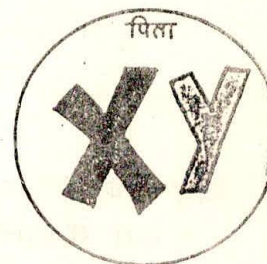
धरती पर सभी प्राणी छोटी-छोटी इकाईयों से बने
हैं, जिन्हें जीव-कोश या सैल कहते हैं।
ये बालू के छोटे से छोटे कण से भी छोटे होते हैं।
सैल अलग-अलग प्रकार के होते हैं। त्वचा कोशों
से हमारी चमड़ी बनती है। हड्डी कोशों से
हड्डियाँ; ऐसे ही दिमाग, खून, नाखून के कोश,
वगैरह होते हैं।

गुणसूत्र

हर इंसानी कोश में 23 जोड़े पतले धागे जैसे रेशे होते हैं जिन्हें क्रोमोसोम या गुणसूत्र
कहते हैं। इन्हीं की वजह से बच्चे की शक्ल माँ-बाप जैसी ही बनती है।

इन 23 जोड़ों में से एक जोड़ा बहुत खास है, जिसे लिंग गुणसूत्र कहते हैं। औरतों में यह जोड़ा दो X क्रोमोसोम का होता है और आदमियों में एक X और दूसरा Y गुणसूत्र होता है।

अब अथर्वन ने पूछा, "इसका मतलब है मेरे शरीर में X और Y गुणसूत्र हैं और देवी के शरीर में सिर्फ X गुणसूत्र हैं।" "हाँ, हाँ," ब्रह्माजी ने सिर हिलाया, "देखते रहो।"

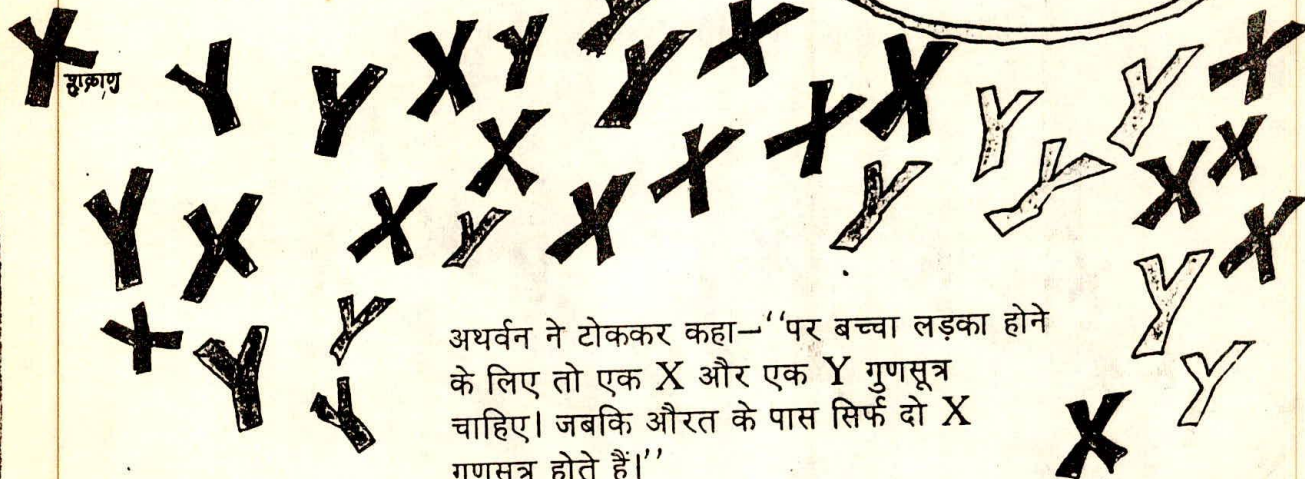
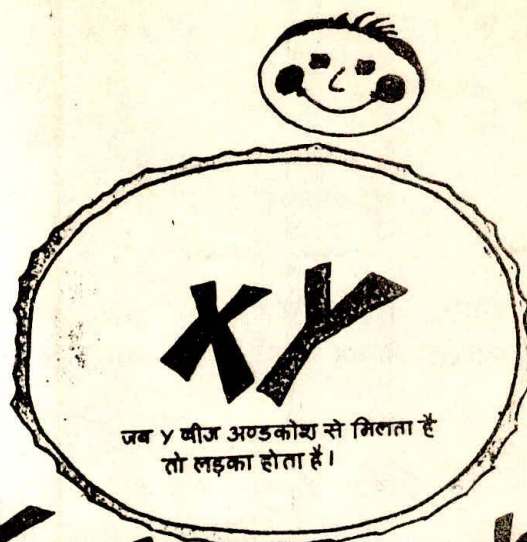


अगर शुक्राणु का इस अण्डकोश से मिलन हो गया तो नये सैल बनपने लगते हैं। यही बच्चा है।

उन्होंने देखा, कि जब आदमी और औरत का मिलन होता है तो आदमी के बीज कोश औरत के शरीर में डल जाते हैं।

आदमी के इस बीज को शुक्राणु कहते हैं। हर शुक्राणु में सिर्फ एक X या Y गुणसूत्र होता है। ये शुक्राणु सूरज की एक किरण से भी सूक्ष्म होता है। हर महीने औरत के शरीर में एक खास कोश तैयार होता है जिसे अण्डकोश कहते हैं। हर अण्डकोश में सिर्फ एक X गुणसूत्र होता है।

अब बच्चे को एक लिंग गुणसूत्र माँ से, और एक पिता से मिलता है। अगर पिता का X गुणसूत्र मिल जाये तो लड़की और Y मिले तो लड़का होगा।



अथर्वन ने टोककर कहा—“पर बच्चा लड़का होने के लिए तो एक X और एक Y गुणसूत्र चाहिए। जबकि औरत के पास सिर्फ दो X गुणसूत्र होते हैं।”

“तुम समझदार शिष्य हो अथर्वन”, ब्रह्मा बोले।

लेकिन अथर्वन देवी की तरफ देख रहा था। “इसका मतलब तो यह हुआ कि मेरे लड़का होगा या लड़की इसके लिए मैं जिम्मेदार हूँ।

बच्चे को देने के लिए Y गुणसूत्र सिर्फ मेरे पास है,” वह धीरे से बोला।

“अथर्वन, ये बात हर इंसान के लिए सच है। बाप का Y गुणसूत्र ही बच्चे को लड़का बनाता है।

ये ही बृहद् वेद है। आपके बच्चे यह न भूले।” ब्रह्मा बोले।

लेकिन अब तक ये बृहद् वेद खो गया था। अब वैज्ञानिकों ने इसे फिर से ढूँढ़ निकाला है। अब जब तुम्हें पता चल ही गया है तो गाँव के सभी लोगों के साथ इस वेद की जानकारी बाँटोगे न?