

307 medico friend circle bulletin

October-November 2004

Negotiating Reproductive Health Needs in a Conflict Situation: A Case of Kashmir Valley

- *Zamrooda Khandey*

The state of Jammu and Kashmir covers an area of 84,571 square miles. Within this is the Kashmir Valley covering an area of 8,639 square miles. The valley has a distinct culture, language and custom that have remained distinct on account of the high mountains that cocoon it.

The total population of Jammu & Kashmir as per the provisional results Census of India 2001 is 10,069,917 persons. The total male population is 738,839 and the female population is 692,343, and the sex ratio is 937.

As per conservative estimates, about 60,000 people have been killed and more than these numbers have been injured in the bloody conflict in the valley. Women and children form the most affected groups. Though there are no accurate records, reliable estimates reveal their number between 16, 000 to 20,000.¹

The fourteen long years of political turmoil, upheaval and strife has left an indelible mark on the health conditions of the valley. The conflict has resulted in a complete collapse of the rural health infrastructure, resulting in an increased pressure on the city-based secondary and tertiary health care facilities.²

The insurgency has resulted in the exodus of a large number of medical and paramedical professionals, thus creating a vacuum in the provision of basic health facilities. The existing health facilities were inadequate and their further denudation has resulted in making

people more vulnerable to various diseases. Further worsening the situation are the incessant curfews and bandhs, which have become a part of life for the people in the valley.³

The worst-hit victims of this exodus are the people in the rural areas where there is a virtual collapse of the health infrastructure. Two decades ago, Jammu and Kashmir was the only state with the provision of 50 percent reservation for training women as doctors. But today it is virtually impossible to find a female doctor in remote areas like Kalakor, Banihal and Ramban.

Lal Ded Hospital, Srinagar the only maternity referral hospital for the entire valley is overloaded and understaffed. The hospital has a sanctioned bed capacity of 450, but at no time is the occupancy less than three times the sanctioned number. There are times when the hospitals' labour room has 60 admissions against 30 beds. Due to the breakdown of the peripheral maternity health services, the hospital often receives patients from far-flung areas. The attendants of these patients also reside in the hospital premises, adding to the already unhygienic conditions of the hospitals.⁴

Ban on Family Planning

Until 1989-90 the Hospital had a full-fledged family planning unit, but the family planning related activities had to be curtailed because of the violent threats received from some fundamentalist militant groups.⁵ This ban on family planning has led to a number of illegal septic abortions being carried out by quacks that often damage the uteruses of the women. Along with this are seen surgical complications like gut and bladder injuries. Increases in early pregnancies are also reported as the lack of family planning services

¹ See Bashir Dabla, 'Impact of Conflict Situation on Children and Women in Kashmir', Srinagar, 1998. *Save the Children Fund (UK)*.

² Siddiqui Nushina. *The Status of Health in Kashmir. Voluntary Health Association of India, Development Communications Unit, New Delhi, 1999.*

³ Siddiqui Nushina, *op.cit.*

⁴ *Records of Lal Ded Hospital and personal observations.*

has affected the morbidity and mortality patterns among women.⁶

The ban on sterilisation has resulted in an increase in the use of intra-uterine devices (IUD) for family planning; the reason being that once the device is installed the user does not have to visit the doctor regularly. The safety aspects of this device are not hidden from anyone.

But, do these women have a choice, with the fundamentalists dictating the lives of one and all? The government is but a silent spectator of this desperate situation faced by the women of the valley.

News of my cousin's pregnancy brought delight to one and all in the family. My cousin resides in a small village in Anantnag district, about 45 kilometres from the state capital Srinagar. As the day approached, we rejoiced but the ease of the doctors vanished rapidly as a complication had developed. However, this was not something new or even something to be perturbed about; after all the doctors were there to take care of it all... were they not?

So why worry, all would be well!

On the day of the delivery, in the dead of the night, my cousin had to be rushed to Lal Ded Hospital, Srinagar for an emergency surgery. The private nursing home where she was to deliver her child did not have the requisite infrastructure to handle her complication. Had it not been for a guest's car in the neighbouring house my cousin would have lost her life and the child, all for the need of a vehicle and a fully equipped hospital.

The above story is of a woman from a middle class family, who could afford a private nursing home and yet, at the end of the day was no better than any woman in the far-flung remote areas of the valley. This is not an isolated incident. Day in and out women in the valley are fighting similar battles.

Caught Between the Crossfire

The Welfare State exists but only minimally and peripherally, the security apparatus fails to elicit the trust of the people. This is in addition to the violence that accompanies 'normal' search operations and the numerous curtailments on people's movements in the name of the security.⁷

⁵ Various articles at web-site of BBC South Asia.

⁶ Personal conversations held with medical practitioners in the hospitals esp. Dr. S. Draboo. See also *Women's Testimonies from Kashmir 'The Green of the Valley is Khaki'*, Women's Initiative, 1994, Delhi, 1994. Things have not changed over the last 10 years—in fact it has become worse.

⁷ Various articles from India Today, Kashmir Times, The Telegraph and The Deccan Herald.

⁸ *op.cit.* footnote 7.

The terror of the State is paralleled by the deeds of the militants. Barely does one get accustomed to one tyrannical whim when another is showered. From the diktat relating to donning of the burkha, to the monitoring of the curriculum of schools and universities, the list is never ending.⁸

Caught between the crossfire of the militants and the government, the people live a life of constant fear. Lack of public transport; ban on private vehicles, curfew after dark, unsafe conditions for women to move out and the fear of uncertainties have made an already difficult life, unbearable.

What choices are left with the people, especially women?

Shabnam (name changed) could not be taken to the hospital for her delivery due to the lack of transport. It was her misfortune that her pains started at night and there was no doctor in her far-flung village. The traditional birth attendant (TBA) after all her efforts, pleaded for a doctor or for Shabnam to be taken to a hospital. When it became clear that at that hour of the night nothing could be done the best option available was allowed - a *veterinary* doctor. Both mother and child were saved that night. As the child slowly gained health, the mother weakened day by day. Innumerable doctors were consulted but none could detect her problem. It was only much later that it was diagnosed that maybe during the delivery the doctor had injured the vagina that turned septic, and late diagnosis resulted in infection that killed her.

Similar is the case of Hanoor (name changed), who I do not know whether to regard as fortunate or unfortunate, who had her delivery pains in the middle of the night whilst her village was in knee-deep snow. The birth attendant managed a normal delivery but was not able to remove the placenta completely. The search for a doctor or for means of transport to carry her to the doctor proved futile. Hanoor was not as lucky as Shabnam to be able to be 'rescued' by the veterinary doctor. Her only chance was a bicycle on which she would have to travel to the nearest town 15 km away and hope that in the district hospital, there will be an ambulance to transport her to the main maternity hospital 40 km away. All this was to be done with her placenta hanging outside her body. I am not sure whether it was the thought of this arduous exercise for survival that killed her or the uncontrollable bleeding but Hanoor never made it to the doctor.

It is then not a thing to wonder why the women of the villages pray that the delivery pains of even their enemy should be during the day rather than the night. No one wants to risk the perils of the night. This is also one of the reasons that one finds long queues outside Lal Ded hospital in Srinagar. For was this not the case why would people weeks before the delivery camp up with relatives close to the hospital or for those unfortunate

ones who do not have this privilege; camp during the day in the grounds and at night in the corridors of the hospital. Why would then people be willing to give deliveries in the bathrooms and corridors of the hospital? They are assured that if there is a complication they will not have to face the plight of a Shabnam or a Hanoor.

Training of TBAs

In the past few years, the government and some non-government organisations have undertaken the job of training the traditional birth attendants. This to an extent has made a big difference in the villages. But even these attendants have not been spared the wrath of the army and the militants. Both sides are interrogating the women constantly. One woman narrates how every time they set out at night for a case; they bid farewell to their families not sure if they will be able to return. They are forbidden to carry torches. The only source of light for them is a lantern, which if the army fancies may not be allowed. The birth attendants confidently state that they are completely geared up for normal deliveries, but even they will not risk the case at the slightest hint of complications. And complications seem to be norm of the day. The birth attendants, along with many women feel that one of the reasons for complications may be the ban on contraceptions and birth control by the fundamentalists.

Parents are forced to marry their daughters young as no one wants to take chances with fate. Abductions, molestations and the biggest nightmare of all, rape, both by the militants and the security forces are rampant. Girls/women are earmarked during the day and abducted by night. Militants are in hospitals, in markets and they have their nexus in the villages to keep an eye on what is happening. Girls conceive at the young age of 14-15 years. People are scared to even talk of the traditional birth control methods and this is one of the reasons that one finds mothers (those who find it successful) feeding children of three to four years till they are ready for the next child.

To make matters worse there is a ban on abortions as well as sterilisation. Doctors all over Kashmir even in the government hospitals are scared for their lives. So what happens in a situation like this? Well women are left no choice but to fall prey to the nexus of illegal abortions or to adopt dangerous methods of prevention of pregnancy. People are often forced to go to the neighbouring province of Jammu for abortions, sterilisation operation or even to install an Intrauterine Device (IUD).

Shameem (name changed) narrates her experience: "After my third child I did not want any more. I spoke to a doctor friend at Lal Ded hospital. Initially she refused stating that it was too risky with militants walking in and out of the hospital and the operation wards. She was scared that if they got caught they

would all be gunned down. After much persuasion she agreed at the cost of Rs 5000, and on the condition that the operation will be performed outside the hospital. A small room was rented near the hospital. The operation was performed in the presence of my husband, the doctor, one attendant and me. As soon as the operation got over the doctor left without a second look asking me to come to the hospital for further check-up. When I reached the hospital I was treated as a fresh patient who had come for a regular check up. I was prescribed medicines and asked to leave. When I inquired about the discharge slip I was told that there was no need for one and that the doctor will handle her case if some complications arose." This is the scenario when one has friends and relatives in the hospitals. From this case it is no guess what it would be if one was a stranger in the hospital.

Situations like these resulted in infections and the cause of uterus removal later. Though there is no concrete data available yet, but from my personal experiences in the field have revealed that out of every 10 women of the ages above 25 years, 4 would either be suffering from a uterus infection or would have had an operation for the same. Ninety percent of these women would have had an abortion in the last 14 years (the period of trouble in the valley.)

Hamida after four children wanted to adopt a contraceptive method. The fear of the fundamentalists brought her to the doorstep of a quack in the village. She narrates that the doctor (quack) gave her eight injections over two weeks and told her that she will not have kids for the next five years. She was pregnant within 2 months. In her fourth month of pregnancy she started bleeding uncontrollably. The loss of blood was so immense that she was not able to move from her bed. The last thing that she remembers is that she was put on a charpoy to be carried to the bus-stand. It was after two days that she opened her eyes in the hospital. By then she had lost her child, and had been injected six bottles of blood.

Return of Peace

This is the way of life for women in Kashmir. These experiences make me question as to where did life vanish after the 1980s. Each time I travel back to this beautiful valley I feel I have yet again gone back in time. Nothing ever seems to move. When I was writing this paper I could not pen down an ending to it and in my brief conversation to a friend, I narrated an experience, which is with what I would like to end this paper. The government and the international political bodies are talking of the return of peace in the valley with the return of tourists, yet as each day passes and I talk to women behind closed doors, voices drop at the mere mention of the letter 'M' what to talk of militants. In hushed tones they whisper, they are here, one amongst us, only now we cannot recognise them, earlier we could for they would roam around freely. They are more dangerous now. Let us not speak of them. Negotiation for life continues.

Involving Men as Allies in Violence Against Women: Are We Pursuing a Mirage?

- Poonam Kathuria¹

The issue of Violence against Women has invited international concern as the single most factor obstructing and affecting women's sense of physical and emotional well-being. It is a universal issue that affects women across caste, class and race in traditional and modern societies. This violence, which occurs in many contexts, including the home, takes various forms: physical battery, sexual and psychological abuse, harassment at the workplace and elsewhere, female feticide, infanticide and infant neglect, dowry-related violence, female genital mutilation and forced prostitution...

Most action and research on violence against women tends to focus on women as victims and their fore on corrective interventions that include capacity building and creating an enabling environment for women to combat violence. The other correctional work has focused on recourse to law. A limitation with both of these is that they tend to place the onus of the crime and remedial action on the victim and not on the perpetrators, who are mostly men. We do not in this paper explore the effects of economic and political systems on the brutalisation of gender relations. That needs a separate, lengthier discussion.

Since male violence accounts for 90 % of violence against women, there is need to explore the role men can play in ending violence against women. Awareness of this factor has grown and we have started talking of the need for 'Engaging Men as Social Justice Allies² in Combatting Violence against Women'.

While it is possible to view men as potential allies in ending violence against women, by changing their personal behavior and or intervening to confront the problematic behavior of other men, we need to examine such an approach in terms of its potentials and limits.

¹ Society For Women's Action And Training Initiative (SWATI), Dt Surendrangar, Gujarat. Email: pswati@satyam.net.in

² An ally can be defined as a member of a dominant group or majority group who works to end oppression in his or her personal and professional life through support of and as an advocate with and for the oppressed population.

³ Kutch Mahila Vikas Sangathan, Samaj Kalyan ane Shikshan Kendra, Utthan- Amreli, Utthan -Bhavnagar, Society For Women's Action And Training Initiative, Navjyot Mahila Vikas Sangathan, Mahila Samakhya Society. Support of Oxfam in the action research is gratefully acknowledged.

Thus there is a need to understand the mindset and influences that inform, shape and perpetuate the patriarchal ideology that legitimizes the male authority to commit violence against women by not challenging but tolerating it. This means that there is need for qualitative and quantitative research, from a male perspective, to recognize the convergence of the broad social and cultural context in which women experience violence.

The present study is an attempt in that direction.

Context

A group of six NGOs³, located in four backward and feudal districts in Kutch-Saurashtra region of Gujarat, India, have initiated a concerted campaign for Combatting Interpersonal Violence against Women. The districts are Amreli, Bhavnagar, Kachchh, and Surendranagar. The initiative includes a) Awareness drive among both men and women b) Setting up of redressal mechanisms at grassroots level by extending counseling and legal aid support. c) Elicit male involvement in preventing violence against women. d) Conduct a study to understand the extent, prevalence forms, of violence, the reasons behind abuse and options for support. Society for Women's Action And Training Initiative (SWATI) is the coordination and support agency for the initiative. The author of this paper is part of SWATI.

The cultural and social norms that support and perpetuate violence against women differ across regions and communities. Thus any effort at combatting has to inform itself of these factors and mindsets and address these. With this objective, a community-based study on violence against women was conducted in 35 villages spread over four districts. In a random sample, 506 married women were interviewed to understand their individual perspective on the issue of violence. The data gathered from women was supplemented with Focus Group Discussions (FGD) with men from the same communities. The aim was to elicit information on factors that determine male behavior in committing violence against women and can become the basis for devising a long-term campaign strategy for involving men in combatting violence against women.

Twenty-two FGDs were carried out in November 2003 with 410 men (about eighteen men per FGD) from seven

social groups of Rabris, Bharwads, Darbars, Dalits, Kolipatels, Patels, and Muslims. The communities were selected based on their level of representation in the population. An exception was made for the particular community of Darbars, though their share in the population is not significant enough to merit an FGD. The Darbars have been included in the study because of their influence in the region and because of culturally exploitative practices followed against women.

Development workers often known to the participants conducted the FGDs. Since the agency and the workers had an image of people who are opposed to Violence against Women, it initially led to answers which ought to be given rather than what they really thought. This we hope would have reduced as the FGD progressed and the people became comfortable. It is also likely that this familiarity may have put them at ease with the research team and therefore the participants may have been more frank in sharing their reasons for violence against women and their perceptions regarding the same. A perusal of the FGDs suggests that both have happened.

While it was decided to conduct FGDs with specific community groups, it was not always possible to create a control group situation (and homogeneous at that), a number of FGDs have had a mixed representation.

Violence differs in form and intensity across castes and communities. In FGDs where men from more than one community were present it may have affected responses, as higher castes tend to impress that it happens more in lower castes/other castes and not in theirs. Maintaining the dignity of one's own caste may have become a concern for the different groups thus preventing an honest response. We hope to have countered this effect by the large number of FGDs that we have undertaken. We present our findings as of date below.

What Constitutes Violence?

This was the basic first question raised and we asked the group as to what according to them is violence. This was supplemented with asking them, what according to them is violence against women?

Men could describe violence in its various forms and dimensions. That they could do so is also indicative of their awareness of the issue. Killing, beating, suspicion, superstitious behavior towards women, to hurt emotionally, to see women as sex objects (to look at women with bad intentions, *burī nazar*), to harass an innocent, abet some one to commit suicide, mental and

physical torture, to abuse, to say nasty things and to harass some one without their fault – are what according to men constitute violence against women.

Only one group of men mentioned that: 'to abort a fetus because it is a female is also violence'. (In spite of the fact that Gujarat has the dubious distinction of ranking third in India in terms of falling sex ratio, which is as low as 914:1000.) (Source: NFHS 2)

Thus according to the respondents violence is said to be committed when it is extreme in nature – killing or abetment to suicide, and culturally unacceptable behavior such as sexual violence. And when, it is carried out for no reason. As a group said: "*To commit violence (mar jhod) without reason is violence.*" (implying that it is all right to abuse if a woman is at fault)

Reasons for Violence Against Women

We then asked the group as to why did men commit violence against women. What are the circumstances that lead to violence being carried out against women? This we felt should bring out the mindset and influences that lead men to commit violence against women.

Most men started with saying that in 'our' (their) community violence does not happen. As the discussion proceeded and they got more involved, they began to admit that it does happen.

Women are taunted (*maina-tona*), harassed but they would not let it out. They have to work more. Whatever happens they cannot complain. Men are suspicious, they suspect them wrongly. There are restrictions on women. They are harassed because of dowry: this in particular happens because of comparisons.

A scheduled caste group -Thakors- had an interesting combination of reasons. According to them, women have to suffer because of superstition, lack of education and because women have greater endurance: "*Their (women's) capacity to suffer is greater, in comparison with men. A woman is the incarnation of Goddess of Strength (Shakti), that is why they can endure.*" (Acceptance of women's suffering)

It is perhaps because women continue to bear, that women are battered for trivial and all sorts of reasons: "*If he asks for water and is not given then he beats her up.*"

"*If she does not allow him to sleep with her (sexual relations) then violence happens.*"

"*If a woman cannot bear a son, then the mother-in-law taunts (maina-tona). Sometimes a woman is sent*

away to her natal home.”

Some of the other reasons that were given for violence being committed on women are mentioned below.

Women are to Blame...

Violence is justified if a woman is at fault is the theme cutting across all groups:

“Some women behave as though they have bought the man.” (dominate over him).

“If women talk to other men than violence is justified.”

“Woman is the one’s who start the fight.” (but not the battering)

According to the respondents, normally violence happens because of fights between the mother-in-law, sister-in-law or between daughters-in-law: “A daughter of our village was harassed by her mother-in-law and sister-in-law. They took her to the field and gave her poison.”

Customs that Lead to Violence...

The phenomenon of lower status and a woman being a man’s property is supported by various beliefs and customs. The main among these are dowry and bride price. The two are diametrically opposite of each other but become a cause for violence being committed. In one, the girl’s family gives dowry to the marital family and in the other the natal family takes money from the marital family.

In the group in Amreli, Bharat was pointed out as someone who gave his wife a taste of the beating every day. To this Bharat responded: “If a woman is ‘like that’, then it has to be done.” (Sense of dissatisfaction). Bharat went on to add: “If she gets good things in her dowry then it is good, but if she gets only a trunk full of clothes it is better that she gets nothing.” (Bharat was obviously dissatisfied with his wife over the dowry that she had brought.)

In the lower weaver caste of Vankars, there is no marriage; there is the custom of bride price. So if a family is poor, they have to borrow on interest and pay it to the girl’s family. “So obviously she is beaten. One has to recover the expense.” Men cited this as a justification for violence. The fact that either way the woman suffers is reflected in this statement: “On the other hand if we have to get a son married, we have to pay 40 to 50 thousand to her parents- because of this girl suffers. We have paid your father extra for you, and not that he has given dowry.”

Should a Woman be Beaten?

Are their times when a husband has genuine reasons for battering his wife? We deliberately asked this question in a cryptic manner. The intention was to find out men’s perception of their own and peer behavior.

Almost all men believe that a woman needs to be beaten, ought to be beaten and that a husband has a right to beat her. The men in this group said that: “Like buffalos have to be kicked in the butt, so do women. If we do not do this, they won’t walk straight (behave themselves) and won’t obey. So they have to be beaten.”

When is Violence Unjustified?

Extreme forms of violence such as to drive a woman to suicide or kill, and illegitimate sexual demands, were considered wrong. A group from Amreli district cited an example of a married woman, whose husband abetted in her suicide.

“The husband said to the wife that if you are so fed up with me, then why don’t you immolate yourself and become free of me.” (Implying that a woman can be rid of her husband only in (her) death. There is no other way out open to her. She cannot take a divorce or leave him.)

“When they took her to the hospital, where she later died, she said to the police that it was an accident.” (The men seemed to think that it was the woman’s fault. She should not have protected her husband. However while the men suggested punishment for the husband, no one suggested that she should have left him. This attitude clearly shows up also in what the man says to the wife: “If you are so fed up, why don’t you die?” This is representative of the societal norms governing women’s lives.

The men categorized sexual assault and illegitimate sexual demands as violence. The group cited an instance in which: “Her father-in-law use to make sexual demands on her. She put up with that for a long time. The girl was ‘cultured’. And so she never told her parents. She told her husband when he came home and he replied ‘it is for this that I keep you here. Then the girl told her parents and since then she has been staying here (parental home).” (The group of men did not express anger at this injustice or condemn the father-in-law’s behavior.)

While sympathetic to the woman, they tended to appreciate women who suffered as compared to those who protest. This is exemplified in the statement: “If a

girl is cultured and if she is, suffering, she would rather drink poison than go back to her fathers' home."

Moments of Truth...

Men admitted that:

"A woman suffers more in her marital home."
(acknowledgement)

"A mother gives birth, a sister is after all a sister, a wife is like an ironing press one can iron (flatten) her any way."

According to a low caste group of Dalit men:

"As such ours is a lower caste. So we are forced to listen and do what others (higher castes) tell us. So if we need to establish our power, we can do so only on women." (moment of self-realization)

Men acknowledged their frustrations as a cause for violence against women:

*"If he has gambled and lost, than he beats up women."
"Among Vankars lack of employment is a major issue. As there is no income, the fights continue. Lack of income leads to fights and violence."*

There is also an awareness that women can protest but they do not:

"Woman, as long as they are good, they are good, otherwise they can even show us the prison bars."

What can be done to End Violence?

Some practical solutions that came from several men in many of the FGDs were:

*"A girl should be married at 18 or 19 and not early."
"Women should be educated, like men."
"There should be freedom to choose, whom one wants to marry."*

"Try to explain to the husband if the fault is his."

"Men are simple. But if he drinks and commits violence than he should be counseled."

The solutions that the men came up with once again tell their mindset. While a woman can be battered for the most trivial of reasons, all that men suggested as solution was counseling for them. None of the solutions offered by men talk of changing the cultural norms that perpetuate the violence.

It is Not an Issue...

A group from Bhavnagar felt that it is not such a big issue:

"There is strife for a short period. Women do not eat for two meals, but then eventually mollify."

"Society is not going to change by what we are thinking today. We should counsel a woman so that she understands her mistake. If she does not understand than beat her a little, so that she goes off to her natal home for four days (some time) and the conflict ends."

An elderly man said:

"All this discussion is happening because now women have time on their hands. Earlier women pounded grain, drew water. Today there are flourmills and taps in each house so.... Earlier women just tied some bread into their saree and ate it while grazing the cattle. Now the times have changed so all these issues are being raised."

"Now a days there is no difference between a boy and a girl. For if after six sons if a daughter is born, are we not happy." (indicative of the son preference and male supremacy)

We cannot do much...

Men felt that society does not easily allow for changes in norms of conduct expected from men and women.

This is exemplified in:

Women do the work. If a man/husband helps her they call him 'bayla' (wife's slave).

If a man does as his wife says, they say the 'rand' (bitch) rules.

If a woman tries to elicit help by give examples of other men who help, they respond, we have brought you to carry out work; we have not brought you to place you on a pedestal.

Drinking, gambling – snatches away even the woman's income. The customs and rituals (riti rivaj) have become a problem. You have not cooked well, so saying they harass. In our families there are incidents of women immolating themselves. Many men do not like this, they understand, but cannot do anything.

Men tended to move from denial of the issue of violence against women; to saying it is a non-issue, to being helpless as it is society that does not allow them to change.

Can Women's and Men's Role Intermix?

The question was raised in order to understand men's perception of women's role and conduct. Questions tended to focus on roles and responsibilities between genders, which in Indian culture is very rigid. We asked

questions related to why are men's and women's roles different? Why cannot women do all that that men do?

Men seem to have a definite role for women in mind. They are threatened if this role divides, particularly in the economic sphere, is challenged:

"Women are born to do house work and cook. God has decided this. So why should men do housework."

"To do a 'job' (nokari) is a man's personality. If he has to work at home that will be shameful in society."

(Men obviously do not want to give up their power of being the 'provider' of having control over resources and the external world.)

They justify this by:

"A woman cannot manage a business. She has just about enough understanding to manage the house hold and the vegetable expense."

A related question was raised about giving women a share of the property. To this the men said:

"So that she does not ask for her share in land, we have to give (dowry)."

"A brother never says no to a sister's right over property. They (women) themselves do not take. They fear that if they take than he will never come to any of her festive occasions (like marriages)."

This is an open threat. The other aspect is that women fear that the she will not have a place to go back to in case of problems in the marital home:

"As such a woman's right is in her marital home."

"Only if a woman is helpless (without support), or widowed can she ask for a share in her father's property." (Here the assumption is that if she has a 'provider' in her husband, she should not ask for her share of the father's property.)

In a research carried out to find women's ownership over land, only 11% of the women surveyed owned land. And this too was fundamentally for reasons of tax benefits, etc., than out of any real desire to give women their right.

To what extent men will go in giving up their power is best summed by what a man from Surendranagar district had to say:

"Now there is a law that allows that a child will have a mother's name. Yet how much more do you want to advance women? Just see that the men are not left too far behind. And that their honor/respect is protected."

(Indicates the extent to which men will give up their power position in society.)

Conclusion

Often in thinking of development and social change strategies, we tend to accept an approach for what we think it can do without also analyzing it for the other question of what it cannot. In this lies a danger that we may pin too many expectations on that one approach. It is therefore important also to examine the limits that an approach may have so that it can be supported with other complementary strategies and approaches. Male involvement in violence against women is an example of such an approach. Since the time of the ICPD and the Cairo Declaration, male involvement in women's concerns and issues as a major objective and approach is being pursued. Such an approach may yield results where the stakes are relatively low, say in reproductive health, where it involves a man to be concerned and informed about a woman's reproductive health needs, or to undergo a vasectomy as against a woman undergoing sterilization. But the application of this approach to issues that involve giving up a share of the power and control that men wield over women, needs to be examined critically.

Male violence against women is as old as patriarchy itself. The roots of this exploitative ideology are so deep that it seems in the natural scheme of things, that men have power over women, to exploit them and their potential in a manner that adds to their material, physical and social well being and worth. Male violence against women differs in precisely these respects as here engaging men as allies challenges men to give up not just their beliefs and attitudes, but doing so involves giving up substantive power over several comforts and benefits that they have taken for granted. It asks men to grow up, in more ways than one. And it is for these reasons that we need to critically examine the possibilities of such an approach.

It is very clear from the discussions with men that they oscillate between an awareness of the injustice being done to women and a mindset that is shaped by a culture that legitimizes this power as their 'natural right' and privilege. The second places limits to the extent to which the strategy of involving men as allies in combatting violence against women will yield results. It may also be said that the limits are to do with male conditioning and not with the condition of being a man and there fore not with the approach per se.

The men-as-allies approach has its limits as men condone and condemn violence, within a cultural framework defined by the patriarchal social order. Thus *"to abuse without fault is wrong"*, implies that it is justified if a woman is at fault. Almost all men engaged

in the FGDs believed that, a woman needs to be beaten...ought to be beaten.... and that a husband has a right to beat her (if she is at fault). That these faults can be as trivial as not giving him a glass of water or whether that whatever be the fault, does a man have the right to beat at all, is another issue all together.

This thinking is so much a part of the male socialization and mindset that it is difficult for them to perceive it as injustice. Like during the third day of a workshop on involving men in Combating Violence against Women, the men were asked to identify the violence/ injustice that they as men may be committing on women in their household. An elderly patriarch sat in deep thought for long and finally said, *"I have been thinking for long and do not know what to say, for if there is violence/injustice being committed against them, then at least somebody should have complained."*

Research in the West has tended to focus on exploring possibilities of men as allies particularly in Sexual Violence against Women. Involving men as allies, to help prevent sexual abuse, is based on the findings that men condemn it, and do not approve of those who do it. This needs to be examined deeper. Men in this study condemn sexual violence but within a patriarchal correctional framework of 'punishment for the man' who does it, but do not suggest radical steps such as the woman should leave him or that she should remarry. They continue to appreciate women who suffer and endure. As was also revealed in the discussion where the father-in-law sexually abused the daughter-in-law, the men felt it was wrong, but also appreciated the girl because *"she was cultured, she did not tell her parents."*

This attitude again clearly shows up in what the man says to the wife: *"If you are so fed up of me, why don't you die?"* implying that a woman can be rid of her husband only in (her) death. That a woman can leave a man, take a divorce, remarry, are avenues legitimized by the law but not culturally acceptable.

The equation between men and woman is one of power in which male violence against women perpetuates and is tolerated by women because of the unequal power relation between the two. Calling upon men to be allies in combatting violence against women is essentially an appeal to men's sense of justice and egalitarianism. It does not really challenge and change the power equation. On the contrary by inviting the patriarch to become a patron, it actually further strengthens the unequal power relation.

Challenges to men's masculinity, as in an advertisement campaign, which said, *"real men do not commit violence"*, are double-edged swords. It does not question the cultural paradigm of men's right to beat

but on the contrary ends up reinforcing the image of 'maleness' that in the first place is responsible for the violence being committed.

The inherent contradictions in the 'men-as-allies' approach aptly shows up in the statement by a man in Surendranagar region, when he said that, *"now there is a law that allows a child to have a mother's name, yet how much more do you want to advance women. Just see that men are not left too far behind and that their honor is protected."* This statement also indicates the limits to the results that such an approach of Combating Violence against Women may yield.

The question then is, why do we, men and women, want to pursue such an approach? One does it for two reasons: a) The hoped for success of the male involvement approach is linked to our belief in changing the world, of the human ability to transform one's reality and the world around us. b) It is important to us as human beings, and as women to think of (most) men as allies so as to keep our faith and hope in this synergistic relationship alive.

The faith is not misplaced. But can work only under conditions when it is matched with other contributory factors of equality and mutuality between men and women. In the context of the men in this study, men feel unsupported in their role as providers, of their roles outside the home and a woman feels unsupported in her role within. Both feel isolated and alone. While one (women) feels dependent and helpless the other (men) feels the pressure to perform to live up to the expectations of masculinity/maleness?

Both men and women have to understand the working of this phenomena and its impact on the self and their relationship. Thus value education with youth, developing an understanding of the socialization process and through dialogue challenging and widening the boundaries of socio-cultural frames, would be the approach to involve men in Combating Violence against Women.

On the other hand women, have to also to be equipped to challenge and act on their mindset defined by the same socio-cultural norms as for men. Empowering women through education, exposure and an ability to deal with the external world is the way to equip women.

But last but not the least changing the power equation between men and woman is the deciding factor in Combating Violence against Women. In a vast majority of the Indian social context, this means working on two core issues of son preference and women's right to inheritance in the natal as well as the marital home. Unless this is done, women will continue to be treated as the other, the outsider, the inferior, and a man's property, and therefore, vulnerable to abuse.

Development of Patients' Charter of Rights and Responsibility for the Public Health Department: An Experience from Mumbai

-Anagha Pradhan¹

Background

In the first four years of its six years duration, the Women Centred Health Project² focussed on a bottom up approach for improving quality of care provided through the municipal health care facilities and establishing quality assurance mechanisms. The activities for mainstreaming quality assurance (QA) in the Public Health Department (PHD) of the Municipal Corporation of Greater Mumbai (MCGM) were developed around sensitising health care providers from the primary health care level to initiate changes leading to improvement in quality of care.

Review of progress of the pilot activities indicated inadequate support from senior and middle level administrators. The inadequate support affected the success of introduction of QA into the PHD. In a brainstorming meeting with resource persons with experience in working on quality of care within public health systems, development of 'Patients' Charter of Rights and Responsibilities' was suggested as a strategy to create ownership among the senior administrators and policy makers. Representatives of the PHD participated in the discussions. It was decided that a group of committed health care providers and administrators be formed to spearhead the process. The participants of the brainstorming meeting believed that active involvement of such groups would increase ownership of the MCGM towards QA activities.

Considering the multi-tiered hierarchical structure of the PHD, It was decided to form two groups of representatives of health care providers and administrators to spearhead QA activities in MCGM. The groups were called the Working Group and the Support Group. The Support Group consisted of

representatives of the primary level health care providers and the ward-level health administrators called Medical Officers of Health (MOH). Working Group consisted of one Deputy Executive Health Officer (DEHO), and four Assistant Health Officers (AHO) who are senior health administrators. (See Box 1)

Box 1: Composition and Role of Working Group and Support Group

Working Group

Members: 1 DEHO, 4 AHOs, 1 WCHP representative

Role

- 1 To review strategies, facilitate decisions and guide activities for mainstreaming quality assurance, gender and management perspective in the MCGM.

Support Group

Members: 4 MOsH, 2 Community Development Officers³ (CDO), 1 Medical Officer in charge of dispensary, 1 Full Time Medical Officer (FTMO), 1 PHN, 1 ANM, 1CHV and one WCHP representative

Role

- 1 To identify methodologies, to develop and pilot interventions for mainstreaming QA, gender and rights perspective in MCGM.

The role of the Support Group was to identify issues affecting quality of health care at the primary level and suggest strategies for tackling these issues. The role of Working Group was to review and ratify suggestions made by the Support Group, to present these issues to senior officers and facilitate / influence policy level decisions regarding Quality Assurance Systems in MCGM. WCHP took on the role of providing support for the activities initiated by the WG and SG. Besides documentation of the process in the form of minutes of routine and special meetings, it was decided that the project would offer assistance in terms of provision of reference material, monitoring of activities following the decisions made by the WG and timely feedback to the WG. SG was formed in December 2000 and WG met for the first time in January 2001. The groups met regularly for one year.

Development of the Patients' Charter of Rights and Responsibilities was the first task undertaken by the Working Group.

¹ Former member of WCHP, Mumbai. Email: anp1002004@yahoo.com. The author thanks Renu Khanna for help and feedback in writing this article.

² Women Centred Health Project was a collaboration of Public Health Department of Municipal Corporation of Greater Mumbai (MCGM) and SAHAJ, Baroda, a non-governmental organisation. The project received technical guidance from the Royal Tropical Institute, Amsterdam. It was an action research project that was implemented in two of the 24 wards (administrative units) of the MCGM between 1996 to 2003.

³ CDOs are trained social workers placed at the ward level and are entrusted with responsibility of community

Process of Development of Patients' Charter

Compilation of a Patients' Charter Suitable for MCGM

The Support Group (SG) and Working Group (WG) were briefed about the suggestions of the external experts. With the Citizens' Charter adopted by the MCGM proclaiming 'Quality Health Care by 2001' as a part of its mission statement and the imminent introduction of the National Reproductive and Child Health Programme, the WG agreed that the issue of institutionalisation of Quality Assurance in the MCGM seemed urgent. The WG believed that acceptance of the Patients' Charter by the Public Health Department of the MCGM would be a progressive step towards acknowledging the rights of the patients and commitment of the MCGM towards ensuring quality of health care provided through the municipal health care facilities. Also acceptance of Patients' Charter of Rights and Responsibilities would prove to be a valuable step in preparation for the RCH programme.

The following samples of patients' rights charter were reviewed: Manual of Patient's Rights by Association for Consumer Action on Safety and Health (ACASH), Pondicherry Declaration on Health Rights and Responsibilities developed at EQUIP-IOCU Workshop on Medicine, Media and Consumer Education, Charter of Health of the People of Gujarat and People's Charter for Health developed for the Jan Swasthya Abhiyan. A draft Patients' Charter of Rights and Responsibilities suitable for MCGM was developed. (See Box 2)

Each point was thoroughly discussed in the meetings of WG and SG. The points were modified to ensure that they were suitable for the Mumbai context. For example '*Right to basic health care services irrespective of ability to pay*' was modified to read as '*Right to basic health care, expensive treatment and emergency services at hospitals irrespective of ability to pay*'. The WG decided that the fee of Rs.10 would be charged to all individuals seeking care but also discussed a number of ways of assisting those unable to pay these charges. The WG discussed possibility of granting the medical officer authority for waiving the fees for a pre-determined number of individuals, collecting and using the money collected through case paper fees at the facility level and making community responsible for supporting any members that might not afford the municipal services.

Another point that was discussed in detail was '*Right to effective outreach services - to the most needy*'. Term 'most needy' was discussed. WG agreed that the

outreach services provided by the Brihanmumbai Municipal Corporation are for all the residents of the metropolis and hence term for the needy seems inappropriate. The statement was modified to read '*Right to need-based, situation specific outreach services as per the demand of the community*'. It was also decided that terms 'need-based', 'situation specific' and 'as per demand' would be defined for the Mumbai context. While discussing the same point, SG members stated that 'most needy' is a context specific and subjective term and in situations like epidemics all, rich and poor become needy.

Box 2: Patients' Charter of Rights and Responsibilities

Patients have a right to

- 1 access: to – information about services, health care system accountable to people, easy access to adequate and appropriate health services, health services sensitive to community's needs and needs of vulnerable groups such as women, children, elderly, sexual minorities etc., and redressal mechanism.
- 1 information: on causes, diagnosis, treatment, drugs and preventive measures, expected outcomes, side effects, after effects, chance of success, about professionals involved in patient care, on bills / receipts for payments.
- 1 referral, and to be transferred to another health care facility after an explanation, second opinion.
- 1 polite and considerate care, refuse participation in human experimentation, research projects affecting his/her treatment, refuse treatment (within limit permitted by law)
- 1 confidentiality: Right to expect that all identifying information, communication and records be treated with confidentiality, consideration of privacy regarding one's medical programme.
- 1 informed consent building
- 1 quality drugs and medical treatment

It is patient's responsibility to

- 1 provide accurate and complete information about one's own health
- 1 be punctual for treatment
- 1 undergo mutually decided therapy and to follow doctors' instructions
- 1 preserve all records for one's illness
- 1 take necessary preventive measures
- 1 respect and accept decisions of doctor
- 1 know and exercise patients' rights
- 1 treat doctors and nurses with respect
- 1 be aware that medical and paramedical staff are human beings and need respite

A number of primary level health care providers the project interacted with during various training workshops and interventions were vehement that if patients have rights they must have responsibilities too. However most members of the WG and SG did not share the view. WG members in an informal discussion said that it is important that patients take responsibility for their well-being but emphasising on patients' responsibilities as a part of the Charter is 'a defense mechanism'.

Points in the Patients' Responsibility were not discussed much and only two of the 15 points were modified. WG found the statement '*To respect autonomy of doctors and nurses*' too authoritative and felt that the language needed to be toned down. The statement was modified to '*To respect and accept decisions of doctors*'. The SG, largely comprising of para-medical personnel, seemed to accept the hierarchy and did not find the statement to be inappropriate. Another statement in the Patients' Responsibilities '*To be aware that doctors and nurses (and paramedical staff) are also human beings and amenable to mistakes and lapses*' was discussed at length. WG felt that this point seemed defensive and should be kept at the end of the list. WG members emphasised that this point I be explained in detail — for example, patients are expected to be considerate towards health care providers if the provider has been on duty for 24 hours and his/her response time is high in 20th hour but otherwise providers must strive to provide best possible care to the patients. This statement was modified to read as '*To be aware that doctors, nurses and paramedical staff are also human beings and need respite*'.

The proposed PC was first discussed in the WG and later with the SG. The members of the SG were informed of the discussions in the WG. It was observed that the SG members' opinions on a number of issues differed from those of the WG members. Independent thinking of members of SG despite hierarchy is commendable.

A review of discussion on rights shows that the WG accepted points related to wider conceptual issues such as 'good health', 'outreach services to the most needy', 'humane terminal care and death in dignity' without modifications. The SG members consisting of the primary health care level providers asked for more clarifications. They found terms as 'good health' vague and declared that this term be removed from the point.

It was also observed that the SG members were sensitive to patients' perspective and could 'put themselves in the patients' shoes' before accepting or modifying a point. For example, the issue of whether patient should be given a choice of referral centre was discussed at length in the WG meetings. The WG felt

that the patient should not be given freedom to choose the referral centre as his / her convenience in terms of distance from residence, timings etc. would be considered in the referral protocol. The WG seemed to perceive right to choose referral centre as a threatening issue and decided to get legal opinion on it. The SG was informed of WG's opinion. The support group members felt that it may not be possible to make it mandatory for the patients to go to hospitals specified in the protocols as "*Patient may have a genuine reason for preference of one referral centre over another.*"

The WG was divided over whether patients should have right to second opinion and whether they should be given a choice to seek second opinion from municipal tertiary care hospitals. It was argued that if a patient under treatment with one facility wanted to seek second opinion he/she could do so 'against medical advice'. The WG could not come to consensus on this point. The SG members felt that the patient has the right to take second opinion. They thought this was important because "if we put ourselves in the patient's shoes, we would like to have this choice".

Even while discussing the Patients' Responsibilities, the SG members were sensitive to patients' perspective. WG believed that the patients should maintain all records for their illness. SG was more sympathetic towards patients. They felt that whether or not the records are important should be clearly mentioned by the doctor as it would be condition specific.

The modifications suggested by the SG and WG members were incorporated in the draft which was then presented to all the MOsH, AHOs and DEHOs in a workshop. The administrators were asked to give feedback on the draft PC. (See Box 3)

Box 3: Feedback on PC

Points from PC to which were not agreeable to one or more health administrators

- 1 Right to health services free of corruption and political interference.
- 1 Right to basic health care, expensive life saving treatment and emergency services at hospitals irrespective of ability to pay.
- 1 Right to need-based, situation specific outreach services as per the demand of the community.
- 1 Right to expect prompt treatment within the available resources in an emergency irrespective of ability to pay, in the working hours of the primary and secondary health care facilities and at all times in Casualty departments of secondary and tertiary hospitals.
- 1 Right to humane terminal care and to die in dignity

(Feedback was received from seven of 52 administrators who participated in the workshop)

It was decided that the draft would be presented to the Legal Department of the MCGM after obtaining feedback of all the MOsH, AHOs and DEHOs on it. Implications for the PHD of MCGM were specified for each of the points which were reviewed and agreed upon by the members of the WG.

Box 4: Patients' Charter of Rights and Responsibilities: Some Implications for MCGM

- 1 Developing a system for upgrading technical knowledge and CME for primary level health care providers
- 1 Review and if required, revision of structure of user fees
- 1 Reviewing health care facilities for accessibility and reallocation of resources if required
- 1 Developing and implementing clinical as well as administrative protocols for prompt treatment in emergency situation
- 1 Developing and implementing QA mechanisms for each level of health care delivery system
- 1 Sensitising health care providers to patients' perspective of polite communication
- 1 Establishing redress mechanisms for patients

The draft of Patients' Charter and its implications could not be finalised since the WG, SG were dissolved. (See Box 4)

Lessons Learnt

The fact that the health care providers and administrators believed that PHD of MCGM should have a Patients' Charter and took the initiative to develop it was encouraging. This countered the more common belief that the providers and administrators from the public health system are unaware of patients' rights and act defensively. Formation of SG and WG as two separate groups was beneficial as they both differed slightly in their perspective of patients' rights. The administrators could add the administrators' perspective and look at various issues from feasibility point of view. The SG members however were more empathetic towards patients and could provide examples from day-to-day interactions with people from community.

Conclusion

The health care providers from the primary level as well as the administrators believed that it was important to develop a Patients' Charter of Rights and Responsibilities for MCGM and did not need convincing. Discussions at the WG and SG meetings provided insights into the health care providers' and

administrators' understanding of the users of the municipal health care services and their perspective towards patients' rights. Both the groups agreed that the health system should be accountable to the people and suggested that community representatives be involved in process of monitoring of the facilities. Putting up a suggestion box was one of the feasible solutions suggested by the WG and SG. Other measures suggested by WG for making health services accountable to people included displaying information about the services available in the facility on a board outside each of the facility and educating people regarding their right.

Key steps for implementation of the Patients' Charter would include besides legal approval: (1) approval by competent authorities; (2) orientation to all staff of Public Health Department regarding the Patients' Charter of Rights and Responsibilities; and (3) developing a mechanism for supportive supervision and grievance redressal at all levels of health care facilities.

Just Released

**Impoverishing the Poor:
Pharmaceuticals and Drug Pricing in India**

Published by Low Cost Standard Therapeutics (LOOCST), Vadodara, and Jan Swasthya Sahyog (JSS), Bilaspur, India. Pages 175, Price Rs 100, Postage Extra. For copies, write to: loocst@satyam.net.in OR jss_ganiyari@rediffmail.com. Or write to: LOOCST, I Floor, Premananda Sahitya Sabha, Dandiya Bazar, Vadodara, Gujarat 390 001, India. Ph: 0265 2413319/2830009 OR Jan Swasthya Sahyog, I-4, Parijat Colony, Nehru Nagar, Bilaspur, Chhattisgarh 495 001, India. Phone/Fax: 07752-247966

"This publication (revised, second edition) addresses pricing and related issues of the drug industry in India. It draws upon the experiences and insights of people, who have, over the past 25 years, consistently engaged the government to ensure access to less expensive, safer, and more rational medicines.

We hope that it would enlarge the circle of public-spirited individuals and organisations that are concerned about these issues and drive them to do something about it. In this sense, it is not a book. It is a plea for action to do something."

Invitation

31st Annual Meet of Medico Friend Circle (MFC) on Right to Health Care, January 21-22, 2005, at Mumbai

The Medico Friend Circle (MFC) is an all-India group of socially conscious individuals from diverse backgrounds, who have come together with a common concern for health. Members of the MFC are primarily medical, public health and social science professionals, researchers as well as community health and gender activists. For more than 30 years, MFC has critically analysed the existing health care system and has tried to evolve an appropriate approach towards health care that is humane and which can meet the needs of the vast majority of people in the country.

The MFC Annual Meet – 2005 will be held at Mumbai between 21st and 22nd January 2005. The Annual General Body meet is on Sunday, i.e. Jan 23, 2005 at the same venue.

The theme for the annual meet is **Right to Healthcare**. Among health activists, there is a broad consensus about the need for strengthening public health, and for greater accountability of the public health system. The question is how to work towards this end. Lately, an approach of viewing health and health care as a right has been gaining considerable momentum. Such an approach has the potential to put pressure on the public health system to improve its functioning and make it more accountable. However, while there is a need to acknowledge the strengths of the rights approach, we believe that it is also necessary to critically examine its limitations in an inherently unequal society like ours, in order to come up with a balanced, yet effective strategy to confront the problems facing the health scenario in our country today.

The meet will address some of the following issues:

- 1 Conceptual issues regarding the Rights approach: Limitations and contradictions of the Rights approach; alternative perspectives regarding the Rights approach
- 1 Conceptual issues regarding the Right to Health Care; the relation between Right to Health and Right to Health Care
- 1 Political economy of Right to Health Care in India today
- 1 Historical experiences of Right to Health Care in other countries; examples of

universal access systems in South Africa, Canada, Costa Rica, Australia, Cuba, China, etc.

- 1 Administrative issues - how to address corruption within the public health system, callousness, negligence and attitudinal problems in the public sector, how to ensure public health care providers are responsive to patients etc.; patients' concerns and redressal mechanisms
- 1 Role of private sector and NGOs in delivery of health care
- 1 Protection of specific health rights of various vulnerable sections such as women, children, HIV-AIDS affected, disabled, mentally ill, etc.
- 1 Content and operationalisation of the Right to Health Care in the Indian context
- 1 Legal issues: National Public Health Act, making Right to Health Care a fundamental Constitutional right
- 1 Financial provisions in achieving universal access to Health Care
- 1 Integration and inclusion of other systems

We invite background papers based on the above themes. The last date of submission is November 10, 2004. A concept note on the theme by Dr. Abhay Shukla has already been circulated and is available in the Aug-Sep 2004 issue of *mfc bulletin*.

We invite you to attend the meeting and contribute to the discussions with your valuable experience. The venue and other details will be circulated soon. Please note, MFC is not a funded network. Hence, participants are requested to bear their travel, boarding and lodging. However, we will organize accommodation for participants at reasonable rates.

For details about submission of papers and participation in the meet, please contact:

N. B. Sarojini, Convener, Medico Friend Circle, G-19, 2nd Floor, Marg No. 24, Saket, New Delhi 110017
E-mail: saromfc@vsnl.net, Ph: +91 11 26562401, 55637632. MFC website: <http://www.mfcindia.org>

Death To Life: Post-Death Counseling the Key

Suresh Gupta¹

Annually, about 80,000 critically ill patients in India are potential recipients of donated kidneys. About half the kidney donors will have to be unrelated citizens (either living or brain-dead) as re kidneys of relatives are unsuitable or unavailable. Liver and heart recipients will however have to rely completely on unrelated brain-dead organ donors. Each year about 5,500 potential brain-dead organ donors exist in hospitals of our four metros and nineteen major cities.

Bodies like the National Human Rights Commission are concerned about the health of donors succumbing to the illegal kidney trade but do not focus on the rights of legitimate donors and organ recipients. They speculate that there are very few doctors offering transplants of organs like livers, lungs or hearts, forgetting that transplant services can only grow when there are signs of an assured source of legitimately donated organs. Some donated organs and tissue are cheap to retrieve and transplant, like eyes and skin and heart valves. The expensive organs are the internal ones like kidneys, liver, etc., which also need costly backup by immunosuppressives for the lifetime of the recipient. **But attention of the media, public and medical professionals are mostly focused inequitably and disproportionately on kidneys alone and the newsworthy scandals associated with its retrieval.**

The human rights of both organ recipients and organ donors are being denied on a large scale because hospitals do not provide post-death support services for ethical organ retrieval from brain-dead donors. The resultant increased shortage of transplantable organs also threaten the human rights of poor donors who succumb to collaboration between affluent kidney patients, unprincipled doctors and organ traffickers.

Without a clinical declaration of brain death, no counseling of potential organ donors' next-of-kin or surgical retrieval of internal organs is possible.

The Eye Bank Association of India first tried to target live citizens with the hope of boosting voluntary eye donations after death by using nation-wide TV ad campaigns. These did not work. Success came only when they used post-death counseling to aim at the deceased potential donors in hospitals. Eye

¹ *Jagran India*, 16 Shivaji Park, Mumbai 400 028, Tel: 022-24465772, Email: suresh@jagranindia.org

donations accelerated and in the process the myth of poor uneducated people resisting organ donation were shattered. Counselors found that relatives of donors **often** found solace in consenting to eye donation. And surprisingly, even though prior awareness helps, many say YES even with no prior knowledge of eye donation.

But this success by counselors cannot be extended to retrieve internal organs because of a bottleneck created solely by doctors, hospital administrators and law makers that drafted the Human Organ Transplantation Act 1994. Counselors can work to motivate eyes, skin and heart valves by targeting relatives of patients who die of causes other than contagious deceases. But they cannot begin to function for internal organs until doctors officially declare 'brain-death' through tests recommended in the Act. *Only brain dead patients hooked on to ventilators can opt for donating internal body organs.* So hospitals need to introduce protocols for declaring brain death, introducing post-death counseling, and providing for organ retrieval. We believe that only ethical organ donations from cadavers can reduce incentives for illegal donations in the long term.

Organ Economics: Purchase of Illegal Kidney versus Cost of Counseling Programmes

Three to four lakhs of rupees reportedly change hands for a single illegal kidney. A fraction of this amount can pay the salary of a trained counselor for an entire year. A good post-death counseling program in a 1000-bed hospital with a busy trauma ward has the potential to motivate the annual donation of at least 150 eyes, a dozen livers, kidney pairs, and heart valve sets.

Social equity demands that affluent organ users should pay for organ retrieval services. The costs of post death counseling and organ retrieval should be recovered and utilized through trust funds at authorized organ retrieval centers. Cash donations can also flow into these trust funds.

Such facilitative measures are included in legislation like the Uniform Anatomical Gift Act of the USA but are omitted from our 1994 Act. We are seeking redressal through the NHRC after being ignored by the Ministry of Health, New Delhi for three years. Our plea to the NHRC has been:

(contd. on next page)

(contd from p.15)

1. Order a review of the 1994 Act by a national panel of experts.

- 1.1 Review of the Human Organs Transplantation Act 1994 by a representative national panel of experts.
- 1.2 Insertion of a Clause in the 1994 Act making it mandatory for all hospitals that provide intensive care services to declare brain deaths and create protocols for sensitive post-death counseling and organ retrieval.

2. Instruct governments to direct all Medical College Hospitals, District Hospitals and Super Specialty Hospitals to introduce protocols for post death organ retrieval.

3. POLICY CHANGES NEEDED

3.1 All District hospitals and Medical College Hospitals to mandatorily create protocols for declaring brain deaths and maintain records about brain deaths and periodically release statistics on brain deaths to the appropriate State / Central authorities.

3.2 All District Hospitals and Medical College Hospitals to create, within an approved time frame, the infrastructure and protocols needed both for counseling next-of-kin of brain dead patients and to retrieve donated organs.

Registration Number : R. N. 27565/76

Subscription Rates

	Rs.		U.S\$	Rest of
	Indv.	Inst.	Asia	world
Annual	100	200	10	15
Life	1000	2000	100	200

The Medico Friend Circle bulletin is the official publication of the MFC. Both the organisation and the Bulletin are funded solely through membership/ subscription fees and individual donations. Cheques/ money orders/DDs payable at Pune, to be sent in favour of Medico Friend Circle, addressed to Manisha Gupte, 11 Archana Apartments, 163 Solapur Road, Hadapsar, Pune - 411028. (Please add Rs. 15/- for outstation cheques). email: masum@vsnl.com

MFC Convener

N. B. Sarojini, G-19, 2nd Floor, Marg No. 24, Saket, New Delhi 110017

E-mail: saromfc@vsnl.net, Ph: +91 11 26562401, 55637632. MFC website: <http://www.mfcindia.org>

Contents

Negotiating Reproductive Health Needs in a Conflict Situation: A Case Of Kashmir Valley	-Zamrooda Khandey	1
Involving Men as Allies in Violence Against Women: Are We Pursuing a Mirage?	- Poonam Kathuria	4
Development of Patients' Charter of Rights and Responsibility for the Public Health Department: An Experience from Mumbai	-Anagha Pradhan	10
Death To Life: Post-Death Counseling the Key	-Suresh Guptan	15

Editorial Committee: Anant Bhan, Neha Madhiwalla, Dhruv Mankad, Amita Pitre, C. Sathyamala, Veena Shatrugna, Chinu Srinivasan. **Editorial Office:** c/o, LOCOST, 1st Floor, Premananda Sahitya Bhavan, Dandia Bazar, Vadodara 390 001 email: chinumfc@icenet.net. Ph: 0265 234 0223/233 3438. **Edited & Published by:** S.Srinivasan for Medico Friend Circle, 11 Archana Apartments, 163 Solapur Road, Hadapsar, Pune 411 028.

Views and opinions expressed in the bulletin are those of the authors and not necessarily of the MFC. Manuscripts may be sent by email or by post to the Editor at the Editorial Office address.

MEDICO FRIEND CIRCLE BULLETIN PRINTED MATTER - PERIODICAL

Registration Number: R.N. 27565/76

If Undelivered, Return to Editor, c/o, LOCOST,
1st Floor, Premananda Sahitya Bhavan
Dandia Bazar, Vadodara 390 001

