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Need for a communication strategy on health issues following the Bhopal gas tragedy

SUMMARY

There is a need to evolve a continuing education strategy for medical personnel and a health education strategy for people exposed to the toxic gas as part of an overall community health approach using different methodologies of communication for different groups of people needs to be developed. One of the aims would be to translate existing knowledge into supportive interventions in the lives of the people. It would also, in some ways, meet the people's need and right to information about their own health. Hence, it will have to be a dynamic interaction responding to new developments in the people's health status as well as to research findings as they become known.

PLAN

1. Objectives

1.1 To evolve:

(a) a continuing education strategy for medical personnel

(b) a health education strategy for the affected people as part of an overall community health approach to the disaster aftermath.

2. Background

2.1 Four months have passed since the occurrence of the Union Carbide gas leak in Bhopal which took toll of thousands of lives.

2.2 Evidence has been building up from dispensary and hospital OPDs and epidemiological surveys that survivors of the exposure to the toxic gas are now suffering from delayed sequelae affecting diverse organ systems within the body.

2.3 Tremendous effort has been made in providing medical and other relief through government agencies, the medical community, voluntary agencies and the citizens groups.

2.4 The ICMR in collaboration with local medical college staff and experts from different parts of the country are engaged in 20 or more research projects "to study sequelae of the lesions produced by exposure to the toxin on a long term basis including the effects on the lungs, growing foetus, teratogenecity gene mutations and carcinogenecity, neurological and mental health effects."

2.5. There have already been positive outcomes of this research effort which can benefit/modify therapy of the affected people, vix.,

(a) Therapeutic efficacy of sodium thiosulfate administration in a significant proportion of victims. This has resulted from clinical toxicological studies and a double blind study using thio-sulfate backed up by blood gas analysis and thiocyanate excretion in the urine.

(b) preliminary observations on mental health status and recommendations by the ICMR team of psychiatrists.

2.6 Voluntary effort too has contributed to medical care:

(a) making public the rationale of using thiosulfate and organizing people to demand that its use be implemented on a mass scale (Morcha, Saheli, mfc)

(b) highlighting and making public the risk to the foetus and advocating preventive contraception till detoxification is over (mfc):

(c) highlighting gynaecological problems of women which have been so far ignored (mfc):

(d) highlighting functional disability (mfc) and implementing occupational rehabilitation (AGAPE/ Union Carbide employees Association)

(e) highlighting the need for and implementing respiratory physiotherapy (Union Research Group):

(f) training community health volunteers (SEWA & BRWS)

2.7 Impact of both the above efforts (2.5 & 2.6), however, have been able to reach only a small segment of the affected population.

2.8 A major lacunae in all the above efforts is the absence of adequate communication of methods/results between medical personnel, between government and voluntary sector, between all the above and the affected people. At the field level, this results in ignorance, confusion, controversy and anarchy reducing the efficacy of the medical interventions.

2.9 Of course this is only one of the factors responsible for the prevailing medical anarchy. Some of the other are:-

(a) lack of coordination of medical relief effort;

(b) research projects though passing through a coordination committee function like vertical programmes;

(c) lack of objectivity/openessiin discussing issues: e.g., thiosulfate;

(d) the strong opposition to the above could make one believe that there are more powerful issues at stake than just the therapeutic efficacy of thiosulfate vested interests:

(e) personality clashes;

(f) ambition - utilizing the research opportunity for career advancement;

(g) a purely drug centred approach, which is reflective of one's medical education;

(h) working in isolation - not seeing the need for a multi-disciplinary approach at tackling this health disaster. Purely medical/technical intervention can never touch the solution to this problem.

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Besides medical personnel, sociologists, anthropologists, physiotherapists, nutritionists, rehabilitation experts, communication experts, journalists need to work along with citizens groups, religious groups, social workers and representatives of the people themselves;

(i) Absence of a community health approach at field/service level;

(j) medical hierarchy;

(k) over secrecy.

2.10 In this paper we shall confine ourselves to the communication strategy.

3. Methodology

3.1 During the second half of March 1985, a sixteen member team of the medico friend circle carried out an epidemiological survey of the gas affected people.

3.2 A 10% sample of families of the most affected JP Nagar and a control from Annanagar were studied.

3.3 The study included the following:

(a) a morbidity survey with detailed history taking and physical examination;

(b) hemoglobin estimation and lung function tests;

(c) a study of the people's perceptions of existing health facilities.

3.4 We also interviewed:

(a) affected people in the bastis;

(b) doctors/para-medics manning government dispensaries polyclinics, community health centres and hospitals;

(c) staff and post-graduate students of Gandhi Medical College;

(d) private practitioners working in the basti area and elsewhere in Bhopal;

(e) voluntary agencies providing relief/rehabilitation;

(f) Citizens groups working with and for the affected people: and

(g) decision makers in the government and voluntary sectors.

4. Existing methods of communication

4.1 Within the medical community these included

4.1.1 Symposia on clinical aspects of disaster aftermath held at Gandhi Medical College open to staff/students/IMA/doctors club members etc., held at bi-monthly or monthly intervals.

Some observations

(a) attendance by private practitioners was low expecially by those working in the affected areas;

(b) They were mainly exercises in one way communication between Gandhi Medical College staff and the audience (reflecting medical hierarchy)

(c) lack of open dialogue/sharing of experiences/objectivity

(d) mat one of the symposia attended (on lung function) attended by our team an anti-thiosulfate lobby dominated the proceeding with an obviously biased approach.

4.1.2 Newspaper (media) reporting seemed to be the only other source of technical/medical information.

Some observations

(a) the infrequent ICMR/voluntary agency press releases are not reported in full and often not accurately;

(b) media coverage tended to favour the strong local medical lobby and hence gave baised information;

(c) they covered the sensational aspects, blowing it our of proportion.

4.2 Between different voluntary/citizens groups

4.2.1 Informal flow of communication through group discussions, meeting and even collaborating in action takes place.

4.2.2 Here also because of ideological and personality reasons some groups were alienated from each other and worked in isolation.

4.3 Between voluntary groups and government services

4.3.1 There is a big communication gap here and lack of coordination

4.3.2 This has resulted in mutual suspicion, questioning of each others motives, working at cross purposes, even negating the work done by the other.

4.3.3 It sometimes has also resulted in duplication of scarce resources: eg., clinics run by a voluntary group and the government were almost opposite each other.

4.3.4 Breakthrough in therapeutic lines of treatment do not reach the people: eg., most doctors manning peripheral clinics (both government and voluntary) were totally ignorant about thiosulfate, its rationale, availability, efficacy etc., while it was being studied and given in a community based hospital just a stone's throw away.

4.4 Between the people and the medical services

4.4.1 Medical services both government and voluntary are strongly clinic based-being distribution centres for a variety of drugs which are available in plenty.

4.4.2 Even basic health education was not being attempted leave alone education responding to this particular health disaster situation.

4.4.3 Only citizens groups were taking health issues to the bastis, discussing them with the people and if necessary, organizing the people to get adequate medical attention.

4.4.4 These attempts were looked at with suspicion and fear by the medical establishment, rather than seeing them as positive steps to let the fruits of their own endeavours reach the people.

5. Perception of the health situation of gas affected people by medical personnel

5.1 In the absence of effective communication of study findings/ recommendations to the treating medical personnel there is ignorance about the clinical presentation/pathology resulting from toxic gas exposure. Hence there are misinterpretations of symptoms resulting in incorrect diagnosis and therapy.

5.2 Fatigability resulting from tissue anoxia produced by an increased "cyanogen Pool" in the body is being labelled as " "laziness" and "wanting to make the best use of the aid pouring in".

5.3 Respiratory symptoms due to lung damage (fibrosis) are being

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diagnosed as TB (without proper investigations) as these slums are supposed to be endemic for TB.

5.4 Genuing psychic entities like depression, anxiety etc., are being seen as "compensationa malingering" when there is adequate evidence that in such disaster situations the experience is stressful enough to produce major psychological changes.

5.5 These judgemental/unscientific attitudes towards the affected people/by some sections of medical personnel are seen both in the government and voluntary sectors.

6 Inferences - general

6.1 From the above observations it was felt that a multipronged approach should be evolved for effective communication of medical health issues relating to the gas affected victims for different categories of people.

6.2 The content of the communication could be decided by a body representing as many groups as possible.

6.3 This would have to be a dynamic process responding to new developments in the people's health status and to research findings as they become known.

6.4 All known existing methodiologies of communication/health education should be used: eg., group discussions, audiovisuals, slide shows, posters, demonstrations, posters, pamphlets, mass media etc.

6.5 Different groups of people (target groups!) should be kept in mind:

(a) the affected people

(b) Service providers:

--government health sector medical personnel;
--staff/students of Gandhi Medical College;
--voluntary agency workers/citizen groups

(c) Decision makers in government - Centre and state

(d) Media

7. <u>Methodology of a communication strategy</u>

7.1 <u>Methodology</u>

7.1.1 Regular newsletters giving main research findings, current understanding of the clinical presentation/pathology, therapeutic guidelines and their rationale should be posted out to individual medical practitioners on a mass mailing system.

7.1.2 Meetings/discussions at convenient times of doctors/ medical personnel actually working in affected bastis should be organized at regular intervals to share/get an up date on the situation.

7.1.3 If possible clinical conferences for this group emphasising the more common presentations rather than the rare should be organized.

7.1.4 Specific care should be taken to involve personnel working in the voluntary/private sector.

7.1.5 It is necessary to build on ~~the~~ and make use of resources of thedifferent groups working there, eg:

(a) Technical information/guidelines: ICMR/Medical Collgege staff

(b) Organizing/implementing program: MP Government Public Health service

(c) Organization of people: Communicating with the people — Citizens Group which have a Community base and credibility.

Zahreeli Gas Kand Sangarsh Morcha/Nagarik Punarvas Aur Rahat Samiti

(d) Respirator physiotherapy/ Nutrition supplementation : Union Research Group

(e) Trained Community Health Workers : SEWA-Bhopal through Bengal Rural Welfare Society

(f) Demystifying health issues producing communication aids : Eklavya

(g) Occupational rehabilitation : Church group

These are given only for example; many more groups may be involved.

7.1.6 The most crucial element is a dynamic, creative people-oriented approach. Too much formalisation should be avoided as this often keeps vital knowledge away from people and may be counterproductive.

7.1.7 The above caution is particularly true at the stage of communication with the people.

(a) open group meetings in different parts of the bastis need to be held;

(b) Health messages need to be adequately demystified;

(c) Audio-visuals would help;

(d) All groups with community base should be enlisted so that there is some consensus on health messages given to people and confusion is avoided.

(e) Health messages have to be built on the life style of the people and their particular socio-economic situation for it to have any meaning. Hence, close interaction and learning from the people is essential This is particularly relevant in the present situation since the disaster aftermath has led to a socio-economic crisis in the life of the victims apart from the health effects.

7.2 <u>Building up content of communication for medical personnel</u>

7.2.1 Only broad areas of content are outlined here. Details have to be worked out locally with the help of specialists of concerned departments and medical personnel from the field. Some of the areas are:

7.2.2 Therapeutic efficacy of sodium thiosulfate giving

(a) ICMR guidelines;

(b) Scientific rationale for this line of treatment

7.2.3 Diagnostic flow charts and therapeutic guidelines regularly to tackle various specific problems, eg: jaundice; pregnant women with fatigability/lung complications etc.

7.2.4 Findings and recommendations of ICMR study team of psychiatrists, to help make diagnosis, avoid mis-diagnosis and play a more conselling role.

7.2.5 Risk to the unborn fetus. Need for preventive contraception till detoxification is over. Copper T and oral contraceptives to be avoided because of status of women's health.

7.2.6 Need for good under five care

7.2.7 Nutrition supplementation

(a) Because of ill health and poor wage earning capacity, there is a role for supplementation particularly for under fives and pregnant and lactating women;

(b) Low cost food mixes made out of locally available cereals, pulses and jaggery can be used;

(c) Preparation of these mixes could become and income generating prject for women.

7.2.8 On lung problems

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(a) Refreshers on diagnostic skills in this area as this covers a large proportion of cases;

(b) Therapeutic guidelines;

(c) Repiratory physiotherapy (breathing exercises) and yoga

(d) Advice to people with lung damage to avoid smoking and if possible dust and fumes.

7.2.9 For eyes

(a) appropriate advice

(b) occupational rehabilitation because though

(c) there may be no structural damages, patients complain of blurring of vision, watering and reness of eye.

7.2.10 For jaundice

(a) awareness regarding higher incidence;

(b) diagnostic aids and therapeutic guidelines;

(c) use of disposable or adequately sterilised syringes and needles

7.2.11 Rehabilitation

(a) Diagnosing and referring the handicapped for appropriate rehabilitation

7.2.12 Drug utilization

Caution against overdrugging particularly steroids and anti-biotics, their side effects and rationale for use.

7.3. Building up content of communication for affected people

7.3.1 Here again broad areas have been outlined. Local initiative is needed to work out details, demystify jargon and use appropriate media/methodologies.

7.3.2 Details about thiosulfate - selection criteria, possible effects, side effects, dose, method of administration, precautions.

7.3.3. Possible risk to the newborn

7.3.4 For couples who were sterilised and have lost all their children, possibilities of recanalisation when, where, how

7.3.5 For mothers with suppression of lactation, details about supplementary feeding. What to give, how to give, when to give etc.

7.3.6 Breathing exercises for those who have difficulty in breathing.

7.3.7 For those with white patches on the eye: to contact the eye department, Hamidia Hospital as surgery may be beneficial.

7.3.8 In case of jaundice: need to report to the dispensary hospital to find out what type of jaundice it is. Details about the different types of jaundice, and what precautions are to be taken.

7.3.9 Caution about over-drugging especially during pregnancy.

7.3.10 Need to keep health record safely.

8. Community Health Approach

8.1 A basic community health approach would be necessary within which this communication strategy would be most effective. This could include the following:

8.2 Organizing local basti health committees and encouraging local leadership. Caution should be taken to see that all caste/class/religious groups are represented/encouraged to participate actively as very often these committees can be dominated by

powerful and vocal who may try to maintain status quo .

8.3 Training community health volunteers

8.4 Strengthening mother and child health services. The entire exposed MCH population can be considered 'at risk' and provided the best possible services, viz:

(a) good ante/intra and post-natal care;

(b) under five services with road to health cards, immunization, curative care and health education for mothers particularly regarding nutrition;

(c) nutrition supplementation would help them fight the pathology and regain as much normalcy as possible;

(d) balwadis and day care centres.

The ICDS Scheme itself could be implemented intensively in this area.

8.5 Health education

8.6 Rehabilitation services to be stressed as the disaster has resulted in some irreparable physical and even mental damage

(a) Assessment of work and wage earning capacity to be carried out and suitable/acceptable occupational rehabilitation provided for those affected;

(b) Respiratory physiotherapy;

(c) Keen watch to be kept for possible congenital abnormalities which will need rehabilitation;

8.7 Enlisting the support of existing groups within society who play a counselling role eg., religious; teachers to support a mental health strategy. Doctors too, to be sensitized on this issue.

8.8 A referral system from health worker, dispensary, polyclinic to hospital to be functioning with the larger institutions/ seniors playing an actively supportive role to the smaller/ more junior.

8.9 Active coordination of all health effort for greater effectivity;

8.10 Follow up morbidity surveys making data/information available to medical community/public.

CONCLUSIONS

1. One of the basic rights of people, that for information regarding their own health status and factors affecting it need to be urgently met.

2. This right to know is usually a casualty in the present scientific social and health system - this has only been highlighted by the dramatic nature of the Bhopal gas disaster.

3. For scientific, research and medical interventions to have any meaningful impact in the lives of the affected people, they have to be sensitive to the needs of the people in this particular circumstances.

4. There is an urgent need to translate existing knowledge research findings into supportive interventions in the lives of people.

5. A communication strategy would be one of the inputs in this process.

6. This would have to build on the various resources in the people, the voluntary and citizens groups working there and the army of government health personnel working in and for the affected people.

7. We believe that this is possible in the present situation of Bhopal if a bold, imaginative and open attitude is fostered by the decision makers.

8. We also believe that this will not be easy in the present situation of Bhopal since the same apathy, vested interests, status quo factors which obstruct action in favour of the disadvantaged in our society operate in Bhopal.

9. We have one hope that people are gradually becoming more aware of their own rights; they will demand these rights and also an accountability from people in responsible positions.

10. The strategy we have outlined is one of the many strategies necessary to support this process.

REFERENCES

1. ICMR, The Bhopal disaster - current status (The first ninedays) and programme of research

2. ICMR, Projectization of ICMR supported research

3. ICMR, Health effects of exposure to toxic gas at Bhopal, An up date on ICMR sponsored researches, 10 March 1985

4. ICMR, Medical research problems in Bhopal (V Ramalingaswami)

5. ICMR, Pathology and clinical toxicology of the Bhopal disaster (S Sriramachari)

6. ICMR, Medical Research on Bhopal Gas Tragedy, Press Release, 31 Jan 1985

7. ICMR, ibid, 12 Feb 1985

8. ICMR, ibid, 27 Feb 1985

9. ICMR, Thiosulfate therapy in MIC exposed, Minutes of meeting at ICMR, 14 Feb 1985

10. ICMR, Guidelines for treatment of Bhopal gas victims, press release, 4 Apr 1985

11. mfc Medical Relief and Research in Bhopal- the realities and recommendations

12. mfc Approache document of a project to evolve a strategy of medical relief and rehabilitation which best meets the people's medico social needs and expectations.

13. Rani Bang, Effects of the Bhopal disaster on the women's health an epidemic of gynaecological disases, reports I & II

14. Praful Bidwai, Bhopal's unending tragedy, Times of India 25-27 March 1985

15. mfc bulletin No. 112, April 1985 Medical Research in Bhopal- are we forgetting the people ?

16. Disaster at Buffalo Creek (Special Section), Am J Psychiatry, 133; 3, March 1976.