# Health Ethics in South-East Asia

**Ethical issues in clinical practice:
A qualitative interview study in six Asian countries**

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# Introduction

The term Health Ethics has gained importance and urgency in the recent past due to a number of reasons. Rapid advances in science and technology, radical changes in macroeconomic planning and the introduction and promotion of market economies and globalization have all contributed to an increased attention being given to ethics, especially in health care. Within the health sector, questions are being asked about the possible threats to the accepted principles of equity and social justice in the delivery of care. In view of these developments, the Governing Bodies of the World Health Organization (WHO), both at global and regional levels, have recommended that health ethics should be promoted through a number of activities, including research and teaching.

With the primary aim of promoting the teaching and practical application of medical ethics in clinical decision-making and health-policy making, an integrated research-cum-teaching project was carried out from 1997-1999 in six countries in the WHO South-East Asia Region (SEAR). The countries involved were Bangladesh, India, Indonesia, Myanmar, Nepal and Sri Lanka. The project consisted of four elements:

(1) A multicentre baseline study on ethical values in teaching hospitals;

(2) Establishment of a regional health ethics network;

(3) Preparation of a teaching module in health ethics, and

(4) Promotion of health ethics through national workshops.

This is the third volume in a series of documents resulting from the joined efforts of the members of a network established in 1997: the South-East Asia Health Ethics Network (SEAHEN). This volume presents preliminary findings of a qualitative, semistructured interview study carried out in the six countries. In India, the study was conducted in two centres, at the All India Institute of Medical Sciences in New Delhi and at the Christian Medical College, Vellore. While a rich material was obtained in Vellore, this material is being analysed by the research team at the centre, and the findings will be presented separately. Hence, the reference to the "India centre" in the present volume refers exclusively to the centre in New Delhi.

The purpose of the present volume is to provide an initial impression of the issues covered by this large-scale study and make selected parts of the material available both for scholars and students of medicine in general and of health ethics in particular. The present volume should be seen as a catalogue of ethical dilemmas in six countries in South and South-East Asia. The work presented here is a first step in our work with the material where we attempt to give a broad overview of the data within a limited analytic framework. We found this approach useful for several reasons. One reason is that the presentation of data here will provide important input for the development of teaching modules for the SEA Region that will be socially and culturally relevant for the setting where medical ethics is or should be taught. Another important reason is that - to the best of our knowledge — no similar large-scale comparative qualitative research project has been carried out before; therefore, we wished to present the material in a somewhat "raw" form. However, subsequent publications are planned to provide in-depth analysis of selected topics.

Against this background, the aim of this report should be understood as describing ethical values and ethical dilemmas among physicians in relation to a range of common issues in clinical practice in big urban teaching hospitals in South- and South-East Asian developing countries. At the same time, we indicate possible differences between patterns of ethical values between different centres in different countries. We hope in this way also to speak up against what may be a prevailing tendency within the global bioethics community to discuss cross-cultural ethics within the futile dichotomy of East vs. West.

## Method

Semistructured interviews were administered by a group of investigators, who had received a short-term training on qualitative research at the South-East Asia Regional Office (SEARO). The principal investigators and their assistants organized interviews with a cross-section of doctors working in the selected teaching hospitals. The sample of interviewees consisted of medical practitioners spanning different medical specialities and levels of clinical experience. One to four interviews were conducted with each doctor by prior appointment. The format of the interview consisted of the investigator explaining to the interviewee the objectives of the present study, including an

operational, but intentionally open-ended definition of what may constitute an ethical dilemma in clinical practice. For example, the following interview began with the interviewer making a distinction between a technical medical dilemma and an ethical dilemma in clinical practice. This was typical for the manner in which first-round interviews were initiated by the investigators.

In this particular interview, we are concerned with your experiences, which are related to certain ethical dilemmas. In your clinical practice, you have got dilemmas of two types. One of them is related to treatment aspect, which is straightforward. You have a dilemma about choosing which type of treatment would be better. And in this, you generally have correct information and a correct answer also. There is one answer; a particular type of treatment would be better than another type in a particular case. But you also come across many cases in which you face dilemmas, which you have to solve not on the basis of scientific knowledge but on the basis of values. What you think is right or wrong in a particular case. And here, you take the decision from your heart and not from your scientific knowledge. So, it is these types of cases, where you have to take decisions based on values, that we are interested in. Is this clear, Doctor?

The reference to dilemmas that continued to trouble the clinician in his or her heart had been developed during pre-testing of the interview guide. It generally turned out to be very fruitful. It tended to trigger discussion on what to the practitioner was conceived to be ethical problems without the interviewer imposing traditional types of ethical problems by way of examples or otherwise. Subsequently, the interviewees were asked to describe the major tasks that they had been involved in on that particular day. In this sense, it was intended to obtain at least a minimal context for the ethical issues under discussion. However, contextual issues were elaborated using various probing techniques, and discussion often revolved around an issue identified by the interviewee as a case of an ethical dilemma in clinical practice. Emphasis was put in the interview on case illustrations to contextualize the ethical dilemma. (See Interview Guide at Annex 1).

Data from field centres in six countries, *viz.*, Bangladesh, Sri Lanka, Nepal, Indonesia, Myanmar and India was subsequently coded with the help of the qualitative data analysis software programme Q.S.R. NUD-IST, v.4. A database with basic information about the interviewees and a case database of case illustrations used by the interviewees were established. Indexing was

gradually developed and refined based on the contents of the interviews. The data analysis presented in this report is based on this indexing procedure and focuses primarily on topical categories.

The use of the computer package allows us to add a quantitatively based tabular part to the presentation of the data in terms of the amount of interview material that has been coded under a particular topic. As will be clear below, there is reason for great caution when interpreting these tables. We shall discuss why upon presenting the method of producing them.

The frequency of text discussing a particular topic was first generated, using the QSR NUD*I.S.T. index search system. The frequencies were derived both in terms of the number of interviews in which the code appears and the number of text units (text lines of approx. 50 characters).

*Figure 1. Example, frequency of interview documents for a given topic*

Subsequently, these results were represented graphically as percentages of centre-wise totals of interviews and text units respectively. However, many

problems remain with such percentages. A percentage is a measure that implies some degree of precision. In the case of measuring frequency of documents and text units, however, it should be clear that firstly, we are directly measuring what has been indexed under a topic. Provided, that the indexing is consistent and precise, we get an indication to what extent a particular topic has come up in the different centres. However, we cannot conclude from such frequencies, that a topic is a greater or smaller problem in the actual setting. We merely see that it was discussed more or less in one centre compared to another.

To discourage over-interpretation of this secondary quantitative information we decided to transform the graphs into less precise tables, grouping results on a relative and topic-specific scale from very high to very low, very high being the maximum frequency of a topic across the centres, and very low being the minimum. For instance, the pattern of indexing frequency of the topic in the above example would be characterized as of low prevalence at the Bangladesh (BAN) centre but of very high prevalence at the India (IND), Indonesia (INO) and Nepal (NEP) centres. Subsequently, these results were tabulated in the form in which they appear in the example table below.

*Table 1:* **Example of cross-centre comparison**

| | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
| | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** | |
| INT | Low | Very High | Very High | Medium | Very High | High | High |

However, as the focus is on relative variation within a given range, the actual range of percentages resulting in the categories in the above table could as well have been from 0 to 5 % as the actual range in the example from 0 to 75%. Therefore, we have added an additional column to give the reader an idea of the frequency of a topic relative to discussions on all other topics, "overall freq." Hence, this indicates whether a topic is often or rarely discussed from an overall perspective.

Another important point is the difference between frequency of interview documents (INT) and text units (TXT, not given in above example, but in most tables in the report). INT frequencies involve a kind of over-reporting in the sense that it does not make a difference whether a given topic is covered in one line or in the full length of the interview; in either case the topic is covered in the document. TXT frequencies, on the other hand, provide a minimal reporting, as only the lines under a topic are reported, but potentially important associations and other patterns of meaning are left out. In a sense, INT may provide too much textual context and TXT too little, which is one of the reasons why we have included both. Another is the statistical problem involved in calculating percentages of limited number of documents in centres, where relatively few interviews were carried out. This problem is more comfortably dealt with at the level of text units.

While we have decided to include these tabular presentations as supplementary information secondary to the much more important narrative discussion of the findings, it should be emphasized that at the most, the tables reflect salient trends and broad clusters of issues that emerge from coded data. The findings are based on inferences from the indexing process. Furthermore, since more than ten interviewers have been involved in the interview process, differences in interviewing skills and other forms of inter-interviewer variation is likely to have influenced variation among centres. Where indications of inter-interviewer variation have been found during analysis, they are mentioned in the text.

In spite of all the above limitations, we do believe that it may be of value to show that, for example, financial constraints play a massive role for discussions of most ethical dilemmas in all centres, or that withholding information to terminal patients seem dramatically more frequent as an issue under discussion in one centre compared to all others. We see the value in these observed frequencies in their potential to cause discussion and raise questions rather than as a basis for conclusions. It should be understood that information provided by very few interviewees may be very important in a particular context. In qualitative research, the importance of a particular result can never simply be based on its prevalence.

## Profile of interviewees

Interviews with a total of 122 clinical physicians in the different field centres produced a large qualitative data set of 256 interviews. The following table presents an overview of the data in terms of number of interviews and text units.

*Table 2:* **Overview of data (No. of interviews and text units) by centre**

|  | BAN | IND | INO | MMR | NEP | SRL | TOTAL |
|---|---|---|---|---|---|---|---|
| Interviews | 20 | 20 | 36 | 25 | 10 | 11 | 122 |
| INT | 50 | 60 | 58 | 63 | 11 | 14 | 256 |
| TXT | 9828 | 25272 | 25130 | 21918 | 4214 | 2698 | 83058 |
| AVG INT/int'ee | 2.5 | 3 | 1.6 | 2.5 | 1.1 | 1.3 | 2.1 |

Note: BAN = Bangladesh, IND = India, INO = Indonesia, MMR = Myanmar, NEP = Nepal, SRL = Sri Lanka, INT = Interviews, TXT = Text Units (1 text unit = approx. 50 characters)

The above table shows that there are important differences in the amount of data obtained from the different centres. While there is some uniformity in number of interviews and text units from the India, Indonesian and Myanmar centres, there is a major difference between these centres and the data from the Nepal and Sri Lanka centres, as fewer interviews were conducted there due to local circumstances and constraints. The Bangladesh centre has a relatively high amount of interviews of relatively short length, typically covering only one or a few topics and/or cases each. These differences should be borne in mind when examining the pattern of indexing of various research categories at the different centres in the tables throughout this report since the foundation for comparing findings from India, Indonesia and Myanmar is obviously stronger than for especially Nepal and Sri Lanka. However, a number of other differences between the data sets from the various centres should also be noted.

Table 3 below illustrates the sex ratio for each centre and the overall sex ratio among participants. Only in Bangladesh is an equal distribution obtained. However, the general picture can be expected to illustrate the overall pattern at the included hospitals.

*Table 3:* **Interviewees by sex (%)**

| Age group | BAN | IND | INO | MMR | NEP | SRL | TOTAL |
|-----------|-----|-----|-----|-----|-----|-----|-------|
| Female | 50 | 20 | 14 | 32 | 20 | 27 | 26 |
| Male | 50 | 80 | 86 | 68 | 80 | 73 | 74 |
| TOTAL | 100 | 100 | 100 | 100 | 100 | 100 | 100 |

Table 4 below shows variations in age group of interviewees among the centres. Most noteworthy is the tendency in the Indonesia centre to include very senior doctors in the study as compared with the other centres.

*Table 4:* **Interviewees by age groups (%)**

| Age group | BAN | IND | INO | MMR | NEP | SRL | TOTAL |
|-----------|-----|-----|-----|-----|-----|-----|-------|
| <35 | 0 | 10 | 0 | 16 | 0 | 9 | 6 |
| 35-50 | 100 | 90 | 16 | 72 | 50 | 73 | 63 |
| >50 | 0 | 0 | 84 | 12 | 50 | 18 | 31 |
| TOTAL | 100 | 100 | 100 | 100 | 100 | 100 | 100 |

Note: BAN = Bangladesh, IND = India, INO = Indonesia, MMR = Myanmar, NEP = Nepal, SRL = Sri Lanka

The participants cover a total of 20 specialities, the most frequent five being obstetrics-gynaecology (15%), surgery (15%), paediatrics (12%), psychiatry (8%) and internal medicine (7%); these five categories covering 57% of the participants.

These major categories of specialization are remarkably (but perhaps not surprisingly) skewed in terms of sex ratio. For example, 95% of the surgeons are male, while 72% of the obstetrician-gynaecologists are female.

An overwhelming majority of doctors had received no formal teaching or training in medical ethics as part of the medical studies or subsequent career.

The participating medical institutions were generally prime tertiary care centres, often the biggest hospitals in the respective countries. They ranged in capacity from 401 beds in the Nepal centre to 1700 beds in the India centre, with 9658 inpatients and 112690 outpatients annually in the former (96/97), and 99586 inpatients and 1812885 outpatients in the latter. The other centres were generally in-between these two centres in terms of capacity. In Myanmar, the research team decided to involve participants from six hospitals in Yangon, with a capacity range from 220 to 1500 beds. However, association between interviewee and individual hospital setting has not been maintained, and the Myanmar data set is treated as from one centre.

It may be readily understood that this study examines ethical values among clinicians at highly specialized medical institutions with primary responsibilities not only for tertiary health care in the respective countries, but also for research, introduction of new technologies and teaching of medical students. The focus on this type of medical institutions rather than ethical values among secondary or primary-level health care providers is linked to the intention of providing background material for the development of teaching modules that can integrate teaching and clinical realities at the teaching institutions. We would like to stress, however, that we are attempting to cover new ground and that further research should include not only health care providers at different levels of care but also providers from different professions (most notably nurses) among the research participants.

## Outlay of the report

The report is divided into three main parts, which are further divided into sub-sections. Part one begins with a general discussion of patient autonomy, which is not only a central issue in health ethics, but also frames the analysis of the data in this study. Subsequently, the section deals with the doctor-patient relationship from the physician's perspective. This part discusses a range of topics, which are central to health ethics, namely, saving life, doing harm, informed consent, etc.

In Part Two, the analysis moves to issues of access and equity in clinical practice. Constraints on access to medical treatment, factors involved in treatment delay and suboptimal treatment are examined.

Part Three examines the institutional context of practice and clinical decision-making under resource constraints, as seen by the interviewed physicians. This section examines a range of themes. On the one hand, issues of contextual features of practice, such as paucity of manpower, medical equipment and facilities, over-treatment and misuse of resources are discussed. Secondly, interaction among doctors in clinical practice, such as teaching responsibility, doctor-doctor conflict and vested interests, is examined. This section also looks at the salient characteristics of clinical decision-making, such as the relative typicality of the ethical dilemmas discussed and the assignment of agency.

Parts one, two and three are each followed by a separate summary. The summary presents the main themes covered in respective part of the report topic-wise. This summary should not be looked at as the summing up of concrete results or findings, but should be read more in the nature of inferences arrived at through a process of indexing the interviews. The purpose of presenting this synoptic view is to simply facilitate discussion, and indicate major areas for future research.

In the Conclusion, the themes of physician responsibility, patient rights and the need for ethics training are brought together. Some preliminary suggestions on topics that should be part of the teaching module on medical ethics in the Region, which are proposed by the participants are highlighted.

Finally, we would like to emphasize one important limitation of any interview study. While many interviewees have been very frank and some perhaps have felt relieved to discuss pressing ethical dilemmas with the interviewers, the interview situation remains an artificial setting where situations and problems are discussed in the context of the interview, not in the context where they happened. The present study should not be misunderstood or misconstrued as showing behaviour or communicational patterns in clinical practice. Only indirectly, through the description of the interviewees, do we get insights into the clinician's perspectives and experiences with some of the perhaps most difficult issues in the practice of medicine.

Part 1:

The Doctor-Patient Relationship from the Physician's Perspective

# Patient autonomy

The idea of autonomy is a central concept in health ethics. It is a derivative of the more general principle of respect for persons, which, along with beneficence (do good), non-maleficence (do no harm) and justice, are generally considered to be basic ethical principles aimed at regulating biomedical research and practice. This principle is rooted in the recognition of the inherent worth and dignity of the individual.

According to the International Guidelines for Ethical Review of Epidemiological Studies, formulated by the Council of International Organizations of Medical Sciences (CIOMS) in Geneva:

(a) Autonomy requires that those who are capable of deliberation about their personal goals should be treated with respect for their capacity for self-determination, and

(b) Protection of persons with impaired or diminished autonomy, which requires that those who are dependent or vulnerable be provided security against harm or abuse.[1]

Respect for persons implies recognition of people as autonomous agents and requires that their choices be observed. For persons who are not completely autonomous, the principle of respect for persons entails that they be protected against risks and adverse consequences. Autonomy and self-determination are meant to ensure that decisions concerning self are made *by* individuals, rather than for individuals on the grounds that others know better what is in their best interest. We show disrespect for autonomous persons, when we either repudiate their considered judgements or obstruct their exercising free choice on the basis of these judgements in the absence of compelling reasons to do so. When applied to the clinical context, patient

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[1] Bankowski, Z., J.H. Bryant and J.M. Last (eds.). *Ethics and Epidemiology: International Guidelines. Proceedings of the XXVth CIOMS Conference.* Geneva. 7-9 November, 1990

autonomy may broadly be used to refer to the patient's inherent right to information regarding his medical status, and a corresponding role in exercising informed choice in clinical decision-making.

Closely connected with the idea of patient autonomy are issues of patient rights and informed consent. The idea of patient rights is based on two principles, namely:

(a) The patient has certain interests, which are not automatically forfeited upon entering into a relationship with a doctor or health care facility, and

(b) Medical personnel and institutions may fail to recognise the existence of such interests or rights, and hence not offer protection against their violation.

Informed consent requires physicians to share information about the risks and benefits of medical procedures and research protocols with patients before taking their consent for participation or treatment. This is particularly applicable in the case of surgery, drugs and invasive diagnostic procedures. The purpose of informed consent is to promote self-determination by patients on the assumption that it is the patient, who has the most at stake in treatment, and who relies largely on the physician for such information. These procedures are also aimed at protecting those patients who are at a disadvantage in the health care system, such as the very young and very old, the illiterate, the mentally incompetent, and those without relatives. Since ethical discussions always prioritize the desires and needs of the subject, the principles of autonomy and informed consent allow competent individuals to exercise some degree of control over decisions about their health and participation in research.

Figure 2 provides a broad overview of major ethical themes for text indexed under patient autonomy and text not indexed under patient autonomy. The figure confirms that patient autonomy as a concept is closely linked to the theme of information management as could be expected, given the central position of informed consent. However, it nevertheless confirms that patient autonomy is a complex concept that should also be looked into in terms of other issues such as doing harm, treatment barriers, access and others. The present document will investigate these themes in the light of the results of the present study.

***Figure 2****: Frequency of "patient autonomy" by*
*main indexing categories (no. of interviews)*
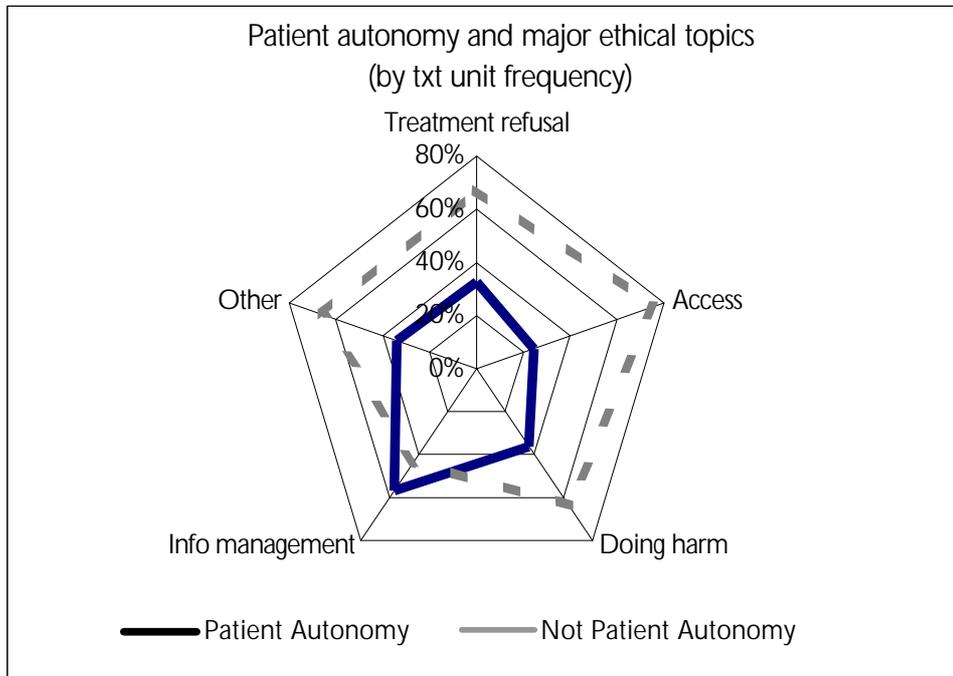


Under the rubric of information management, we have indexed themes of informed consent, disclosure of confidential information to third party (such as the family), and withholding information (from the patient and/or family). Consequently, it appears that from the physician's perspective issues of individual choice and decision-making arise more in the area of clinical communication in the doctor-patient relationship. This topic will be examined in the first part of this report.

The following themes will be discussed in this part of the report:

➢ Information Management in Clinical Communication

➢ Doctor-patient Interaction

➢ Assessment of Patients

# Information management

This section will examine three themes that emerged as central to clinical communication in the interviews. Table 5 presents a global picture of the themes connected with information management in the different centres.

*Table 5:* **Pattern of indexing frequency of "information management" by centre**

| Variation Among Centres | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | **Overall freq.** |
| **Informed Consent** | | | | | | | |
| INT | Low | Very High | High | Medium | High | High | Very High |
| TXT | Very Low | Very High | Medium | Medium | Low | Low | Very High |
| **Disclosure of Information** | | | | | | | |
| INT | Very Low | Low | Very Low | Medium | High | Very Low | Medium |
| TXT | Very Low | Low | Very Low | Medium | Medium | Very Low | Medium |
| **Withholding information** | | | | | | | |
| INT | Very Low | Low | Low | High | High | Very Low | High |
| TXT | Very Low | Low | Low | Very High | Medium | Very Low | High |

Three main categories are covered by information management, namely, informed consent, disclosure of confidential information to third person and withholding information from patient and/or the family. As can be seen from Table 5, there are some interesting differences in the relative emphasis being

placed on these themes in the different field sites. During analysis, it was found that informed consent is a major concern in India, followed by Indonesia and Nepal. While the issue of withholding information is also more prominent in Nepal, it is not an overriding concern in India and Indonesia. This means that informed consent does not necessarily involve only disclosure of and withholding confidential information from the patient; it was also discussed in relation to other topics. There is, however, a correspondence between disclosing and withholding information. The contents of the interviews show that this appears logical, given the fact that if patients are not given access to confidential information about their medical condition, a third party has to enter to represent them in the doctor-patient communication network. This is most often the patient's family. On the basis of these general differences, the centres can be grouped into three major groups. One comprises India and Indonesia, where the issue of informed consent is predominant, but not significantly connected with disclosing and withholding confidential information. On the other hand, in Myanmar and Nepal, the latter two themes take on greater salience. Lastly, while in both Sri Lanka and Indonesia, there is a marked emphasis on informed consent, disclosing and withholding information are relatively of lesser concern. These differences will be elaborated below.

## Informed consent

### The concept

Informed consent is a central concept in medical ethics. The voluntary consent of the subject of research or medical intervention is absolutely essential before the subject or patient is inducted into research or therapeutic procedure. A precondition to informed consent is that the person involved should have the legal capacity to give such consent. Potential subjects and patients should be informed about the risks and benefits of the intervention in a manner commensurate with their educational and intellectual capacities. They should be allowed to make an informed choice without duress, after a detailed explanation of the research or medical procedure has been provided to them. On the basis of the above, four attributes may be identified as constituting valid consent. Consent is valid, if it is 'voluntary', 'legally competent', 'informed' and 'comprehending'.[2] Implicit in this is a vision of

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[2] Levine, R.J. 1991. Informed consent: Some challenges to the universal validity of the western model In *Ethics and Epidemiology: International Guidelines.* Proceedings of the XXVTH CIOMS Conference. Geneva, 7-9 November 1990.

informed consent as a two-way process. Firstly, information is presented to subjects or patients by the investigator or clinician in a lucid manner. Secondly, the subjects either agree or refuse to participate based on their understanding of the information communicated by the competent authority. This is the traditional formulation of informed consent, which, however, does not rule out the possibility of other ways of formulating informed consent in different cultures and social contexts.

### Informed consent in the interviews

As Table 5 shows, informed consent emerged as an important topic of discussion in the interviews. The interviewees discussed it in a variety of circumstances, ranging from abortion and genetic counselling to the discontinuation of life support to neurologically dead patients. Informed consent was also discussed by the respondents in terms of a set of issues, which confers certain distinctiveness to the way in which informed consent is conceptualized in the research centres. An analysis of the interviews reveals that it seemed to be understood by the interviewees mainly in terms of communication of medically relevant information by the physician to patients or/and families. Lack of economic resources and time were cited as important impediments to the operationalization of the procedure of informed consent in routine clinical practice. Doctors said that work pressure prevented them from spending enough time with patients in order to provide adequate and detailed explanations about their medical condition(s).

Some participants revealed a critical assessment of the concept of informed consent as applied in their day-to-day practice. A distinction was made between written and verbal procedures of obtaining informed consent. Some doctors critically evaluated the traditional definition of informed consent as a dialogue between an individual patient and a physician. They argued that it was not congruent with social practices and cultural beliefs of the Region. For example, informed consent was rarely discussed by the interviewees in isolation from the patient's family. A basic question of who is actually responsible for giving informed consent was raised. Summing up the situation, one doctor at the Indonesian centre said:

*About informed consent, I think that the hospital should truly respect the patient by giving the explanation. Until now, it is not clear who is responsible for providing informed consent. This poses a problem for me. To the best of my*

*knowledge, those who have the right to sign an informed consent are the patients themselves, who are considered as adults. But in our country, this is not always the case. Sometimes, we cannot perform an intervention that should be done because of interference from the patient's family. The case is like this: I have already explained the operation to be performed to the patient, and I ask him to obtain the informed consent the next day. But he would say I could not do that because his wife did not give the consent, because his parents, in-laws would not agree. To be frank, this puts us in a difficult situation in carrying out the intervention. Finally, we have to call on the patient's wife, parents-in-law, etc.* (Chest Specialist, male).

Many interviewees pointed out that giving priority to the family in medical decision-making was part of the culture of the Region. Several interviewees said that even in the face of patients' resistance to a medical intervention, they had gone ahead with it at the behest of their families. Although issues of patients' rights to information and freedom to decide the course of their treatment were emphasized by a number of respondents, it was again more in normative terms. At the level of actual action, the family played a determinative role in all clinical decision-making. The idea of 'family informed consent' emerged as an important concept in the interviews.

In addition to the expressed wishes of the patient's family, interviewees discussed informed consent in relation to their assessment of the patients. Communications around informed consent, in some cases, were linked to physicians' assessment of patients. Interviewees seemed to be putting emphasis on various assessment criteria, such as patients' intellectual, emotional capacities and their socioeconomic status. Social support was discussed more frequently in connection with informed consent in comparison to other assessment parameters. The patient's family was identified as the most important variable in the patient's social support system. This is understandable in the light of the important role played by the family in decision-making in an individual's life in the Region.

An in-depth analysis of the interviewees, however, reveals that, although the family was, by and large, given a significant decision-making role in the patient's treatment, its authority could be by-passed by the physicians in the larger interest of the patient. For instance, a gynaecologist at the Bangladesh centre described a case in which she had performed tubal ligation on an

anaesthetized patient undergoing a caesarean section without the consent of the patient's husband. She justified her decision on her evaluation of the patient's social situation. She said that she knew the patient's husband would never consent to a sterilization procedure being performed on his wife. However, since in this doctor's opinion, another pregnancy would seriously endanger the patient's life, she took the decision while bearing the overall welfare of the patient in mind.

In their discussions of informed consent, doctors seem to be trying to balance a number of variables in clinical decision-making, *viz.*, patients' welfare, the demands of patients' families, and the diagnostic and treatment options open to them in an institutional context of resource constraint. In this exercise, interviewees reiterated that their approach was case-based, depending on the particular context framing a problem of a more general nature.

The assessment of the patient's mental or emotional capacity was also assigned an important role in the overall evaluation of the patient in the context of informed consent. Patients' perceived psychological or emotional status was connected with physicians' willingness to confer with patients about their medical condition. A number of interviewees, for instance, said that they did not inform patients suffering from conditions like cancer and leprosy about their diagnosis for fear of causing undue emotional trauma.

The perceived intellectual capacity of patients, measured mainly in terms of education level was used as a yardstick for judging their capacity to grasp significant information about their medical condition. Several respondents said that they only discussed patients' medical condition in detail with them, if they (the doctors) felt that patients would be able to understand the information. Given the high levels of illiteracy in the Region, this issue carries important implications for informed consent in clinical decision-making.

In their discussions on informed consent, some physicians also highlighted the role of the economic factor in a range of situations. In addition to the contextual constraints on clinical practice in terms of shortages of medical equipment, facilities and manpower, patients' economic capacity was

also cited as an important factor in clinical decision-making. For instance, several physicians reported that in some cases they scaled down the treatment, offering less expensive treatment alternatives to poor patients. Other physicians expressed their unhappiness at having to tell the families of terminally ill patients that nothing more could be done for the ill person, because they knew that the families would not be able to afford the costlier treatment option, which might bring some short-term relief.

At a more general level, existing procedures for obtaining informed consent for operation and other medical procedures were also felt by a majority of doctors to be inadequate with existing international guidelines. A respondent from Myanmar felt that the existing informed consent form was too perfunctory. Some interviewees suggested that the informed consent procedure should be made more formal and uniform through the intervention of professional medical associations. The often taken-for-granted practice of having another family member, such as the parent or husband, sign the informed consent form on behalf of a mature, mentally sound patient was questioned. The need to streamline this procedure in the context of the doctor-patient relationship was repeatedly underscored.

Thus, it may be said that the concept of informed consent was critically examined in the interviews, both as a theoretical construct and as applied in routine clinical practice. Physicians' assessment of patients, the demands of patients' families and the institutional constraints on practice were the main parameters within which informed consent was discussed by interviewees. The idea of family informed consent was proposed. The need for implementing formal procedures of informed consent, which were both in consonance with international guidelines, and yet sensitive to the specificities of the Region was underscored.

### Informed consent and research

Ethical dilemmas around informed consent were not only cited by interviewees in the area of medical diagnosis and treatment; the issue also came up in the area of research. The following table shows the indexing frequency categories of research by centre.

*Table 6:* **Pattern of indexing of "research" by centre**

| | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
| | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** | |
| INT | None | Very High | Medium | Low | Medium | None | Very Low |
| TXT | None | Very High | Low | Very Low | Low | None | Very Low |

While research did not emerge as a topic of discussion at the Bangladesh and Sri Lanka centres, it was an important topic of discussion at the India and Nepal centres. It was also discussed to a lesser degree at the Indonesian and Myanmar centres. Overall, it was not a frequently discussed issue.

Whenever the topic of research was broached, it was invariably in connection with informed consent. There was a consciousness among respondents that there might be at times a clash between the interests of science and of medical care. Some interviewees expressed anxiety about inducting patients in research that involved testing of new therapeutic agents. They expressed a discomfort at having to decide between choosing a safe and time-tested treatment and a novel, and perhaps more efficacious, therapeutic regimen. A few participants cited communicating about the potential experimental risks to subjects and their families as a difficult task. On the one hand, patients might refuse to participate in the study, if told that they were being exposed to a new and untested drug. Given the low level of literacy prevailing in the Region, patients might refuse to participate making it impossible to undertake the research. Consequently, a few physicians said that many a time they chose not to inform patients that they were part of a research protocol. A physician at the Nepal centre put the issue in perspective as follows:

*I think I am following the medical ethics. But sometimes, we are doing some studies, which do not involve any extra invasion. We are doing routine studies. Patients come and are admitted. They may be under case studies; and we are not taking consent of the patient. The fact is that we are not doing anything extra. It's just a clinical work-up. But from that clinical work-up, we extract the data. This is why we think that it may not be necessary to take the consent of the patient. Even if I am not doing research, this procedure will be*

*done to this patient. If I have to undertake some unnecessary or extra procedure or expensive invasive procedure, then I would have thought of taking consent of the patient. But it's like a case study in which no finance is involved, no extra financial burden to the patient and no additional investigations are involved. There is no additional invasive procedure. So, I simply think it is not necessary* (Physician, male).

The above discussion indicates that there are differences, on the one hand, between the way informed consent is generally understood as the right of the patient to be informed, and on the other, the way that it takes shape in routine clinical practice and research.

More introspection on the concept of informed consent in clinical care and research is questioning this traditional understanding. For instance, pointing to the fine distinctions between clinical care and clinical research, Truog, Robinson and Randolph have recently questioned the necessity of taking formal consent for clinical research, which does not involve a significant risk to the patient.[3] Making a distinction between general and specific tiers of informed consent, the authors argue that patients give a general informed consent, whenever they enter into a fiduciary relationship with a physician. Specific informed consent is necessary, whenever the intervention (research or therapeutic) involves a high risk-benefit ratio, whenever the preferences and values of the patient are relevant to the decision at hand. Within this framework, they aver:

We believe that as with clinical care, in the case of many randomized, controlled trials, the patient's participation can and should be considered to be authorized by his or her general consent for treatment and that specific consent should not be required. (Ibid.)

In conclusion, it maybe said that a few interviewees highlighted the difficulties involved in operationalizing criteria of informed consent in the context of medical research on patients. Communicating experimental risk was perceived to be especially difficult to illiterate and poor patients. A distinction was made between informed consent in the context of clinical trials and clinical care.

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[3] Truog RD, Robinson W, Randolph A, Morris A.: Is informed consent always necessary for randomized, controlled trials? *N Engl J Med.* 1999 Mar 11;340(10):804-7.

### Withholding and disclosing information

The interviews pointed to the existence of a strong pattern, wherein issues of informed consent repeatedly came up when the physician had to communicate a potentially fatal and/or socially stigmatizing diagnosis, such as cancer, HIV-AIDS or leprosy, to the patient and/or family. This is the theme of this section.

Table No. 7 shows the degree of overlap in interview text between disclosing and withholding information by centre:

*Table 7:* **Pattern of overlap of "disclosing and withholding information" by centre**

|  | Variation Among Centres | | | | | |
|---|---|---|---|---|---|---|
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** |
| INT | Very Low | Very Low | Low | Very High | Low | None |
| TXT | Very Low | Very Low | Very Low | Medium | Low | None |

The above table shows that the degree of overlap between disclosing and withholding information is overall highest in Myanmar. The degree of overlap between disclosing and withholding confidential information is low in Nepal, and very low at the Indonesian, Bangladesh and India field centres, and entirely absent in the case of the Sri Lanka centre. Since the overlap is measured, an overall frequency is not given.

Withholding confidential information from patients was connected with disclosure of the same to the patient's relatives. The interviews reveal that there was a controversy among doctors on this issue. A large number of physicians said that they preferred to initially inform the relatives about a patient's condition, especially if it was a question of a serious, potentially life-threatening or socially stigmatizing disease. However, there seems to be no consensus on the matter. Other interviewees felt that it was better to tell the patient directly. They justified their decision on the ground that, eventually in the course of treatment, patients, suffering from a terminal illness such as cancer, would come to know about their condition, either from the staff or fellow patients. This might prove, they argued, more traumatic in the long run

to patients than being directly informed by their physician at the outset. Furthermore, it was also argued that it was not correct to expose the patient to the side-effects of radiotherapy and chemotherapy without prior preparation and consent.

A large number of doctors, however, preferred to withhold a potentially fatal diagnosis from the patient, at least during the early stages. This is depicted in connection with withholding information about a cancer diagnosis in Figure 3.

*Figure 3:* *Cancer and communication (NB: Scale begins at 40%)*

Fig.3

The figure shows that the themes of (only) disclosing and (only) disclosing and withholding information come up more often in the cases involving a cancer diagnosis than other disease conditions. The issues of withholding information and both disclosing and withholding information come up more often in cases involving the communication of a cancer diagnosis to patients and/or their families. As Table 5 shows, this issue came up more often at the Myanmar and Sri Lanka centres.

*Table 8:* **Overlap in cases of "cancer" and "withholding information", by centre**

|  | Variation Among Centres | | | | | |
| --- | --- | --- | --- | --- | --- | --- |
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** |
| CASES | Medium | Very Low | Low | Very High | Medium | High |

Discussions on cancer and withholding information emerged as a topic, albeit to a lesser degree, at the Bangladesh and Nepal centres. Although many cancer cases were discussed at the India and Indonesian centres, they were not discussed in connection with withholding the diagnosis from the patient and/or the family.

Physicians' decision to disclose or withhold the diagnosis of a condition like cancer was influenced both by an individual assessment of the patient's psychological condition to receive such information and the decision of the patient's relatives. When asked to explain why they chose to withhold information regarding cancer from the patient, several reasons were put forward by physicians to justify their line of action. First and foremost was a concern for the psychological well-being of the patient. As a participant from Myanmar explained:

*I came across a 35-year-old cancer stomach of the case, but I did not explain he had cancer, Although every patient ... every patient ... should know about the nature of his disease and possible prognosis, I did not explain he had cancer due to the psychological stress* (Oncologist, male).

Interviewees pointed out that one reason why they chose to conceal the diagnosis of cancer from patients was linked to the frequently observed tendency of such patients to suffer mental trauma when informed that they had cancer, and subsequently drop out of treatment. Consequently, the respondents, who discussed the issue, justified their decision on the grounds that it was in the best interest of the patient to withhold this information, at least during the initial phase of treatment.

Some physicians also said that their assessment of the patient's intellectual capacity (primarily in terms of formal education) to understand the meaning of the diagnosis and its treatment modalities also played a role in their decision to withhold or reveal a cancer diagnosis. The relationship between communicating a cancer diagnosis and assessment of patients is given below in Table 9.

*Table 9:* **Pattern of indexing frequency of "assessment of cancer patients" by centre (interview documents)**

|       | BAN      | IND    | INO      | MMR    | NEP       | SRL    |
|-------|----------|--------|----------|--------|-----------|--------|
| AIC   | Very Low | Low    | Medium   | Low    | Medium    | None   |
| AMC   | Very Low | Low    | Medium   | Low    | Low       | None   |
| AEC   | Low      | Medium | Medium   | Medium | High      | None   |
| ASC   | Very Low | Medium | Very Low | Medium | Very High | Medium |

Note: AIC=Assessment of intellectual capacity, AMC=assessment of mental capacity, AEC=Asessment of economic capacity, ASC=Assessment of social support capacity

Even though the theme of cancer and withholding information was relatively high in Myanmar as seen in Table 7, the emphasis in assessment at this centre seems to be more on cancer patients' economic capacity and social support (Table 9). On the other hand, in Indonesia, where this issue also came up in a relatively smaller number of cases, the emphasis seems to be more on assessment of mental, intellectual and economic capacity of cancer patients. In the Sri Lanka centre, only social support of cancer patients was assessed.

Physicians pointed out that their decision to withhold information from patients was most often done at the behest of their family members. Proxy consent is a well-recognized concept in cases where the patient is legally incompetent on grounds of age, mental incapacity or some other medical condition. However, the current study revealed many situations where the family members took decisions on behalf of a mature, mentally sound person.

On the other hand, a few doctors also reported treatment situations, when they had chosen to conceal confidential information from the family at the behest of the patient. For instance, a dermatologist justified his decision not to disclose the diagnosis of leprosy to the relatives of a married female patient on the following grounds:

*We made a medical diagnosis. I am comfortable with the decision. Patient's confidentiality? Sometimes we do impart the diagnosis to the relatives, if they are supportive. But it is a secret between the patient and doctor; and if the patient wants it to be that way, then we try to keep it like that* (Dermatologist, male).

However, there was also some divergence of opinion among doctors espousing the viewpoint that disclosure is not always the best policy. One group said that if a patient asked them directly about the diagnosis, they would tell the truth, even if it went against the expressed wishes of the patient's family. A very small number of physicians said that they would not disclose the diagnosis to the patient without the permission of the patient's family.

The above analysis shows that information management in the clinical context is a very complex process involving the physician's assessment of the patient's medical condition and wider social circumstances, the demands of the patient's family and resource constraints on practice. Interviewees' also highlight the fact that information management in clinical communication entails introspection and critical reflection on their part. Most of them admitted that they had found it difficult to make decisions involving withholding and disclosing confidential information to patients and families. They did not appear to have a blanket approach to information management, but it was situation-based, depending on the case at hand.

The strategies of information management discussed above carry important implications both for the definition of informed consent and for the concept of patient autonomy. If the doctor-patient interaction occurs in the backdrop of the patient's family, then the meaning of informed choice and self-determination take on very different connotations. While patients are not always silent and passive participants in this scenario, their exercise of autonomy is inseparable from the involvement of their respective families.

Similarly, informed consent from the clinician's perspective must also take account of patients in their social context. This means that the ideal typical conceptualization of informed consent as a transaction between subject and investigator or patient and physician needs to be reformulated when applied cross-culturally. This also raises the question about the meaning of such ethical notions as confidentiality and truth-telling in clinical communication. The obligations of physicians and the rights of patients and families also need to be re-examined in the light of this discussion.

## Doctor-patient interaction: Beyond information management

In addition to informed consent, disclosing and withholding confidential information to third party, interviewees discussed other factors that influenced the doctor-patient relationship. Their accounts make ample references to such foundational ethical principles as saving life and not doing harm. They also discussed other aspects of the doctor-patient interaction. The last issue deals with those aspects of the doctor-patient interaction, which can neither be included under communication nor under the rubrics of saving life and doing harm.

Looking at these issues in relation to the ethical principles of beneficence and non-maleficence, it was found that in delineating their ethical dilemmas in clinical decision-making, physicians framed their descriptions in terms of their moral duty to save life and not bring harm to their patients. During analysis, the theme of doing harm was classified into three sub-categories, *viz.*, physical, mental and social harm. Furthermore, discussions of doctor-patient interaction were not divorced from physicians' emotional reactions to their work and to the plight of their patients.

This section on doctor-patient interaction is sub-divided into the following four sub-sections:

➢ Saving Life;

➢ Doing Harm: Physical, Mental and Social Dimensions;

➢ Doctor-Patient Interaction: Other Aspects, and

➢ Physician's Emotional Reaction.

## Saving life

This category was used to index all those situations, where the physician was primarily concerned with ensuring the safety or prolonging the life of the patient. Physicians' concern regarding saving life came up more often in the interviews with regard to abortion and end-of-life decisions involving the discontinuation of life support to patient suffering from multiorgan failure or declared to be neurologically dead. The best course of action for terminally ill cancer patients, with or without radical treatment, was also discussed.

The following table shows the distribution of this category by centre.

*Table 10:* **Pattern of indexing of "saving life" by centre**

|  | Variation Among Centres | | | | | |  |
|---|---|---|---|---|---|---|---|
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** |  |
| INT | Low | High | High | Low | High | Very High | High |
| TXT | Low | Low | Low | Very Low | Low | Very High | Medium |

From the above, it appears that the issue of saving life is a frequently discussed topic at all the centres, except Bangladesh and Myanmar, where discussions are few both in terms of number of interviews and text units. Although it is mentioned in a large number of interviews at the India, Indonesian and Nepal centres, it is not discussed in great detail as revealed by the comparatively fewer number of text units covered by it. On the other hand, saving life shows a high salience both in terms of text units at the Sri Lanka centre. Discussions on this issue often revolved around topics concerning end-of-life decisions and abortion.

It will be noted that, in place of euthanasia, the phrase 'end-of-life decisions' was used for analysing situations, where physicians expressed a dilemma between their moral duty to save life unconditionally, and the actual context of clinical practice and patients' life circumstances. This presents us with a wide range of situations involving life and death decisions. For example, a number of interviewees discussed the theme of saving life in the

context of distributing the very limited number of ventilators among the larger clientele of potential candidates. The physicians, who brought up the matter, expressed anguish when being forced to discontinue life-saving treatment in order to make the equipment available to others. In connection with a 10 year-old child on a respirator in the Intensive Care Unit (ICU), a doctor at the Sri Lanka centre said:

The only other option is to keep the ventilator till the child recovers or dies from other complications, which frequently happens with patients on long-term ventilation. The problem for us is the shortage of beds and rapid turnover. Just ventilating a patient, whose outcome is not so sure, may mean that several others die because of the lack of a ventilator (Physician, male).

Another doctor at the Myanmar centre discussed his predicament in connection with choosing patients for blood transfusion, in the face of the extremely limited supply of blood in the hospital. Limitations of manpower and equipment were repeatedly cited as major constraints providing the best care to those who needed it the most. Many doctors expressed helplessness and anguish at having to refuse admission to a patient, who might otherwise die, for want of an empty bed in the ward.

Quality of life emerged as an important variable in the discussions on treatment and management of terminal medical conditions. For instance, in his treatment of a geriatric patient suffering from a severe malignancy, a physician at the Indonesian centre justified his decision against using any invasive treatment on the grounds that it would not improve the quality of life of the patient. He said:

*Sometimes, we have cases with very advanced malignancy, where we know that even if we put the knife on a patient, we may not achieve much. Even if we give chemotherapy, probably we may just improve her survival by a few months. In such cases, we have a combined discussion and then we take a decision. Even if the medical literature says, you can do this, you can do that and achieve a little more survival, normally my tilt is toward giving her a better quality of life rather than disease-free survival. It is not possible to achieve much with this patient through chemotherapy or radiotherapy. She is vomiting all the time, not able to tolerate food. So, if she lives with all those problems another month, I don't feel it is worth it. So, we try to do minimum palliative therapy for such patients and make them as comfortable as possible* (Oncologist, male).

In addition to cancer, several physicians illustrated their ethical dilemmas around saving life in connection with the prolongation of life of renal failure cases. Some doctors showed a disinclination to continue with the dialysis if the patient was from a poor family or very old with other medical conditions like diabetes. Putting the dilemma in perspective, an endocrinologist at the Delhi centre said:

*The largest patient load is patients with diabetes. And the most dangerous complication of diabetes is the involvement of kidneys. Kidney failure is the most life- threatening condition associated with diabetes. Once you develop a kidney failure, because of diabetes, eventually there is only one solution, a kidney transplant. You cannot do anything else. Now, the problem occurs, when we see a patient of diabetes with kidney failure. Due to constraint of resources, most of the times dialysis is done only for those patients on whom there is a prospect for transplant in terms of an available donor and funds. We are talking of a large sum of money, which a significant majority of patients will not be able to afford. Now, do I tell the patient who has got diabetes-related kidney failure that you do not have the money, just go home and die. Perhaps, that is what eventually happens* (Endocrinologist, male).

Thus, it can be seen that end-of-life decisions are mediated by the doctor's overall assessment of patients' medical condition and their socioeconomic status.

The issue of saving life also came up in discussions on abortion. By contrast to the traditional debates on abortion, ethical questions around abortion were discussed by the interviewees more in terms of ensuring the safety and welfare of the mother than that of the foetus. In addition to privileging the life of the mother in obstetric emergencies such as craniotomy, a number of physicians enumerated cases where they had advised and then terminated a pregnancy in order to save the life of the mother or ensure her a better health status. For instance, one gynaecologist justified her decision to terminate pregnancy of a woman suffering from severe diabetes and its related complications, such as renal disease and retinopathy in order to save the life of the mother. This decision was taken despite the opposition of the patient. On the other hand, in another case a doctor decided to terminate the

pregnancy of a patient, who said she did not want another child because she already had three children, the youngest being only a few months old.

However, this is not to say that the fate of the unborn child was not discussed at all. Several physicians reported difficult situations, when they had advised medical termination of pregnancy in cases where the foetus was severely disabled or HIV positive. However, the ultimate decision in such cases often rested with the mother, who had the last word in the matter. These discussions encapsulate a particular tension between physicians' moral duty to save life and observing respect for the right of patients to make informed choices.

Thus, it can be said that the issue of saving life emerged as an important topic of discussion in the interviews. Physicians' concern regarding saving life came up more often in the interviews with regard to abortion and end-of-life decisions. It was also discussed in connection with treatment of terminally ill cancer patients. These discussions highlight a particular tension between physicians' moral duty to save life, the specificities of the clinical context of practice characterized by resource constraints, and respecting patient's right to make informed choices.

## Doing harm

Clinical decisions on preserving life in the face of overwhelming odds are one type of ethical dilemmas in clinical work. There are other less extreme situations, which also provoke ethical deliberation on the part of physicians in connection with their moral duty not to do harm. During analysis, the category of doing harm was used to code those situations, wherein interviewees expressed a consciousness of the harmful consequences of health care activities on the physical, mental and social well-being of their patients. Consequently, the category of doing harm was further sub-divided into physical harm, mental harm and social harm. It must, however, be noted that this tripartite division is only a heuristic device to facilitate the discussion, since overlap was often seen. Table 11 shows the relative indexing frequency of these sub-categories by centre.

*Table 11:* **Pattern of indexing of "doing harm" by centre**

| Variation Among Centres | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | Overall freq. |
| **Physical Harm** | | | | | | | |
| INT | Low | Very High | High | Low | Low | High | Medium |
| TXT | Low | Very High | High | Low | Low | High | Medium |
| **Mental Harm** | | | | | | | |
| INT | Very Low | Low | Very Low | Very Low | Low | None | Very Low |
| TXT | Very Low | Low | Very Low | Very Low | Low | None | Very Low |
| **Social Harm** | | | | | | | |
| INT | Very Low | Medium | Very Low | Low | Low | Very Low | Very Low |
| TXT | Very Low | Medium | Very Low | Low | Low | Very Low | Very Low |

From the above table, it appears that issues of physical harm are discussed most often in the India, Indonesian and Sri Lanka centres as well as from an overall perspective. Mental harm is not a major topic of discussion at any of the centres, and there is no discussion on it at the Sri Lanka centre at all. Social harm is found to be a concern in India in terms of frequency of occurrence of the theme in interviews. Again, let us note that these findings do not indicate actual occurrence of these types of doing harm. They only tell us whether or not medical doctors expressed ethical dilemmas in these connections. One would expect to find a very different picture in a patient-centred study.

*Physical harm*

When speaking about physical harm, a number of factors were mentioned by interviewees, which, in their estimation, threatened the physical health of their patients. Physical harm was, in the main, discussed in connection with treatment and prognosis. Thus, the side-effects of medication, over-medication, adverse reactions to drugs, invasive diagnostic procedures and inadequate sterilization of medical equipment, were some of the issues raised by the respondents in this regard. Several participants said that in the absence of alternatives, they were at times forced to provide expired or cheaper drugs to patients. Some physicians pointed out that they were concerned with the post-hospitalization status of their patients, especially at those coming from far away areas, which would deteriorate in the absence of follow-up.

The issue of physical harm also came up in connection with norms of practice, teaching responsibility and research. Some doctors said that their decision to see patients outside of official visiting hours was based on their assessment of the physical harm that the patient might suffer in case of treatment delay. A physician at the Indonesian centre raised the question of the repercussions on the health of patients, when attended to by a substitute physician. Some doctors felt uncomfortable at having to delay commencement of treatment of patients, whose condition made them good cases for teaching purposes. The anxiety expressed by doctors on inducting patients into clinical trials has already been alluded to earlier in the section on information management.

Thus it can be seen that the issue of physical harm was raised in a variety of different contexts, where the physical health of the patient was perceived to be at stake.

*Mental and social harm*

In the analysis of the interviews, it was found that not only were respondents concerned with physical harm, but they were also concerned about the mental and social repercussions of the disease process, diagnostic and treatment modalities on patients and their families. As shown in Figure 4, mental and social harm converged more often in the accounts of interviewees than either physical + mental or physical + social harm. There were also fewer accounts wherein all the three types of harm converged.

Not surprisingly, interviewees made references to mental and social harm most often in connection with patients suffering from psychiatric illness. The issue also came up in discussions on leprosy and HIV/AIDS.

*Figure 4. Physical, Mental and Social Harm and the overlap between them*

Fig.4

In the case of psychiatric treatment, doctors voiced concern over the negative consequences of involuntary hospitalization on the patient. The possibility of self-harm such as attempted suicide was also discussed. Some psychiatrists referred to the difficulties they faced in reconciling the interests of patients and their families. Rejection by families, over-medication and inadequate follow-up were described in the context of the interface between patients' psychopathology and their familial networks. A number of psychiatrists said that they were caught on the horns of a dilemma when it came to advising families on the marriage of mentally ill patients, especially female patients. In addition to the plight of the mentally ill in their homes, the negative consequences of long-term hospitalization were also discussed.

The issue of mental and social harm also came up in communication about infectious and stigmatizing diseases, such as leprosy and HIV/AIDS. For instance, one participant at the India centre said that he often conceded to the wishes of leprosy patients not to inform their families about the disease, but only if the patient was suffering from the non-infectious type of leprosy, and was also on regular treatment. The need for concealment occurred, he pointed out, more in the case of female married patients, who might otherwise be ostracised by their conjugal families, if they came to know that the patient was suffering from leprosy. Another doctor at the Indonesian centre said that he had not informed the employer of a male patient suffering from a mild attack of leprosy about the diagnosis in order to protect the patient economically.

A few doctors in the context of AIDS raised similar concerns. One doctor bemoaned the absence of a sound hospital policy on the management of HIV-diagnosed patients, who were very much left on their own to cope with the disease. In addition to the impact of the disease on the individual patient's life, the social consequences of such an ad hoc approach on the community at large were also discussed by the physician. He reiterated the need for both pre- and post-test AIDS counselling in this regard.

In discussions on infertility, several gynaecologists also expressed concern over the social and mental consequences of infertility on the lives of women in the marital homes. These doctors pointed out how at times they chose to keep the matter a secret between themselves and their patients to the exclusion of the latter's family.

From the above, it can be seen that both mental and social harm were in many cases closely tied to issues of information management, especially withholding/disclosing confidential information to third party.


## Doctor-patient interaction: Other aspects

Saving life and doing harm do not exhaust the range of themes brought up by informants in connection with doctor-patient interaction. Some of the more frequently mentioned facets of the doctor-patient interaction, excluding issues discussed under saving life and doing harm, are discussed below. Table 12 depicts the distribution of doctor-patient interaction (other aspects) theme by centre.

*Table 12:* **Pattern of indexing of 'Doctor-patient interaction: other aspects" by centre**

|  | Variation Among Centres | | | | | |  |
|---|---|---|---|---|---|---|---|
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** |  |
| INT | Very Low | High | Very High | Low | High | Very Low | Medium |
| TXT | Very Low | Medium | Very High | Low | Low | Low | Medium |

Although this theme occurs in a large number of interviews at the India and Nepal centres, the issue of doctor-patient interaction takes on greater salience at the Indonesian centre. Interestingly, it was discussed more in terms of the professional norms of practice governing the doctor-doctor interaction than in terms of the direct interface between physicians and their patients. For instance, it came up in connection with issues such as physician responsibility in multidisciplinary treatment, office confidentiality, second opinion and the public-private interface in medical practice. Interviewees mentioned difficulties in balancing their moral duties as physicians and their professional interests working in specific institutional contexts. They delineated their dilemmas in terms of the impact of these factors on treatment of patients and on their own moral conscience.

One of the important themes in doctor-patient interaction: other aspects was that of privacy. Several interviewees spoke about the difficulties in conducting proper medical examination of female patients by male doctors. This issue came up more commonly in the specialities of dermatology and gynaecology. The interviewees, who raised this matter, pointed out that due to lack of physical space and female personnel, it was difficult to examine female patients. One female doctor said that she faced the same problem with young male patients. This situation is illustrated in the following excerpt from Bangladesh:

*A thirteen or fourteen-years-old girl has come with scoliosis. I have to examine her back. She will only have her undergarments on, only little undergarments, so that I can examine her back as well as front, her chest. That*

*should be done in a proper place, and that proper place is not available in this hospital. When this girl will be examined, another girl will be ready for the examination. We don't have much time. For that reason, we sometimes just put our hand over her clothes and we examine the patient. This is very much unethical. And I think there is every chance for making a wrong diagnosis* (Orthopaedic Surgeon, male).

Some interviewees said that they resolved this problem by permitting a family member of the female patient to remain in the room while she was being examined. The issue of privacy not only came up in connection with the actual physical examination, but some doctors also reported that at times they found it difficult to ask patients (again especially female patients) about their sexual behaviour and practices. This problem, it was stated, came up more often in the treatment of sexually transmitted diseases. Thus, the gender of the patient and an underlying anxiety of causing physical harm seem to be influencing the manner in which the doctor-patient relationship takes shape in the particular socio-cultural context.

Thus, it can be seen that a number of disparate themes emerged when the doctor-patient interaction set was examined, when excluding the themes of saving life and doing harm. Gender emerged as one major theme in this regard, placing women at greater risk of possible harmful consequences of medical treatment.

## Physician's emotional reaction

It has been noticed that physicians' articulations of their ethical dilemmas, be it in the area of information management, saving life or other aspects of the doctor-patient interaction, resonate with their emotional reaction. A number of participants depicted their ethical predicaments as arising out of their interactions with patients in emotionally charged terms. Expressions like *I felt sorry; I felt guilty; I was happy: I was shocked* punctuated their speech. The plight of patients provoked emotional reaction in a large number of interviewees. Table 13 shows the pattern of indexing frequency of physicians' emotional reaction by centre.

*Table 13*: **Pattern of indexing of "physicians' emotional reaction" by centre**

| Variation Among Centres | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | Overall freq. |
| INT | Low | Medium | High | Very High | Low | Medium | High |
| TXT | Very Low | Medium | low | Very High | Very Low | Medium | Low |

From an overall perspective, it emerged as a frequently discussed topic. Physician's emotional reaction was an important topic of discussion at both the India and Sri Lanka centres; the issue was discussed far more frequently at the Myanmar centre. Significantly, issues of disclosing and withholding information from the patient were also more often discussed by physicians at this centre, as described earlier.

Interviewees referred to other situations in clinical practice which aroused an emotional response in them. Some doctors said they felt bad when they were forced to discharge one patient prematurely in order to make the bed available to another patient, whose need was adjudged greater. Other doctors reported how they had at times been forced to scale down the treatment, or even discontinue it altogether, because patients could not afford the medicines, and the hospital could not provide them the requisite drugs. Interviewees pointed out how they often faced painful decisions, when they were compelled to choose one patient over another in the provision of health-care in a situation of severe resource constraint. This issue was brought up by one physician at the Myanmar centre in connection with choosing potential candidates for blood transfusion in the face of limited supply of blood. He said:

*It's not the first occasion. I think it must have happened about six or seven times that I had to choose between two patients. I find it very difficult, but I always choose one patient. I never regret my decision. Of course, I feel sorry for the person who died. But it's not always necessary that the other patient, who did not get the blood transfusion, always dies. For example, that*

*night in my surgical ward too, I chose one from out of patients, but luckily both of them survived. In another situation also, I chose one patient. The patient, who received the blood transfusion, died but the other person survived. There are many factors in this. I mean, you are playing the role of God and deciding who lives and who dies. I think it's a very big ethical dilemma* (Physician, male).

Some interviewees said that they were especially affected, when it came to treatment of children. One paediatrician said that she had cried when she turned off the respirator on a comatose baby. Clinicians' experiences of end-of-life decisions requiring the discontinuation of life support systems were described in highly emotionally charged terms. Several doctors said that they had prayed before taking such decisions.

Such expression of emotions on the part of participants contests the stereotype of the doctor as an impersonal professional. The fact that respondents expressed a whole gamut of emotions, both positive and negative, in connection with patient care, reflects the intrinsically humanist character of clinical practice.

While some doctors expressed discomfort at withholding a fatal diagnosis like cancer from the patient, there were others who did not regret their decision. As one doctor at the Myanmar centre said:

*I have already decided that, telling the truth to the patient may harm him. It may make him depressed or very unhappy. That will not do him any good. In this case, I believe that telling the truth to the patient is wrong. I told the truth to the relatives and I believe that I have done what I should have done. So, I don't feel anything. I should say I feel very comfortable, because I am strongly of the opinion that telling the truth to the patient at the moment is not correct, but it is very difficult to make a hard and fast rule of it, whom to tell and whom not to tell* (Physician, male).

An analysis of the themes covered under this section shows that clinical decision-making was influenced by clinicians' commitment to basic ethical principles of saving life and not doing any harm. With regard to the issue of patient autonomy in the context of various aspects of doctor-patient interaction, we observe an individualization of the patient to the extent that the family comes to play a secondary role in the physician's overall assessment

of the welfare of the patient. Although the family still continues to play a determinative role in clinical decision-making, the voices of patients are more salient in issues of saving life, doing harm, other aspects of doctor-patient interaction and in physicians' emotional reactions. This is not surprising given the direct physical interface involved between physicians and their patients when it comes to such themes. How this direct interface relates to patient autonomy is, however, a matter that requires more investigation.

## Assessment of patients

Throughout the preceding sections of the report, it was found that physicians' delineation of their ethical dilemmas, be they in the area of information management or doctor-patient interaction, was strongly influenced by their assessment of patients. During analysis, six assessment criteria were identified, which physicians seemed to be using in their evaluation of patients. These are:

> ➢ Assessment of Patients' Economic Capacity;

> ➢ Assessment of Patient's Social Support;

> ➢ Assessment of Patient's Intellectual Capacity;

> ➢ Assessment of Patient's Mental Capacity, and

> ➢ Age and Gender in Patient Assessment.

The following table shows the centre-wise distribution of assessment of patient capacity criteria.

*Table 14*: **Pattern of indexing of "assessment of patient capacity" by centre**

| | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
| | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** | |
| Economic Capacity | | | | | | | |
| INT | Medium | Very High | High | Medium | Low | Very Low | Very High |
| TXT | Low | Medium | Medium | High | Low | Very Low | High |

|  | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
|  | BAN | IND | INO | MMR | NEP | SRL | |
| Social Capacity | | | | | | | |
| INT | Low | High | Medium | High | High | High | Very High |
| TXT | Low | High | Low | Very High | Low | High | High |
| Intellectual Capacity | | | | | | | |
| INT | Low | Medium | Medium | Low | Low | Low | High |
| TXT | Low | Very Low | Very Low | Very Low | Very Low | Very Low | Low |
| Mental Capacity | | | | | | | |
| INT | Very Low | Medium | Medium | Low | Low | Low | High |
| TXT | Very Low | Low | Low | Low | Very Low | Very Low | Medium |

Note: Variation among centres is given for all assessment categories within a single range, i.e. any INT or TXT value (EC, SC, IC *or* MC) at a particular centre is relative to INT or TXT values, respectively, for all centres for all (EC, SC, IC *and* MC) categories.

When examining the frequency of distribution of various assessment criteria document-wise, we may divide the centres into different groups. For instance, economic capacity was assessed more often in the Bangladesh, India, Myanmar and Indonesian centres. In addition to economic assessment, social support emerged as the most frequently indexed assessment criterion, except in Bangladesh. Mental capacity and intellectual capacity were discussed more often at the India and the Indonesian centres.

When the same themes are examined in terms of text units they cover, social support is discussed in more detail than economic capacity at the India centre. Similarly, in the case of Nepal, social support appears in a relatively large number of interviews, but the quantity diminishes when examined in terms of number of text units. However, assessments of social and economic capacity of patients continue to maintain a similar pattern of medium-to-high prevalence at the Myanmar centre, irrespective of the unit of analysis.

Each of these assessment criteria will be discussed separately below.

## Economic assessment of patients

The economic factor was seen to be playing a predominant role at two complementary levels. It was an important criterion in physicians' assessments of patients, and it was the most important determinant of patients' access to health services. It produced a dual constraint on the doctors, as they were forced to negotiate between a practice context characterized by massive shortages of manpower, equipment and facilities, on the one hand, and a patient population that was more or less on the edge of survival on the other hand. It is the widespread prevalence of poverty in the Region, which lends distinctiveness to the discussion on health ethics in the present context.

Physicians' assessment of the economic capacity of patients played an important role in both the processes of diagnosis and treatment. For instance, several interviewees said that they had been forced to forego certain investigative procedures, such as CT scanning or MRI, because neither could the patient afford to get these investigations done from the market, nor could they be done by the hospital at rates affordable to poor patients. Long waiting lists and the non-availability of equipment were also cited as institutional constraints in this connection. Some physicians said that, under such circumstances, they chose the less expensive investigation e.g. X-ray instead of CAT scanning, giving preference to the investigative procedure available in these advanced teaching hospitals, which could be availed of by the patient either free of cost or at highly subsidized rates. A few interviewees said that they refrained from recommending expensive diagnostic procedures to poor patients in the first place, if the hospital was not in a position to carry them out.

A large number of interviewees cited similar dilemmas in prescribing medicines. Sometimes a cheaper, but less efficacious, alternative was chosen, if patients' financial position did not permit them to opt for the more expensive drug. This issue was discussed by some physicians in the context of prescribing for tuberculosis, epilepsy and functional psychiatric disorders. For instance, a neurologist at the India centre explained his position in terms of a cost-benefit analysis:

*There are a lot of cases for which I would like to prescribe a particular brand of an anti-epileptic drug, which costs around Re.1 or Rs1.25 a tablet. On*

*an average, a patient would require 3-4 tablets a day, which means around Rs 5 per day. And the treatment may continue for three, four or five years. On the other hand, there is another drug, a tablet of which would cost about 40 paise, and daily treatment would be around Rs1.20. So, when there is such a large difference in cost, and since it has to continue for three to four year, on many occasions, we are not in a position to write the expensive drug. The expensive drug may not be very different in terms of control of the fits. But it is certainly better in terms of the side-effects. So, people who cannot afford, have to bear the side-effects* (Neurologist, male).

While most respondents said that they informed the patients and their families of all the alternatives, a few said that in order to save the latter unnecessary mental trauma, they simply did not tell them about the more costly treatment option. The situation was summed up by a dermatologist in the following words:

*That is another dilemma. You know highly effective drugs are available but they are out of reach of the patients. In those situations, I usually care more for the financial status of the person, his ability to afford medicines rather than for using this specific drug, which I know will get rid of his illness very quickly. Often I make the decision on my own irrespective of what patients tell me. Patients, who have an illness for a long period of time or who have seen several practitioners before coming to us, will be at a stage when they are willing to say that they don't care how much it costs. They will say "I am willing to take the treatment". But you know it's not true. What they are actually saying is that they are desperate for a remedy, but the words they use mean something else. What they really mean is that they would have an extremely large financial burden to carry, if you indeed took them at face value* (Dermatologist, male).

And if it was not a matter of life and death, this doctor said he sometimes did not inform patients about the more expensive alternative, if he was sure it was beyond their economic capacity. He said:

*There you cannot even offer them a choice. I do not tell them that this treatment is available. We just use the less effective and cheaper treatment* (Dermatologist, male).

Several other physicians pointed to the suffering of patients and their families, when they found out that the life-saving drug was beyond their financial capacity, especially when the patient was a young child or the breadwinner of the family.

Several participants highlighted concrete instances, when they were unable to provide any treatment because of patients' economic inability to procure the necessary treatment. A physician recounted at the India centre a situation where a patient who was put on a temporary pacemaker in an Emergency, could not be transferred to a permanent pacemaker, because the device was beyond her financial capacity.

Similar problems came up in connection with liver and kidney transplant cases. In the absence of donor-related transplants, some doctors pointed out how patients' inability to procure such organs commercially meant that they were effectively consigned to a certain death. While most respondents showed a more pragmatic approach in connection with older patients with poor prognosis e.g. those suffering from renal failure and diabetes, they expressed more sympathy in case of children, whose prognosis was favourable, if the necessary medical facilities were made available to them. For instance, one paediatrician at the India centre cited the case of a child suffering from biliary atresia. The child had a good chance of survival, if provided with a donor liver. However, the child could not be treated because his family did not have the resources to procure a donor organ from the market.

Another category of patients, whose treatment was directly affected by the financial capacity of their families, were those suffering from such disabilities as cerebral palsy and mental retardation. Several interviewees pointed out how helpless they felt in such cases, since they could not do much for such patient, if their families could not afford the special training and gadgets required for their rehabilitation.

The economic status of patients also came up in discussions on growth hormone therapy and on sophisticated procedures in cardiology, which required substantial financial inputs from patients and their families.

Ethical dilemmas related to economic assessment of patients were not confined to discussions on poor patients alone. A few doctors mentioned that

they faced difficulties in the treatment of well-to-do people as well. Some of the questions raised in this connection were: in the context of public hospitals, should well-off people be provided services free of cost or at subsidized rates, or should they be referred to private clinics? How should treatment modalities be determined when the patient had adequate access to health insurance and other types of reimbursement? These issues came up more often at the Indonesian centre, where there were more discussions on the public-private dimensions of health care.

Thus, it appears that patients' economic capacity not only determines the treatment options, which they may actually exercise but also the treatment choices that will be made available to them by health care providers. Interviewees strove to strike a balance among patients' economic status, optimum treatment and contextual constraints on practice rather than adopt a context-blind health maximization approach.

## Assessment of social support of patients

During analysis, it was found that the social support network of the patient was a significant factor in physicians' over-all assessment of patients. The patient's immediate family emerged as the most important and influential determinant of the patient's social support system. The importance of the patient's family in medical treatment has already been discussed earlier in the sections on information management and doctor-patient interaction.

A number of situations were mentioned by interviewees in which patients' social support system were taken into consideration. The impact on the family system of hospitalization of a key family member, such as the breadwinner or housewife, was cited by a few doctors. Similarly, some other respondents dwelt upon the impact of a handicapped patient on the family network and vice versa.

As in the case of social harm, the assessment of the patient's social support system took on greater salience in the case of psychiatric patients. The issues of involuntary hospitalization, admission and discharge in ambulatory psychiatric care were discussed, especially in situations where there was no cooperation from the patient's family. Other psychiatrists made reference to situations wherein treatment was influenced by their assessment of the

patient's social support. For instance, one psychiatrist admitted that in giving medication to reduce a child's over-activity, he was in fact helping the family to cope with the child' s disruptive behaviour rather than the patient, who would probably benefit more from psychosocial intervention. Other psychiatrists noted the indispensability of the cooperation of the family in the treatment of alcohol and drug dependence disorders. Doctors also mentioned that in many cases the decision to seek alternative treatment was a family decision. A psychiatrist from Sri Lanka said in this regard:

> One problem, that I came across in the ward today, is that some relatives want to take the patients away against medical advice for ritual treatment. Because they believe that the patient is not suffering from mental illness but is being possessed by the devil, spirit or something like that. So, they want to take the patients away for ritual treatment. I have explained to them that it is a common problem, a mental illness, which can be treated. But after discussing among themselves, they still decided to take the patient away for ritual treatment. So, we have had to let them do what they want. We have no setting to keep the patient against the patient's relatives' will, since this is a general hospital. But in a mental hospital, you can keep the patient against patient's relatives' views. There are laws (Psychiatrist, male).

The accounts of interviewees reveal some overlap between the assessment of patient's economic capacity and social support system. Thus, some doctors said that while recommending treatment options, they weighed the costs of treatment with the economic resources of the family. For instance, one doctor said that he had discontinued chemotherapy on a terminally ill child on the grounds that the family's limited resources could be better utilized in the care of the patient's healthy siblings.

In view of the importance assigned to the family in all aspects of medical treatment, a number of participants underscored the need to formally incorporate the family during hospitalization. In addition to providing waiting space for relatives in the OPD and ward, one cardiologist at the India centre suggested that one family member could even be allowed to remain with the patient in the ICU.

In general, the assessment of the patient's social support system framed both the evaluation of the patient's medical condition and the formulation of the treatment plan.

## Assessment of intellectual capacity of patients

In the section on informed consent, it was found that many physicians felt that the educational level of the patient and relatives was an important factor in the area of information management. A large number of interviewees drew attention to a perceived relation between education and health status and consequently reiterated the need to increase health awareness of the population in general. Some interviewees also expressed certain stereotypes such as a perceived tendency of illiterate people not to follow contraceptive advice, and to show medical non-compliance in general. A number of doctors said that they found it difficult to explain the nature of the diagnosis and the modalities of treatment to illiterate patients, not only because they had to simplify their explanations, but more importantly, they just did not have the time. Some interviewees said that they gave detailed explanations only to those who they felt could understand. And these patients were generally those who were educated. However, a few clinicians said that they made individual assessments of their clients' levels of understanding (irrespective of their formal educational level) to structure the process of clinical communication.

Earlier in the discussion on informed consent and patient autonomy, it was pointed out that under certain circumstances, choices may be made for patients in situations where the patient is a minor or is mentally ill. In the present context, it appears that lack of education may also be viewed as criterion for disabling patients from exercising informed choice in decisions that have a bearing on their health.

The educational level of patients was perceived to be an important factor in judging their capacity to understand diagnosis, investigative and treatment procedures. This issue carries important implications for the informed consent procedure in the case of illiterate patients.

## Assessment of mental or emotional capacity of patients

An analysis of the interviews reveals that interviewees were conscious of the psychological stress experienced by patients and their families in coping with the disease process and undergoing the trials and tribulations of hospitalization. Such institutional factors as overcrowding, long waiting queues and rude behaviour of hospital staff were regarded to be stressful for patients

and their relatives. Some doctors also pointed out that diagnostic procedures, such as endoscopy, and other aspects of the medical examination could be stressful experiences for some patients, especially those who were illiterate and/or coming from far-flung rural areas. Thus, in the accounts of many respondents, assessment of emotional capacity of patients is closely connected with issues of causing mental harm.

The impact of psychological factors on treatment outcomes was also discussed by some doctors. For instance, a dermatologist at the India centre presented the ethical dilemma that this issue raised in his practice. Discussing the case of a young man suffering from lupus vulgaris, he said:

*Now, the patient's attendants want you to tell the patient that he will get well. I'm not sure what the outcome will be. He is now extremely ill. If he gets over this phase, then he will become alright. I do not know whether he will. The truth is I do not know. The patient's relatives and also my own feeling is if I hold out hope and tell him that he is going to get completely well, then the chances of his getting over his depression and beginning to cooperate with the treating team is going to be better. His compliance is going to be better. So, I've to make a choice between those two, and I find it difficult to take the decision. Generally, I do not like to tell people that there is hope, when I do not really think so. But I make an exception in some cases, and I do tell them that they will get well* (Dermatologist, male).

We also saw in the section on information management that clinicians in the field sites showed sensitivity to the psychological trauma of patients and families, especially in cases of life-threatening conditions. We saw how the physician's assessment of the patients' mental capacity played a crucial role in the communication of a cancer diagnosis to patients. In some cases intellectual and emotional capacities were given equal importance in the decision to communicate such a diagnosis. Thus, a doctor at the Myanmar centre said in this regard:

*It depends upon the person. In cases where the educational status is high, and he can accept the real situation, we should tell the patient. For example, in cases of early breast cancer, most of the patients suspect that they were suffering from cancer. In the latter part of the treatment plan, not only do they get operated, but they also have to undergo chemotherapy or radiotherapy. Although we did not tell the patients in these cases, they would know about their real situation. So, in this sort of cases, we should tell the patient from the very beginning. But patients who are mentally weak or whose*

*educational status is low, may not follow the treatment plan. For such patients, we do not tell the diagnosis* (Physician, Male).

While mental illness and mental retardation are widely accepted criteria of defining impaired autonomy, using assessment of the patient's mental capacity to withstand the stress of the disease process and treatment as yardstick for communicating information and making decisions carries important implications for the concept of patient autonomy. It is not only that decisions can be made on behalf of mentally disturbed and mentally retarded individuals by doctors and their families, but the same analogy seems to be used in the case of assessment of patients' emotional capacity and educational level.

## Age and gender in patient assessment

Intertwined in this assessment grid is attention to two other factors, which are also significantly positioned in the overall assessment of patients, namely age and gender. Table 15 depicts the indexing frequency of assessment of age and gender in the different research centres.

*Table 15:* **Pattern of indexing of "age and gender" by centre**

| | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
| | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** | |
| **Age** | | | | | | | |
| INT | Low | Very High | Medium | Medium | Medium | Very High | Low |
| TXT | Low | Very High | Low | Medium | Low | Medium | Very Low |
| **Gender** | | | | | | | |
| INT | Very Low | Very High | Very Low | Low | Medium | Low | Low |
| TXT | Low | Very High | Very Low | Very Low | Low | Very Low | Low |

Assessment of age and gender of patients occurs most often at the India centre. Assessments of both these criteria are less often made at both the Bangladesh and Indonesian centres. At the Sri Lanka centre, there are more discussions on age than gender.

Two restrictions need to be placed on examining the role of age and gender in patient assessment. Firstly, age and sex play an important role in the natural history of diseases, such as the higher incidence of osteoporosis in post-menopausal women or the greater occurrence of cardiovascular disease in men than women. These differences are an integral part of the medical assessment of the patient. However, many interviewees referred to the existence of strong status hierarchies based on age and sex in the Region. It is the latter theme, which we will focus on in this section.

*Role of age in patient assessment*

It was observed that interviewees, in the main, expressed greater sympathy when discussing cases of babies and young children. A gastroenterologist said that he felt unhappy when he had to do endoscopic examination of children, because of the discomfort caused to them by this diagnostic procedure.

While some doctors said that they preferred to disclose a cancer diagnosis to adult patients, others said that they did not convey such information to very old patients. Age was also cited as an important criterion by a number of doctors in choosing between various treatment options, i.e. conservative treatment over surgery in the case of geriatric patients. The following excerpt from an ENT specialist at the India centre shows how age emerges as an important criterion in clinical decision-making:

*I will have many factors in mind. Number one, both of them are cancer patients. If not treated in time, they will progress. And I presume that both of them are curable also, in the sense they are in a stage when surgery is possible and the entire tumour can be removed. The first priority I would give to a person, who is in the earning age group. Like twenty, thirty or forty years' age group. If he is compared with a person who is seventy years old, I will still give priority to a person who is still very important for his family. So, the first priority goes to him* (ENT Doctor, male).

The age of the patient was also a factor in end-of-life decisions. A few doctors gave examples of cases of very old terminally ill patients, who chose to discontinue treatment in the hospital, in order to go home and pass their last days in peace with their families. One physician said that he had conceded to the wishes of a very old cancer patient to discontinue the treatment, because both the patient and his family wanted to go home, where he could die in peace. These cases point to the operation of the principle of patient autonomy, where the clinician is respecting the wishes of the patient to refuse any further medical treatment, which might bring him short-term relief.

*Role of gender in patient assessment*

Discrimination against women was cited as an important factor responsible for their poorer health status in comparison to men. The greater investment of families in the health of male children was repeatedly mentioned. This issue was raised by some interviewees in the context of women's limited access to antenatal care. Physicians also noted the greater tendency of families to channel their limited resources in the treatment of the breadwinner, which was most often a young male over other family members. For instance, one urologist noted that in the case of renal transplant, he often came across situations where the wife was willing to donate her kidney for her husband, but not vice versa. He said that he had also not observed parents donating a kidney for a child. It is not only individual families which exercise such gender and age-based preferences, they may also enter clinical decision-making as seen in the treatment of a male patient from a very poor family in the following excerpt:

*We took a conscious decision that this boy is precious. Why is he precious? He is the only brother to six sisters. He is 12 years old and youngest to his sisters. We felt that he had a very fair chance of making it, if we could organize money for him. Now, in this particular situation, we organized money. Obviously, there was lot of luck. Well, we are going to send him off. You can say this is not a dilemma. Where is the dilemma? To me, there is a dilemma. I can't do this for every patient. And I'm sure that 30% or 40% of the patients who come to us definitely require financial assistance. How much do you do and for whom do you do? That is the dilemma* (General Surgeon, male).

The role of gender in the context of the physical examination of female patients has already been discussed in the section on doctor-patient interaction: other aspects earlier in the report.

Some respondents also discussed the social and psychological consequences of infertility on the lives of women. A couple of interviewees cited cases when a termination of pregnancy was medically indicated, but the patient chose to go ahead with the pregnancy because of the immense familial pressure on her to bear children. Failure on this count could have the effect of her being thrown out of her marital home. The theme of marriage influenced clinical decision-making in the case of young female patients. One doctor discussed the negative consequences of abortion on the future reproductive health of an unmarried pregnant woman. Cosmetic considerations were discussed by a few dermatologists in the treatment of young unmarried women.

Gender also emerged as a factor in interviewees' choice of case illustrations. There was a strong relationship between sex of doctor and sex of patient chosen for discussion. While female doctors almost exclusively discussed female cases, male doctors discussed both female and male cases, with the majority being male. Furthermore, when either male or female interviewees raised the issue of gender the theme was often discussed exclusively in connection with female patients (two-thirds of the cases). Also, there was a close relationship between the themes of social harm and gender. Female interviewees cited more cases of social harm than their male counterparts, whereas male doctors discussed cases of social harm equally often, irrespective of the gender of the patients. When it came to discussions on doctor-patient interaction, female interviewees used female and male case illustrations more or less equally; male doctors referred to more female cases in discussing this topic.

Thus it appears that gender was an important variable not only in patient assessment; it also influenced the choice of patients for case illustration during the interviews, perhaps pointing to more ethical dilemmas in some gendered doctor-patient combinations compared to others.

While proxy consent is a well-recognized procedure in the case of children and very old persons, the role of gender in shaping ideas of patient

autonomy have not been adequately examined. What are the implications of discrimination against women and girls in most spheres of life, including health care, on the health choices and options made available and actually exercised by them? These issues need to be examined from a gender-sensitive perspective.

# Physician responsibility

In the process of analysing the interviews, it was found that in framing their ethical dilemmas, respondents were generally self-reflective about their moral duties as responsible professionals. This concern led them to reflect upon their responsibilities to their patients and to their profession. Participants' reflections upon their functions as teachers and researchers are discussed in the context of informed consent and research ethics in Part One and teaching responsibility in Part Two. In this section, we will focus on how interviewees, as physicians, viewed their responsibilities to their patients. Physician responsibility was discussed by the respondents in the context of such topics as saving life, doing harm, doctor-patient interaction, withholding confidential information, patients' rights, treatment refusal, etc. The following table shows the pattern of indexing of physician responsibility by centre.

*Table 16:* **Pattern of indexing of "Physician Responsibility" by centre**

| | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
| | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** | |
| INT | Low | Low | Very high | High | High | None | High |
| TXT | Very Low | Low | Very High | High | Very low | None | Medium |

The table shows that discussions on physician responsibility were the most frequent at the Indonesian centre, high at the Myanmar centre and comparatively low at the other centres, except Sri Lanka, where there was no discussion on this theme. Furthermore, it was found that, while physician responsibility was discussed in Myanmar primarily in the context of

withholding information and patient's rights, discussions at the Indonesian centre focused more on physician responsibility in relation to professional practice.

In discussions of their duties as physicians, participants were emphatic that their basic duty was to provide effective and timely treatment to patients. In the context of the doctor-patient relationship, participants affirmed that they were duty-bound to save life and prevent harm from coming to patients. Describing a case of a divorced pregnant woman, a gynaecologist said that she lied to the patient's family about the pregnancy taking into consideration the best interest of the patient, which she regarded as her primary responsibility. She said:

*There's a lot of difference between what we were taught and what we actually do. In so many cases, you have to leave aside the theory aspect and you have to think of the social problem and the ethical problems we face. So many times we have to tell a lie. According to the oath of Hippocrates, you are not supposed to lie. But then, for the patient's well-being, there are many situations when not only me, but other doctors also lie; so for the patient's sake we have to lie* (Gynaecologist and Obstetrician, female).

Even though the role of the family in all aspects of medical treatment and management was repeatedly underscored by respondents, it was pointed out that when there was a conflict of interests between the patient and his family, it was the welfare of the patient, which was the primary responsibility of the physician.

However, this does not imply that the wishes of the patient were not taken into account. For instance, a doctor recounted the case of a patient, who refused to undergo an amputation, even though the intervention was a life-saving measure. The treating physician expressed some uncertainty regarding the best course of action under the given circumstances. He said:

There are two aspects, which I consider to be important with respect to the right of the patient, or his autonomy to determine what is to be done for him. One thing is that he did not want to be amputated. It is his right that we must pay respect to. On the other hand, we have the reason that in order to save the patient's life, we must undertake that intervention. Which one should take precedence over the other, if there is a clash between two, is the question (Orthopaedics Specialist, male).

The issue of physician responsibility was discussed by a number of interviewees in connection with withholding confidential information from the patient even though there was a consensus that this violates the patient's right to information and exercise choice in treatment. Describing the ethical dilemma in this regard, a physician at the Myanmar centre said:

*The patient must know the actual situation about his disease. I should tell about his disease and its prognosis and probable outcome. Although the patient was suffering from cancer, we did not tell him about the disease, because we were afraid that his mental state would be weakened. Furthermore, we were afraid that he would not follow the treatment plan, if he knew about his disease. The patient has the right to know his diagnosis, but we did not tell the diagnosis, and thus the ethical issue arose* (Physician, male).

The discussion of physician responsibility and patients' rights was posed in terms of the classical conflict between is and ought. While participants agreed that there should be discrimination in the treatment of patients on grounds of their economic status or educational level, yet many patients were given suboptimal treatment because of their financial incapacity. Similarly, although several doctors discussed the right of the patient to terminate treatment, yet the psychiatrists did sanction the involuntary hospitalization of mentally ill and substance-dependent patients at the behest of their respective families.

Some doctors said that they were perplexed at what they should do, when it came to seeing patients outside practice hours for minor problems. Criticising the tendency of some patients of assuming that the doctor can always be contacted, a doctor justified his decision to refuse routine cases when he was on vacation. He said that as a doctor, he was also entitled to his leisure.

Physician responsibility was also discussed in connection with the doctor-doctor relationship. It was raised by one doctor in connection with the practice of having a substitute physician, when the treating physician was on leave. He posed the question of primary responsibility to the patient i.e. who was responsible for the patient's health during the period of absence: the substitute physician or the original treating physician. This doctor was of the view that the patient has the right to reject the substitute physician.

# Summary

The following summary presents the main themes covered in Part One of the report topic-wise. This summary should not be looked at as a sum of concrete results or findings, but should be read more in the nature of inferences arrived at through a process of indexing of a set of qualitative interviews. The purpose of presenting this synoptic view is to simply facilitate discussion, and indicate major areas for future research.

### *Patient autonomy*

Patient autonomy in the interviews was most often related to issues of information management in the doctor-patient relationship, i.e. informed consent, withholding confidential information and disclosing confidential information to third party.

### *Informed consent*

This concept was critically examined in the interviews both as a theoretical construct and as applied in routine clinical practice. Physicians' assessment of patients, the demands of patients' families and the institutional constraints on practice were the main parameters within which informed consent was discussed by interviewees. The idea of family informed consent was proposed. The need was underscored for implementing formal procedures of informed consent, which were both in consonance with international guidelines and sensitive to the specificity of the Region.

### *Informed consent and research*

Some interviewees highlighted the difficulties involved in operationalising criteria of informed consent in the context of clinical research. Communicating experimental risk was perceived to be especially difficult to illiterate and poor patients. A distinction was made between informed consent in the context of clinical trials and clinical care.

### *Disclosing and withholding information to third party*

The issue was discussed most often in communicating a serious diagnosis such as cancer. Physicians' choice to disclose or withhold such information was

influenced both by an individual assessment of the patient's psychological condition to receive such information, and the decision of the patient's relatives. While proxy consent is a well recognized concept in cases where the patient is legally incompetent on grounds of age, mental incapacity or other medical condition, a situation where the family takes decisions on behalf of a mature, mentally sound person appeared to be common in the SEA Region.

### Doctor-patient interaction -beyond information management

In addition to information management, other issues of ethical concern in the doctor-patient interaction from the physician's perspective were examined. These include the themes of saving life, doing harm and doctor-patient interaction: other aspects.

### Saving life

Physicians' concern regarding saving life came up more often in the interviews with regard to abortion and end-of-life decisions. It was also discussed in connection with treatment of terminally ill cancer patients. These discussions encapsulated a particular tension between physicians' moral duty to save life, a clinical context of practice characterized by resource constraint and observing respect for the right of patients to make informed choices.

### Doing harm

During analysis, three categories of harm, namely physical harm, mental harm and social harm, were identified.

### Physical harm

A number of factors were mentioned by interviewees, which threatened the physical health of their patients. Physical harm was mainly discussed in connection with treatment and prognosis. Thus, the side-effects of medication, over-medication, adverse reactions to drugs, invasive diagnostic procedures and inadequate sterilization of medical equipment, were some of the issues raised by the respondents.

*Mental and social harm*

Mental and social harm refer to physicians' perceived harmful consequences of the disease on patients' mental state and social situation. They were discussed most often by respondents in connection with treatment of psychiatric patients, diagnosed cases of leprosy and HIV/AIDS and infertility. The issue of social and mental harm was also tied to disclosing information to third party.

*Doctor-patient interaction*

Other Aspects: Some of the more frequently mentioned facets of the doctor-patient interaction, excluding issues discussed under saving life and doing harm, were examined. Age and gender emerged as important themes in this regard.

*Physicians' emotional reaction*

Many interviewees showed themselves to be emotionally moved by the predicament of their patients, and this was perceived to exert an influence on clinical decisions. The expression of emotions on the part of participants contests the stereotype of the doctor as an impersonal professional. Respondents expressed a whole gamut of emotions, in connection with patient care ranging from pity and guilt to satisfaction and anger.

*Assessment of patients*

Respondents' descriptions of their ethical dilemmas were intertwined with their assessment of patients. During analysis, six criteria of patient assessment were identified, *viz.*, economic capacity, social support, intellectual capacity, mental capacity, age and gender.

*Economic assessment of patients*

The economic factor was seen to be playing a predominant role at two complementary levels. It was an important criterion in physicians' assessments of patients, and it was the most important determinant of patients' access to health services. Poverty was adjudged to be a major barrier to obtaining

optimum treatment. Economic assessment of patients was discussed in the context of prescribing investigations and drugs. The issue also came up in connection with expensive treatment, such as organ transplant and rehabilitation of disabled persons. Interviewees strove to strike a balance between patients' economic status, optimum treatment and contextual constraints on practice.

### Assessment of social support of patients

The patient's immediate family emerged as the most important and influential determinant of the patient's social support system. The role of the family in treatment was discussed in a range of situations, especially in connection with psychiatric treatment. The assessment of the patients' social support system framed both the evaluation of the patient's medical condition and the formulation of the treatment plan.

### Assessment of intellectual capacity of patients

The educational level of patients was perceived to be an important factor in judging their capacity to understand diagnosis, investigative and treatment procedures. This issue carries important implications for the informed consent procedure in the case of illiterate patients. The importance of educational level for issues of person autonomy in clinical practice warrants more attention.

### Assessment of mental or emotional capacity of patients

The stressful consequences of illness and hospitalization on patients and their families was discussed. The psychological status of patients was perceived to be an important factor in judging their capacity to receive information about their disease condition, such as a cancer diagnosis, and to be able to participate in informed consent procedures. While mental illness and mental retardation are widely accepted criteria of defining impaired autonomy, using assessment of the patient's mental capacity to withstand the stress of the disease process and treatment as yardstick for communicating information and making decisions carries important implications for the concept of patient autonomy.

### *Age and gender in patient assessment*

Status hierarchies associated with age and gender in the context of clinical decision-making were highlighted.

### *Age in patient assessment*

A number of examples were given by respondents, which showed that diagnosis and treatment of young children and very old persons were influenced by patients' age. The issue came up for discussion, especially in the context of information management, resource allocation and end-of-life decision.

### *Gender in patient assessment*

Gender was an important variable not only in patient assessment, but it also influenced interviewees' choice of patients for case illustration in the interviews. Gender was discussed in the context of a range of topics, such as social harm and doctor-patient interaction. While proxy consent is a well-recognized procedure in the case of children and very old persons, the role of gender in shaping ideas of patient autonomy have not been adequately explored. What are the implications of discrimination against women and girls in most spheres of life on the health choices and options made available and actually exercised by them? These issues need to be examined from a gender-sensitive perspective.

### *Physician responsibility and patients' rights*

Participants were self-reflective about their duties as responsible professionals. This issue was discussed by interviewees in connection with such topics as saving life, doing harm, doctor-patient interaction, withholding information and patients' rights.

Part 2:

Access and Equity in Clinical Practice

While the principles of beneficence and non-maleficence establish affirmative duties on clinicians and researchers to maximize benefits and reduce risks, the principle of equity or justice requires that human beings be treated equally, unless there is strong ethical justification for treating them differently. However, in the face of unequal distribution of material resources and the existence of strong hierarchies of power and influence, it is very difficult to operationalize these principles.

In the area of health care, justice may simply be defined as universal coverage of health services, according to need. This operational definition is based upon the recognition of health as a basic right of people. The claims of justice and equity take on special significance in a situation characterized by vast need and great scarcity. It is these concerns which are examined in this part of the report, namely, how clinicians balance patients' demands for treatment under conditions of resource constraints. The discussion will be arranged in terms of two broad issues:

- ➢ Identified Access Factors
- ➢ Barriers to Delivery of Optimal Treatment

## Identified access factors

In the process of analysing the interviews, the following five access factors were identified as influencing the nature and course of treatment. These are:

- ➢ Access Factor: Economy;
- ➢ Access Factor: Network;
- ➢ Access Factor: Distance;
- ➢ Access Factor: Time, and
- ➢ Access Factor: Fairness .

In the discussion of each of these access factors, it will be noted that they are being discussed by the interviewees from two complementary but distinct perspectives. One focus of the discussion was the institutional constraints on clinical practice in terms of paucity of medical equipment, facilities and manpower, which adversely affects the quality of health services. The other focus of the discussion is on the limitations stemming from the social and economic conditions of existence of patients and families, which affect their health-seeking behaviour and treatment options. For instance, network as a factor of access refers to situations where some patients are at an advantage in the public hospital, because they are either relatives or friends of hospital staff, or of higher socioeconomic status. Consequently, patients, who have such contacts, may be seen out of turn and have longer consultations with doctors in comparison to other patients, who are not so well connected or well placed. Living at a distance from the health care facility may also impose constraints on accessing medical services by patients living in far-away rural areas. Time as an access factor is used to refer to interviewees' perceived work pressure, which prevents them from providing adequate individualized attention to patients. Fairness refers to those situations, wherein clinicians delineated ethical dilemmas that challenged their notions of fairness. How these access factors pose ethical concerns will be discussed below.

Table 17 presents a broad picture of the centre-wise indexing frequency of these various access factors.

*Table 17:* **Pattern of indexing of various access factors by centre.**

| Variation Among Centres | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | Overall freq. |
| Economy | | | | | | | |
| DOC | Medium | High | Very High | High | Low | Low | High |
| TXT | Medium | Medium | Very High | Medium | Low | Low | High |

| Variation Among Centres | | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | Overall freq. |
| **Network** | | | | | | | |
| INT | Low | Very High | High | Low | High | None | Very Low |
| TXT | Medium | Low | Low | Very Low | Low | None | Very Low |
| **Distance** | | | | | | | |
| INT | Medium | High | Medium | Low | Very high | Very Low | Low |
| TXT | Low | Low | Very Low | Very Low | Medium | Very Low | Low |
| **Time** | | | | | | | |
| INT | Low | Very High | Medium | Very Low | Low | Medium | Low |
| TXT | High | Very High | Medium | Low | Very Low | Medium | Low |
| **Fairness** | | | | | | | |
| INT | Very Low | High | Low | Low | Medium | High | Low |
| TXT | Very Low | Low | Very Low | Very Low | Very Low | Medium | Low |

The table shows that economy was the most frequently indexed access factor, accounting for over 70% of total access. Network was a major topic of discussion at the India, Indonesia and Nepal centres, but was not discussed at all at the Sri Lanka centre. Distance as an access factor was frequently discussed at the India and Nepal centres and moderately so at the Bangladesh and Indonesia centres. Time as an access factor was discussed more often at the India centre, while fairness was overall relatively low on the agenda in the interviews, though more frequently discussed in Sri Lanka and India.

### Access factor : Economy

Economy was the most frequently indexed access factor at all the centres. The poverty of patients compelled clinicians to scale down the required investigative procedures; treatment regimens have been discussed in the section on economic assessment of patients. The issue of economy, however, also came up in discussions on many other topics as well.

Discussions on economy as an access factor were framed by contextual constraints on practice. Interviewees pointed out that in many cases, a substantial cost of treatment in government hospitals was borne by patients due to chronic shortages of equipment and long waiting lists. A couple of doctors also discussed how the chronic shortage of blood in the hospital at times forced them to use blood of doubtful quality obtained by the family commercially. A few participants at the Myanmar centre said they were sometimes forced to resort to a surgical intervention in the case of orthopaedic injuries as the hospital could not provide the treatment of choice, i.e. a prosthesis to the needy patients. One orthopaedic surgeon explained how he tried to balance the demands of treatment efficacy and economic feasibility. He said:

*I have four cases. They are all cases of fractured neck of femur. Some people are in a position to buy the prosthesis, which costs here about sixty thousand Kyats, but for others sixty thousand is too large a sum of money. So, actually I would like to put the prosthesis for every case of fractured neck of femur in cases of old patients. But for those who can't afford to buy the prosthesis I have to excise the head of the femur. That is what we call excisional arthroplasty, which is painless, but it is not very strong, not stable. Prosthesis is the best treatment option. But due to their economic problem, I have to do the excisional arthroplasty in these cases* (Orthopaedic Surgeon, male).

Some paediatricians said that they felt especially uncomfortable when they informed poor parents about expensive treatment options, such as interferon enzyme replacement therapy and growth hormone therapies treatment for children suffering from genetic disorders. These doctors said that they were torn between their moral duty to provide reliable information, while knowing fully well that they were increasing the trauma of parents, who would not be able to avail of such expensive treatment options for their children.

Many clinicians pointed out that not only were patients and their families forced to bear a bulk of the costs of investigative procedures and medicines, but they also had to incur other expenses in the course of hospital treatment. Cost of transportation to the hospital, accommodation, especially of family members accompanying the patient, food, etc. all had to be borne by individual patients and their families. The expenditure was all the greater for out-station patients and their relatives.

In view of the economic limitations on optimal treatment, interviewees underscored the need to enhance provisions for needy patients. Making available investigations and medicines at subsidized rates, if not entirely free of cost for poor patients, was reiterated, especially by participants at the Bangladesh centre. Several respondents from the India centre said that low-cost gadgets for the disabled, such as those suffering from paraplegia and cerebral palsy, should be made available on a larger scale. The need to enhance welfare facilities such as increasing financial allocations for hospital welfare funds was emphasized by some interviewees. Other participants suggested greater effort should be made by hospitals to obtain donations from charitable organizations. Some doctors called for more systematic networking between hospitals and non governmental organizations. These recommendations become all the more important in a situation where the state is not capable of adequately financing the health care system.

Economy was also discussed in the context of private practice. Some doctors pointed out that patients should be given a clear breakdown of costs for various medical procedures in advance to enable them to make rational choices about the treatment options available to them. Some doctors questioned the practice in some hospitals of charging different rates for similar procedures, depending on the capacity of the patient to pay. This issue was discussed in the contest of cross subsidy, i.e. use resources for the financially unable, which are originally meant for the financially able. Other doctors questioned the practice of company patronage, i.e. promoting drugs produced by a particular company. It was repeatedly stated that, while striving for a decent income is legitimate, doctors should not become businessmen.

Economy was the most frequently indexed access factor at all the centres. Discussions on economy were framed by contextual constraints on practice. Shortages of medical supplies and facilities prevented doctors from

providing optimal treatment to patients, who had to bear the major burden of cost of investigations and medicines even in the public health system. Recommendations were made to increase resource mobilization for the public health sector. Economy was also discussed in the context of private practice.

## Access factor : Network

Patients' social network was found to exert an important influence on the delineation of clinicians' ethical dilemmas in the area of patient's access to treatment. Network influence on treatment and on priorities seemed to vary a lot from centre to centre, being an issue in some centres more than in others (Table 17).

Several doctors pointed out how they were often compelled to see patients out of turn because they were related to colleagues or other hospital staff. Some physicians expressed discomfort at having to oblige their colleagues at the expense of other patients. The ethical dilemma around this issue was described by a dermatologist as follows:

*I do not know if it's an ethical problem, but certainly it disturbs me, sometimes more than at other times. It troubles me that there are people, who have been waiting to see me for two to three hours, and there are others who want to be seen right away. Now, that's a big dilemma. Sometimes, they will come along with the people you cannot say no to. And so you push that ethical dilemma aside in favour of friendship or a colleague and see the patients straight away, as soon as they walk in. But there are others who will give you a number of reasons for wanting to be seen right away. And the reasons range from being somebody important in an office, having to go to catch a bus, or having children alone at home. There is a dilemma here between somebody, who is making out a case for being seen immediately, and the desire to stick to the queue. Just because somebody can walk in and tell you why they need to be seen immediately, you should not punish those who cannot walk in and tell you why they need to be seen immediately, though their need may be as much as or even greater. There are times when you have five or six patients related to staff members to jump the queue, then it can interfere with the functioning in the OPD, because you are doing something*

*you don't want to do. While trying to provide patient care, I know how much stress that causes, because when I have finished with those five or six patients, then I am so much more comfortable in dealing with the rest of the OPD* (Dermatologist, male).

Several physicians accounted for this practice in terms of professional etiquette. A physician explained the situation as follows:

*The thing is this; when some of our colleagues come to us with their dependants, they always wants help from us. And it is nationally and internationally accepted that the dependants are supposed to get help from us. This is our professional etiquette. So, depending on that, I usually follow this, but at the same time I make sure that the other patients do not suffer. Rather, I try to help both the other patients and my colleagues' dependants* (Urologist, male).

In the context of private practice, some doctors also said that professional etiquette demanded that relatives of colleagues be provided treatment at reduced costs or entirely exempted from paying fees.

It is not only that network factors increased access to treatment for some. Sometimes they could intervene in medical decision-making to the detriment of the patient. For instance, one physician recounted the case of a patient scheduled to undergo amputation, whose family managed to convince some senior hospital functionaries to cancel the operation. Subsequently, the patient developed gangrene and had to undergo emergency surgical intervention a short time later to save his life.

Thus, patients' social network was perceived to exert an important influence on the delineation of clinicians' ethical dilemmas in the area of patient's access to treatment. Network factors were most often discussed by interviewees in the context of treatment of patients connected with hospital staff and dependants of colleagues.


## Access factor : Distance

The centres in this study are all tertiary-level health facilities situated in urban areas. These centres cater to a large patient population, including many

patients from rural areas and small towns. Consequently, distance was identified by a number of interviewees as an important issue in relation to access. Some respondents pointed out that patients from rural areas came at a much later stage of the disease than their urban counterparts. Furthermore, follow-up was also reported to be more difficult, as the dropout rate was higher among out-station patients. Some respondents said that they felt particularly unhappy when they had to refuse admission to a seriously ill patient coming from a far-away area due to the non-availability of a vacant bed.

There was dovetailing of various sources of access, such as economy and distance. People coming to access health services in the cities are, by and large, of a low socio-economic status. Furthermore, they also have to incur other overhead expenses on transportation, accommodation and food, when coming for treatment to the city. For instance, in connection with the treatment of a glaucoma patient coming from out of the city, an ophthalmologist at the Nepal centre said:

*I have a child with congenital glaucoma. We diagnosed the case, picked him up, and admitted him. He has had surgery in both eyes. And now we want to send the child away. We would like to see the child two months later. The mother says she cannot come. So, that presents certain ethical problems. They don't have enough money to stay here in Kathmandu. But we need to see the child. There is a problem whether to let the child go and let him be seen by somebody else nearer home, or keep the child here, which will put the parents into difficulty. As far as the child is concerned, he is receiving free treatment, free food. But the parents; they do not have sufficient money to live in Kathmandu, and Kathmandu is an expensive place. So, that's the kind of difficulty we face* (Ophthalmologist, male).

A couple of physicians described cases of seriously ill patients, who could not avail of treatment facilities made available to them free of cost, because they could not come to the hospital on a regular basis. For instance, an oncologist at the Indonesian centre cited the case of a twelve-year-old boy for whom he had been able to get a donation for treatment from the National Cancer Foundation after a great deal of effort. But this child could not come for treatment, because his family could not bring him on a continuous basis as they lived far away from the hospital.

Being tertiary-level health care facilities situated in urban areas, the centres in this study cater to a large patient population, especially patients from rural areas and small towns. The difficulties of outstation patients in accessing health services at urban hospitals and the impact of distance on providing optimum treatment to such patients were discussed.

## Access factor : Time

Many doctors lamented that their busy schedules did not allow them to spend enough time with patients. One urologist described the case of a patient in the ward, who had requested to speak to him; but before he could find the time to go to her, she died. Interviewees pointed out that since they could not spend beyond a few minutes with each patient, they could not in most cases engage in a detailed evaluation and counselling of individuals patients. As one psychiatrist explained:

There are too many patients and not enough time. So one is bound to follow the most feasible approach within the short time. Suppose we have only ten minutes time with the patient, then obviously on top of the agenda is the actual medical treatment rather than other issues. So, shortages of manpower as well as the doctor's time are quite important in making decisions. We need more time, if we want to look after patients, not only medically but also ethically correctly (Psychiatrist, male).

Just as a relation was observed between various contextual features, such as inadequate hospital facilities, and the access factor economy, there was also a relation between time and inadequate manpower in the interviews.

In addition to not having enough time for OPD and ward consultations, interviewees also pointed to other situations that resulted in treatment delay. Coordinating with colleagues in the context of multidisciplinary treatment, getting results of investigations and making medicines available to patients on time were perceived to be time-consuming tasks.

Many physicians were sensitive to the fact that patients had to spend a lot of time, when coming for treatment at public hospitals. It was realized that this adversely affected their income, since time in the hospital was for many patients and family members time away from work. This was also cited as a

major factor contributing to patients dropping out of treatment. It was also pointed out that long waiting queues for investigations and operations were major sources of frustration for patients and their families as well as for treating physicians. In view of these time constraints, some interviewees underscored the need to develop an effective appointment system and to streamline referrals.

In general, interviewees lamented that their busy schedules did not allow them to spend enough time with patients. Furthermore, some respondents put recommendations forward to improve time management in hospitals.

## Access factor : Fairness

In their discussions on medical ethics, most interviewees reflected on issues of fairness and equity in clinical decision-making. In the face of scarcity of resources, which patient gets what, and how much, were major concerns. Many examples were given to illustrate actual practices, which were seen as ethically indefensible.

We have already discussed the roles of age and gender in determining the distribution of scarce resources. The issue of fairness was also raised in connection with saving life, especially with regard to end-of-life decisions and blood transfusion. Many doctors pointed out that they felt it was unfair to give substandard drugs or refuse treatment just because the patient could not afford the optimum treatment. Other interviewees highlighted institutional barriers, saying that it was unfair to turn away patients for want of an empty hospital bed. Some respondents said that they also thought it was unfair to conceal the diagnosis from patients.

Two criteria emerged as central, when it came to choosing among patients who would be provided the limited treatment facilities. One criterion was that the patient whose need was perceived to be greater, should be given priority. Secondly, the patient, who would stand to benefit more from the intervention, should have a higher claim to it. These two principles were often in conflict, as seen in this example from a rehabilitation specialist at the India centre:

*Due to constraints on the number of beds in the ward, we have to make a couple of decisions, which bother us ethically. One is that, in case we have two patients but we have only one bed, we tend to look at that person in whom we can have a better outcome, a better result. For instance, we had one patient of quadriplegia and another patient of paraplegia. If I look at both the conditions from the patients' point of view, quadriplegia is a more serious condition, because both the hands and the legs are paralysed. Paraplegia is relatively less grave from the point of view of the patient. However, if we look at it from the other point of view, in terms of the amount of work, the number of hours we put in, we will be putting in less labour and getting better results in paraplegic; and more labour and not so good results in quadriplegia. So, we have to make a choice, who should be admitted on one available bed. From the logical point of view, we say we should aid those persons who get more benefit. So, we admit a paraplegic rather than a quadriplegic. Though from the patient's point of view, our decision is questionable because a quadriplegic patient needs much more treatment. This is again one of the problems, which I think would be bothering a number of people. So, ethically what is right and what is wrong are big questions* (Rehabilitation Specialist, male).

## Barriers to treatment

In the above discussion, it was found that there were many obstacles to the delivery of optimum treatment. It was found that the execution of the optimal treatment regimen could be subject to a number of hindrances. These obstacles could either stem from the side of the health care provider or from the side of patients or their relatives. These hindrances could either result in the delivery of suboptimal treatment, or in some cases, no treatment at all. These themes will be discussed in this section under the following broad topics:

➢ Barriers to Treatment from Health Services Providers' Side

➢ Waiting List

➢ Suboptimal Treatment

➢ Barriers to Treatment from Health Services Users' Side

Some of the barriers to the delivery of optimum treatment have been discussed in the context of various sources of access. The access factor of

economy was most frequently associated with barriers to the delivery of optimum treatment. This is not surprising, given the salient role assigned by interviewees both to the paucity of resources in the provision of health services and the overwhelming poverty of patients. Scarcity of time was also identified as a barrier to the provision of effective treatment, especially in connection with long waiting periods.

## Barriers to treatment from providers' side

Table 18 presents the relative indexing frequency, by centre, of various obstacles to optimum treatment from health care providers' side.

*Table 18:* **Pattern of indexing of "barriers to treatment from health care providers' side" by centre**

|  | Variation Among Centres | | | | | |  |
|---|---|---|---|---|---|---|---|
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** |  |
| INT | Medium | Very high | Medium | Low | High | Medium | Very High |
| TXT | Very High | Very High | Medium | Low | Medium | Medium | High |

References to barriers to treatment from health providers' side appeared in a substantial number of interviews at all the centres, except Myanmar. On the other hand, the theme was a major topic of discussion at the India centre, followed by Bangladesh.

A majority of interviewees were of the opinion that the major obstacles to the delivery of effective treatment were shortages of manpower, medical equipment and facilities in the hospitals. Refusal of admission to patients due to non-availability of vacant beds was mentioned by a large number of interviewees. Interviewees also highlighted the strategies they had developed to cope with these problems. A few respondents, for example, said that, if an OPD case could not be admitted through the normal hospital admission procedure, then they admitted the patient through the emergency, if they felt that the patient did indeed require hospitalization. Some participants said that

they sometimes discharged old cases, whom they felt were well enough to be managed at home, on admission day, so that beds could be made available to incoming patients, whose need for hospitalization was perceived to be greater. Many doctors said that they were especially troubled, when they had to refuse hospital admission to a patient in need of emergency treatment for the simple reason that there was no available vacant bed in the ward. Under these circumstances, interviewees pointed to two courses of action. Mostly, such patients were referred to other hospitals after being provided emergency treatment to ensure that they did not deteriorate on the way. For instance, violent psychiatric patients could be sedated before being sent to another hospital. This had the double effect of calming down the patient and making it easier for the family to transport the patient to another health care facility. Several doctors, however, said that they allowed patients to be accommodated on the floor in the ward, if a bed was not immediately available. A few interviewees said that accommodating two patients in a single bed was allowed in the emergency, depending on the nature of the case. Respondents pointed out that in their attempt to balance the competing demands of hospital facilities and patient care, they were often forced to deviate from established standard treatment procedures.

The factors influencing clinicians' decisions to discontinue treatment in the context of end-of-life decisions have already been discussed. For instance, in deciding to discontinue the treatment of a patient suffering from renal failure, a physician justified his decision on the following grounds:

*In the renal patient, I took a decision and that patient died. I'm happy, because that patient suffered for months and years. Now, I see the family members, who were also suffering, are living happily getting on with their business. When this patient was alive, the whole family suffered with that patient. I deal with lots of renal patients and their life is very pathetic. Slowly, they die. Their whole family, wife and children suffer because they don't have enough facilities to look after them: and we in the hospital also can't keep the patient for a long time. Then, we take this type of decision, and we give up treatment. After the patient's death, sometimes maybe six months later, you see that the wife and children get on with their life. The children are going to school, the wife is doing a job. Although they don't come out with their words, we feel that they are now living. Earlier, they were slowly dying with their patients. So, every day we are happy. This is a common incident* (Physician, male).

In another case, in which the prognosis was equally unfavourable, the treating oncologist was however, not so certain of the best course of action, as inferred from the following excerpt. He said:

*I have been seeing a patient for the last ten days. This patient has carcinoma. We are not sure where it is arising from. Six months ago when he was operated outside, the impression given by the surgeon to the patient was that there is some kind of a blockage in the intestine, which has been by-passed. Five months later, he came up with a lump in the abdomen and after that he developed jaundice. He has now come to us with a huge lump and jaundice. And now his main problem is the jaundice. Now, getting relief from jaundice is his primary concern. There are numerous options available but none of them is very safe; and none of them is of value on a very long basis. What I have been trying to work out is what is best for him. Should I leave him alone? I still don't have an answer. I probably will at the end leave him alone. Just explain to him and his relatives that medical sciences can do nothing for him now. But the dilemma is that should we go ahead and do some kind of intervention, which might help. On the other hand, it may kill. So, whatever months or weeks he has, we shorten that also. One could obviously argue the other way around and say he is going to die anyway. So, if he dies now or two or three months later, how will it make a difference? You are sure he is going to die anyway. Yes, I am sure he is going to die. No doubt about it. He has a confirmed cancer. It is not curable. It is not treatable. We all know about it. So, should you, should you palliate his symptom, and to what extent?* (Oncologist, male).

A few other doctors also said that they considered discontinuation of treatment in the case of cancer which had metastasised beyond hope, especially if the patient came from a very poor family, and could not afford the cost of chemotherapy.

It is not only in the context of saving life and end-of-life decisions that interviewees discussed the issue of stopping treatment. Some doctors said that they had chosen to discontinue treatment, when in their considered judgement, the available treatment regimens could not help the patient. For instance, a pulmonologist justified his decision to discontinue administering drugs to a tuberculosis patient on this ground. He said:

*I did not administer anti-tuberculosis medication anymore. Because all had been administered and all had failed. There were several criteria for not treating. Firstly, there was no medication, which was able to kill the resistant bacteria. If I kept administering, it meant that I just wasted his money. He was not a well-paid employee and also had dependents. Also, I had the impression that he did not work in a productive way anymore. That's what is happening in my heart: whether I have fulfilled the ethical principles or not. That's the problem I faced* (Pulmonologist, male).

Some other doctors said that they also found it difficult to decide whether to provide medical treatment to severely handicapped persons, whose real need was rehabilitation through psychosocial intervention rather than medication and hospitalization. In the absence of facilities to provide the more effective treatment, these doctors were in a dilemma whether to discontinue treatment altogether or not.

Similar dilemmas were also raised in connection with other debilitating conditions for which the treatment options were very few and of limited value. For example, some doctors wondered what was the best treatment strategy in connection with children suffering from severe congenital abnormalities like hydrocephalus and spinabifida. A few other respondents noted that their treatment options in case of a diagnosis of HIV AIDS were also limited in the absence of a system of pre- and post-test counselling and other psychosocial interventions.

Several psychiatrists discussed the issue of withdrawing from treatment in connection with specific cases. One male psychiatrist said that he had chosen to refer a female patient, who had developed a dependency complex on him, to a colleague. Another psychiatrist cited two situations when he felt compelled to refuse treatment of patients. One situation was of patients selling psychotropic medicines, which they took free of charge from the hospital, in the market. Secondly, he spoke of a case of an alcoholic patient, who regularly turned up in an intoxicated state at the community de-addiction clinic, and threatened the female staff.

Some participants pointed out that they were often confronted with situations, when patients or their relatives insisted on a more serious intervention than what they thought was clinically indicated. For instance,

some doctors said that they were at times forced to refuse mothers' demands for medicines for their children, who were suffering from common coughs and colds, for which no medicines were required. Similarly, some clinicians also said that they had to turn down demands for injections, which were considered by many patients and families to be the ideal form of treatment in the hospital, more efficacious and rapid in action than pills and syrups.

A couple of interviewees said that patient care was at times pushed to the background, when their busy schedules compelled them to give priority to other duties, such as organizing seminars and conferences, taking classes, conducting examinations, etc.

The decision to discontinue treatment was not only discussed in the context of the welfare of patients and physician's responsibility. Some doctors discussed the dilemma they faced, when confronted by patients wanting a consultation outside of visiting hours, or when they (doctors) were on holiday. The doctors, who brought up this issue, said that although they did not like to refuse to see patients, they followed the practice of referring such patients to colleagues, if the case was not an emergency. These interviewees were of the opinion that while doctors should organize time rationally, patients should also show respect for the doctors' privacy, and not make unreasonable demands on them outside of practice hours.

Thus, it can be seen that a majority of interviewees were of the opinion that shortages of manpower, medical equipment and facilities in the hospitals formed the necessary (though not always sufficient) context for understanding ethical dilemmas in relation to barriers to treatment from the providers' side. Case illustrations of acute, chronic and life- threatening conditions were used to inform the discussion.

## Waiting list and treatment delay

Many interviewees pointed out how they were unable to deliver timely treatment because of delays in diagnosis and treatment. The relative distribution of discussions on treatment delay, waiting and waiting lists in the interviews is presented in Table 19.

*Table 19:* **Pattern of indexing of "Waiting and waiting list " by centre**

|  | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** | |
| INT | Medium | Very High | High | Medium | High | Very Low | High |
| TXT | Medium | Very High | Very Low | Low | Low | Very Low | Medium |

The issue of treatment delay is a commonly indexed topic at most of the centres in terms of the number of interviews in which it appears, with the exception of the Sri Lanka centre. However, it was discussed in more detail at only the India and Bangladesh centres, as seen in the TXT row in Table 19.

Interviewees pointed out that most patients often came to them in acute stages of the illness process and required speedy intervention. In addition to delays on the part of patients and relatives in accessing health care facilities, the existence of long waiting lists for hospital admission, investigations and operative procedures was identified as a major barrier to the delivery of optimum treatment. Some physicians pointed out that due to the long queues, the results of investigation could take months in reaching the doctor delaying the diagnosis and commencement of the appropriate treatment regimen. These respondents said that often they were compelled to bypass the hospital, and ask patients to get the investigation done from the market in order to start the treatment at the earliest. Other interviewees noted that operation theatres were often booked months in advance. This backlog of cases made it difficult to offer timely treatment, especially to emergency cases.

A paediatrician at the India centre summed up this ethical dilemma in the following words:

*You have more patients than you can accommodate in a given operating time on the number of beds available to you. And therefore you always have a long waiting list, and patients always spill over. Secondly, you have a situation when you've given dates for surgery one year ago, one and a half years ago. But if in today's clinic, I have a child, who is there for a routine surgery, for*

*example a surgery which can wait, but the child has been scheduled for surgery on that day. And at the same time, another child has come to me for the first time. He needs to be taken immediately for operation. Then, obviously the child who has been given the date earlier, but can wait, will have to be given another date. And the child, who requires priority treatment will be taken in, although he may not have been dated for that particular day. So, this again is a big problem (Paediatrician, male).*

Interviewees pointed out that prioritizing cases in the context of long waiting lists was a difficult task. Differentiating urgent from non-urgent cases was cited as an important criterion for prioritizing cases. Although they realized waiting for long periods in the hospital was a frustrating experience for patients, the respondents pointed out that they were also overworked. Some doctors said that, under the given circumstances, frayed tempers on both sides were a common occurrence, especially in the OPD.

The plight of patients being forced to endure the long queues for want of a more viable option, was summed up by a physician at the Bangladesh centre. She said:

*For two reasons I think it raises an ethical issue. One is that, many of those patients are waiting for last few months for admission. But unfortunately, we could not provide them a bed. As these patients are poor and unable to go in for surgery in a private clinic or hospital, they have to depend on government hospitals. On every admission day, they have to come and see whether an empty bed is available or not. I feel very uncomfortable to tell them again and again 'please come in the next week, I will try for your admission'. Most of these patients come from very distant places. It's troublesome and expensive for them to come every week (Physician, female).*

In view of the fact that patients have to spend a long time waiting in the OPD, a gynaecologist at the India centre suggested:

*If again there was a proper waiting area, where they could sit down comfortably, bring along some work, may be a book, may be a magazine, may be some knitting, then perhaps they will be able to wait patiently. But they are made to wait in a situation when there is so much overcrowding, standing in a squeezed waiting area. So, maybe it's hard for them to do that. Most often that is what causes the problems (Gynaecologist, female).*

The interviews revealed that long waiting periods were perceived to be a frustrating experience for patients and relatives. This also resulted in delays in both diagnosis and commencement of treatment. A physician at one of the centres suggested creating more user-friendly waiting spaces in the OPD for the convenience of patients and their attendants.

## Suboptimal treatment

Discontinuation of treatment from health care providers' side occurred either due to severe shortages of beds and other facilities or, alternatively, under what was perceived as exceptional circumstances. In contrast, suboptimal treatment was found to be a common treatment outcome. The barriers from both the providers' side and users' side had the effect of affecting the quality of treatment made available to the patient. Suboptimal treatment was discussed by interviewees both in the context of technical and ethical dilemmas. Table No. 20 shows the indexing of suboptimal treatment by centre.

*Table 20:* **Pattern of indexing of "suboptimal treatment" by centre**

|  | Variation Among Centres | | | | | |  |
|---|---|---|---|---|---|---|---|
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** |  |
| INT | Low | Very High | High | High | None | Low | Very High |
| TXT | Low | High | Medium | Very High | None | High | High |

Suboptimal treatment was overall very frequently discussed in the material. It was more frequently found at the India, Indonesian and Myanmar centres. The topic was not at all discussed at the Nepal centre, and very sparsely at the Bangladesh centre. However, even though it did not appear in a large number of interviews at the Sri Lanka centre, it was discussed at some length, whenever it was brought up by the interviewees.

One of the often cited reasons for early discharge of patients was the need to make the bed available to another patient, whose need was

perceived to be greater. For instance, a number of doctors said that they had to send home patients without allowing complete post-operative recovery, because of the need to have the bed vacated in order to make room for other patients. The shortage of beds also ruled out in many cases the possibility of keeping patients for observation in the ward, unless it was deemed absolutely necessary. This issue was brought up by respondents in the context of head injury and heart disease, since the sequelae of these conditions were not always immediately detectable.

Shortage of essential medical equipment resulted in delivery of suboptimal treatment. For instance, a doctor at the Sri Lanka centre pointed out that in the absence of blood products, he was forced to choose other forms of treating a cancer patient, which in his opinion constituted the second line of treatment. A couple of doctors also said that in the absence of dialysis machines, they resorted to peritoneal dialysis instead of haemodialysis.

Other participants said that even when patients were in the ward, the care that they received was not of the best quality, because hospitals simply did not have the manpower to provide good nursing care. Under the circumstances, the provision of such nursing care was the responsibility of the relatives.

Suboptimal treatment was also linked to cost of treatment by a large number of interviewees. The issue of using a less expensive investigation and cheaper drugs in the treatment of poor patients has already been discussed in sections on economic assessment of patients and access factors. Doctors reiterated that deciding on the best treatment option entailed striking a balance between costs and benefits in the context of the material constraints on practice and patients' financial incapacity. This is illustrated by an orthopaedic surgeon at the Indonesian centre in the treatment of a patient suffering from spondylitis in the following excerpt:

*If the first choice is surgery, which cannot be done, then we have to find an alternative. Even though it is the best, we take a second choice or alternative with the second best results or advantages. However, it suits the patient's conditions. It would be no problem because there are numerous alternatives available. Spondylitis must be treated with surgical intervention. Presently, the patient's condition does not permit. Perhaps because the equipment is too expensive, which the patient cannot afford, we resort to an*

*intervention without that equipment in the hope that it could cure the patient as well* (Orthopaedic Surgeon, male*)*.

Interviewees felt unhappy at having to give substandard treatment in the absence of a better option. Justifying her use of expired drugs, a paediatrician said:

*I think it will be better to give the expired drugs rather than not giving any drug at all. If we didn't give this drug, the patient can't buy also, and we have no other drug to give. Then, we have to wait and see the child die, if we do not give the expired drug* (Paediatrician, female).

Some interviewees working in the areas of psychiatry and physical medicine and rehabilitation felt that psychiatric patients and those suffering from various types of disabilities could not be given optimum treatment in medical settings, relying primarily on medicines and surgery. It was pointed out that sedation of psychiatric patients was more beneficial for the family, making it easier for such patients to be managed, but it did not help them resolve their underlying problems. These categories of patients required psychosocial interventions, which were not always available in the research centres.

Sometimes respect for the wishes of patients resulted in their being given a treatment modality, which was medically not seen as the best course of action. For instance, one gynaecologist said that he performed hysterectomy on a patient without removing the cervix because she was against such removal for fear that it would adversely affect her sexual life. He said that he conceded to the patient's wishes, and thus respected the principle of patient autonomy, even though in his opinion it increased her chances of developing cancer later in life.

The issue of suboptimal treatment was also discussed in the context of the relationship between colleagues. A number of doctors described cases, wherein other doctors had treated patients inappropriately. The disagreements brought up were more in the nature of technical dilemmas revolving around differential diagnosis and treatment regimens. However, the physicians, who brought up this issue, pointed out that in many such cases, patient care suffered. For instance, one chest specialist described the case of a child brought to him with diagnosis of respiratory tract infection for which he

had received several rounds of antibiotics. However, this doctor felt that the child was suffering from a viral infection, and the patient had actually been harmed by consuming antibiotics. Two questions were raised in this connection. Should the patient be informed or should the doctor cover up for his colleague in the eyes of the patient? Secondly, should the treating physician inform the other doctor about his mistake?

Other interviewees pointed out that patients at times did not receive quality care, because some doctors refused to adhere to their specialities. For example, a general practitioner treating psychiatric cases or a psychiatrist treating neurological disorders. This practice, it was pointed out, was more common in the private sector. This could result in deterioration in the patient's condition and delay in delivery of efficacious treatment. The interviewees, who brought up this matter, reiterated the need to streamline the referral system, so that patients did not suffer at the hands of practitioners not adequately qualified to treat them.

In conclusion, one may say that suboptimal treatment was perceived by many interviewees to be a common treatment outcome in a clinical context characterized by scarcity of resources and by financial incapacity of patients. Suboptimal treatment was discussed both in the context of technical and ethical dilemmas in a range of situations.

## Barriers to treatment from users' side

In addition to obstacles to treatment from the side of the hospital, interviewees also identified a number of barriers to optimum treatment stemming from the side of patients and relatives. Table 21 sums up the pattern of indexing frequency of this topic.

*Table 21:* **Pattern of indexing frequency of "barriers to treatment from health services users' side" by centre**

|  | Variation Among Centres | | | | | |  |
|---|---|---|---|---|---|---|---|
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** |  |
| Patients | | | | | | | |
| INT | Very Low | High | Very High | Low | Very High | Very Low | Medium |

| | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
| | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** | |
| TXT | Very Low | Very High | Very High | Low | Very High | Medium | Low |
| **Relatives** | | | | | | | |
| INT | Very Low | High | High | High | Very High | Low | Low |
| TXT | Very Low | High | Low | Medium | High | Low | Low |

Note: Patients = Barriers perceived on patients' side, Relatives = Barriers perceived on relatives' side.

While discussions on both barriers from patients' side and relatives' side were discussed often at the India, Indonesian and Nepal centres, they were comparatively less often brought up at the Sri Lanka and Bangladesh centres. The striking finding is, however, that of Myanmar where, although discussions on barriers from patient' side were few, the issue of barriers to treatment from relatives' side emerged as a major topic of discussion. It will be remembered that the theme of withholding and disclosing confidential information was also a major topic of discussion at the Myanmar centre.

*Barriers from patients' side*

Not following the prescribed medical regimen and dropping out of treatment were cited by interviewees as the two most common obstacles to the delivery of effective treatment from patients' side. A number of interviewees were of the opinion that the major reason for discontinuing treatment was the poverty of patients. For instance, one ophthalmologist pointed out that dropout in the case of glaucoma was very high, because most patients, that he saw, just could not afford long-term treatment with costly drugs like timolol.

Distance was also cited by some doctors as an important factor leading to patients dropping out of treatment (also see discussion on distance as an access factor above). For instance, a doctor at the Indonesian centre cited the case of a severely dehydrated patient requiring immediate admission, who insisted on being treated on an outpatient basis because he lived too far away to remain in the hospital for long.

The factor of gender was a also a factor in patients refusing treatment. For instance, the refusal of female patients to be physically examined by male doctors has already been mentioned in the section on 'doctor-patient interaction: other aspects' in Part One. This issue was exclusively raised by male doctors. Similarly, the case of female patients' unwillingness to undergo a medical termination of pregnancy, which is medically indicated, has also been discussed in the section on 'age and gender in patient assessment' in part One.

Another factor cited by some interviewees, which was perceived to obstruct the execution of the treatment of choice, was patients' fear of surgical procedures. For instance, a doctor at the India centre recounted a case in which he was forced to give palliative treatment to a patient having an ovarian cyst, because she refused to undergo a surgical intervention. He said that the patient preferred to wait and see if the cyst increased in size before agreeing to undergo the operation. Other respondents gave examples of cases where patients refused to undergo several surgical interventions in succession. For instance, a surgeon at the Indonesian centre cited the case of a male geriatric patient requiring two surgical interventions, *viz.*, one for a fractured elbow and one for a hernia. He chose to only be operated upon for his fracture even though he was considered to be medically fit to undergo both the operations.

Several participants noted that patients' resistance was especially high in cases, where an amputation was offered as the only treatment option. Commenting on the refusal of a diabetic patient to undergo amputation, an orthopaedic surgeon at the Indonesian centre said:

*It was the patient's decision. He wanted to go home and signed the letter to that effect. We could not do anything. I rarely found the case of diabetes in which such intervention was performed right away. At most, I myself would not perform such an intervention, when the patient was not willing to undergo surgery. In that case, we could not do anything* (Orthopaedic Surgeon, male).

The issue of treatment refusal on the part of patients was also discussed by a couple of psychiatrists. A psychiatrist at the Myanmar centre wondered whether it was ethically acceptable to forcefully medicate a patient, who felt he had no mental illness. He said:

*There are many patients who come, who are definitely suffering from mental illness, but they do not recognize and accept the fact that they are ill. Hence they are not willing to be either seen or examined clinically, or to accept admission in the ward. In such cases, we have a major ethical dilemma on our hands. Should we administer any treatment, which they are openly not accepting, on the information provided by family members as well as our own observation of the 0patient? Legally and ethically, one would not be justified in forcing a patient to get treatment against his will* (Psychiatrist, male).

It was not only in connection with refusal to undergo a particular treatment procedure that patient refusal was discussed. Some doctors pointed out that patients at times refused to cooperate with junior doctors, because they felt they were receiving inferior quality treatment. One doctor discussed refusal of patients to cooperate with a substitute physician, while their own doctor was on leave.

Thus, interviewees through a range of case illustrations discussed the discontinuation of treatment on the part of patients. Discontinuing medicines, refusing to undergo physical examination and surgery etc. were discussed. The importance of access factors like economy and distance was highlighted. This discussion carries important implications for the concept of patient autonomy, since respondents stressed the need to observe patients' choices even if they went against what was medically indicated as the optimum line of treatment.

*Barriers from relatives' side*

The family often carries a major portion of the economic and psychological burden of the patient's illness. The role of the relatives in treatment has already been discussed in the section on information management in Part One of the report. The factors responsible for treatment refusal from the relatives' side may be classified into two groups. One set of barriers identified by interviewees was connected with the limitations imposed on treatment by the family's socioeconomic status, such as the family's inability to bear the cost of investigations and drugs. These factors were related to access factors like economy, time, distance etc. However, the interviewees also identified other situations, when the relatives were unwilling to invest in treatment of the patient for other reasons.

Some interviewees mentioned cases, when the parents of a terminally-ill child decide to discontinue treatment, preferring to channel their limited resources for the care of their other children. For instance, one physician at the Indonesian centre mentioned how the father of a child, suffering from leukaemia, took him home after being informed of the poor prognosis. One reason given by some respondents for not wanting to disclose the diagnosis of a fatal or socially stigmatizing condition to the relatives was the fear of their abandoning treatment. For example, a doctor at the Myanmar centre said that he did not tell the mother of a child suffering from cancer the actual diagnosis because he felt she would immediately take the child back to the village.

The issue of the family's unwillingness to cooperate in treatment was brought up a by a number of psychiatrists. They discussed the disinclination of many relatives to take home patients, who were mentally fit to live in the community, thus preventing their integration into normal society. Fear of stigmatization and the burden of managing a psychiatric patient at home were cited as important factors in such cases.

The issue of relatives' refusal to cooperate in treatment was also discussed by some interviewees in the context of blood donation. One reason put forward accounting for relatives' unwillingness to donate blood was the fear of becoming debilitated themselves. Respondents pointed out that relatives' unwillingness was observed to be more common, when it involved male family members being required to donate blood for a female patient. For instance, a gynaecologist observed that husbands were unwilling to donate blood for their wives. In the face of a chronic shortage of blood in public hospitals, interviewees reiterated the need to encourage voluntary blood donation.

Examining the relationship between barriers to treatment from patients' side and from relatives' side, some amount of overlap was observed between the two categories during analysis. For instance, in a gynaecological case wherein a husband was unwilling to donate blood for his wife, the wife also refused to undergo the operation, if it involved her spouse to donate blood for her.

It was seen that the family's role in treatment extends beyond the issues of information management and access factors. Relatives' refusal to cooperate in treatment was perceived to be common in connection with discharge of psychiatric patients and blood donation.

The above discussion on access and equity in clinical practice reveals that interviewees were very conscious of the harm suffered by patients in the face of multiple barriers to treatment.

# Summary

## *Access and equity*

This part of the report examines how clinicians balance patients' demands for treatment under conditions of resource constrains.

## *Access factors*

Five access factors were identified to be influencing participants' ethical concerns in clinical decision-making. These were economy, network, distance, and fairness.

### *Access factor: Economy*

Economy was the most frequently indexed access factor at all the centres. Discussions on economy were framed by contextual constraints on practice. Shortages of medical supplies and facilities were perceived to prevent doctors from providing optimum treatment to patients, who had to bear the major burden of cost of investigations and medicines even in the public health system. Recommendations were made to increase resource allocation for the public health sector. Economy was also discussed in the context of private practice, pointing to the issue of transparency of costs, differential pricing and vested interests of physicians.

### *Access factor: Network*

Patients' social network was perceived to exert an important influence on the delineation of clinicians' ethical dilemmas in the area of patient's access to treatment. Network factors were most often discussed by interviewees in the context of treatment of patients connected with hospital staff and dependants of colleagues.

*Access factor: Distance*

Being tertiary-level health care facilities situated in urban areas, the centres in this study cater to a large patient population from rural areas and small towns. The difficulties of outstation patients in accessing health services at urban hospitals and the impact of distance on providing optimum treatment to such patients were discussed.

*Access factor: Time*

Interviewees lamented that their busy schedules did not allow them to spend enough time with patients. Some respondents put forward recommendations to improve time management in hospitals.

*Access factor: Fairness*

Most interviewees reflected on issues of fairness and equity in clinical decision-making. In the face of scarcity of resources, which patient gets what, and how much, were major concerns. Two criteria were identified, when it came to choosing among patients, who would be provided the limited treatment facilities. One was the patient, whose need was perceived to be greater, should be given priority. Secondly, the patient, who would stand to benefit more from the intervention should have a higher claim to it.

**Barriers to treatment from health care providers' side**

A majority of interviewees were of the opinion that the major obstacles to the delivery of effective treatment were shortages of manpower, medical equipment and facilities in the hospitals. Case illustrations of acute, chronic and life- threatening conditions were used to contextualize the discussion.

**Waiting and waiting list**

The interviews reveal that long waiting periods were perceived by doctors to be a frustrating experience for patients and relatives. This also results in delays in both diagnosis and commencement of treatment. Consequences were often seen to be worse for patients living at greater distance from the hospital, as waiting would increase costs connected with being away from home.

*Suboptimal treatment*

Suboptimal treatment was perceived by many interviewees to be a common factor in a large number of cases. This was attributed to a clinical context characterized by scarcity of resources and by financial incapacity of patients. Suboptimal treatment was discussed both in the context of technical and ethical dilemmas in a range of situations.

Barriers to Treatment from Health Service Users' Side. Interviewees identified a number of obstacles to the delivery of optimum treatment both from the side of patients and relatives.

*Barriers to treatment from patients' side*

Discontinuation of treatment on the part of patients was discussed by interviewees through a range of case illustrations. Discontinuing medicines, refusing to undergo physical examination and surgery etc. were discussed. The role of access factors like economy and distance were highlighted. The discussions were linked to the concept of patient autonomy, since respondents stressed the need to observe patients' choices, even if they went against what was medically indicated to be the optimum line of treatment.

*Barriers to treatment from relatives' side*

It was seen that the family's role in treatment extended beyond issues of information management and access factors. Relatives' refusal to cooperate in treatment was discussed in connection with discharge of psychiatric patients and blood donation.

Part 3:

Resource Management and Decision-making
at Institutional Level

This section examines how institutional factors, such as shortages of manpower and medical supplies, impinge upon clinical decision-making. Firstly, the ethical dilemmas attributed by interviewees to material constraints on clinical practice will be discussed. In addition to material constraints, ethical dilemmas may also arise in relation to other institutional factors, such as physicians' teaching responsibilities, vested interests and conflicts with colleagues. How clinical decision-making is executed in a situation of resource constraint will also be discussed. The headings under which these issues will be discussed are given below:

> Constraints at Institutional Level

> Conflict and Conflict-Solving

> Decision-Making under Resource Constraint

## Constraints at institutional level

This section will examine the material and human resource constraints, identified by participants, that were considered to exert on impact the delivery of optimum treatment. The discussion will be organised around the following sub-themes:

> Shortage of Medical Equipment and Facilities (Including Blood)

> Shortage of Manpower

> Comments on Wider Health care System or Infrastructure

> Misuse of Resources (Including Over-Treatment)

Table 22 depicts the pattern of indexing of discussions on institutional constraints on clinical practice at the different centres.

Table 22: **Pattern of indexing of various institutional constraints on clinical practice by centre**

| | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
| | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** | |
| **Facilities** | | | | | | | |
| INT | Very High | Very High | Very High | High | Very High | High | Very High |
| TXT | Very High | Medium | Medium | Medium | Low | High | Very High |
| **Man-power** | | | | | | | |
| INT | High | High | Medium | Medium | Medium | High | High |
| TXT | Very High | Medium | Medium | High | Very Low | Low | Medium |
| **Blood** | | | | | | | |
| INT | Low | Low | Low | Low | Very High | High | Very Low |
| TXT | Very Low | Very Low | Very Low | High | Very Low | High | Very Low |
| **Infrastructure** | | | | | | | |
| INT | High | Medium | Very High | Very High | Low | Low | Very High |
| TXT | Medium | Low | Medium | Very High | Very Low | Low | Medium |

The above table shows that discussions on shortages of medical facilities and equipment were generally high at all the centres. At the Nepal centre, although the topic did appear in a large number of interviews, it was not discussed in great detail. Discussions on manpower were also frequently indexed at all the centres. However, in the case of Nepal and Sri Lanka,

although the topic came up in a number of interviews, it was not discussed at great length. Discussions on shortage of blood were sparse at most of the centres with the exception of Nepal and Sri Lanka. At the Myanmar centre, the issue was discussed at great length in a small number of interviews. Discussions on health infrastructure were brought up in a fair number of interviews at most of the centres with the exception of Nepal and Sri Lanka. The topic was discussed in most detail at the Myanmar centre. When interpreting Table 22, it may be necessary to recall that the Nepal and Sri Lanka centres had much fewer interviews than the other centres. The marked differences on 'blood' and 'infrastructure' compared to the other centres may be due to this fact.

## Shortage of medical equipment and facilities, and blood

In their discussions on institutional constraints on clinical practice, a majority of interviewees pointed out that shortages of medical supplies and facilities were a major obstacle to the delivery of optimum treatment. Shortages of hospital beds and drugs were repeatedly cited as major impediments to the provision of effective treatment. Some respondents said that quality of antibiotics and other medicines provided by the hospital was inferior, and they wondered whether it was fair to give such suboptimal drugs to patients, when more efficacious preparations were available outside. The justification for using cheaper drugs was the hospitals' inability to provide the best available treatment, and patients' economic inability to avail of the treatment of choice. Some doctors pointed out that at times even muscle relaxants and anaesthetic agents had to be procured by the patient for both emergency and elective operations.

The issue of patients being given expired drugs or having to buy drugs and get investigations done from the market have already been discussed in the section on economic assessment of patients and on access factor economy in Part One and Part Two of this report respectively. Commenting on the use of cheaper quality drugs available in the hospital, a psychiatrist at the India centre said:

*There are certain other issues which come up. One of them is whether to use medicines that are expensive and not available in the hospital and the*

*patient can ill afford them. We have a number of newer medicines, which are available in the market. They are much more expensive than routinely used drugs, but they may be more effective in particular cases. Since the hospital does not supply these medicines and they have to be bought we have the ethical dilemma on deciding whether to persuade the family to spend more money for quicker or better treatment, or to rely on older medicines, which may not be as good. We face this problem very often in the ward* (Psychiatrist, male).

Shortage of beds was cited by many doctors as a major factor in treatment refusal and premature discharge of patients. One orthopaedic surgeon pointed out that although there were an equal number of male and female patients suffering from orthopaedic disorders, the male-female bed ratio in his ward was 30:4.

As mentioned earlier, several respondents pointed out that patients were discharged prematurely, if the bed occupied by a patient was required by another patient, whose need for hospitalization was perceived to be greater. One doctor recounted the case of a child suffering from pneumonia, who was sent home before he had fully recovered, because another child needed immediate admission. It was further argued that if the two children were put on the same bed, then the chances of the child suffering from pneumonia contracting a secondary infection were increased.

In the face of paucity of space and other medical facilities and the heterogeneity of medical conditions doctors were called upon to treat, a number of suggestions were made to make hospitals more responsive to the needs of different categories of patients. A physician at the Bangladesh centre suggested the creation of a maternal and child health centre to provide both antenatal and postnatal care. Another physician at the India centre felt there was a need to create separate beds for medico-legal cases, who were forced to be hospitalised for longer time periods. Another doctor at the same centre raised the same issue in the context of wandering mentally ill patients brought to the hospital by the police. After emergency treatment, doctors had no choice but to transfer such cases to mental hospitals: an option which was not considered to be in the patients' best interest, given the deplorable living conditions in many such establishments.

The issue of shortage of blood was discussed by only a small number of doctors. In the face of extreme shortage of blood, we have already seen the dilemmas faced by physicians in selecting potential beneficiaries in the section on saving life in Part One. Another doctor at the Myanmar centre said that he had not told the family of a patient suffering from cirrhosis of the liver that they could obtain blood for their ailing relative from the market. He justified his decision on the ground that if the family somehow managed to obtain blood and still the patient died, then it would be a double loss for the family, i.e. financial and emotional.

The issue of doctors suggesting to patients' family members to buy blood was raised in the context of treatment of dengue haemorrhagic fever and exchange transfusion in neonates. Articulating his dilemma, a physician at the Myanmar centre said:

*My conscience is clear when I write down the name of the medicine to be bought downstairs. But, to tell the family to go and buy blood is another thing* (Physician, male).

In a situation the demand far exceeds the supply, and in the face of legal sanctions against trade in blood in some countries, problems of collecting and storing blood were briefly discussed. A few interviewees discussed the drawbacks of holding blood donation camps in the absence of adequate refrigeration facilities to store the collected blood. They also pointed to lacunae in the hospital policies on blood donation. For instance, since blood was most often required on an emergency basis, it was difficult to contact potential donors on the hospital rolls, especially if they lived at a distance from the hospital.

Some physicians said that due to inadequate number of operation theatres in hospitals, emergency care could not be provided to all those in need of it. For instance, a gynaecologist dwelt on the criteria of selecting patients for operative procedures in the face of an extreme shortage of hospital facilities. She said:

*Last week at 10:00 pm. when I was in the observation ward, one after another within half an hour, three patients came from emergency. One came with full-term pregnancy with cord prolapsed. Another patient came with*

*retained placenta with postpartum haemorrhage (PPH) and a third patient was in shock due to severe PPH. At that time, we had one operation theatre with one theatre table, one anaesthetist and one anaesthesia machine. But all those three patients were emergency patients and needed emergency management. At that moment, we had to decide whom we should give preference to and take into the operation theatre for management. Taking into consideration the life of both mothers and babies, the patient with cord prolapsed seemed to be important to us, and we did emergency caesarean section, preferring her among the three patients* (Gynaecologist and Obstetrician, female)[4].

A neurosurgeon said that even though there were enough doctors in his department, yet lack of operating facilities compelled them not to perform more than five to six operations a day. He pointed out that if there was another operation theatre, the same staff members could perform ten to fifteen operations a day.

Shortage of equipment to perform CAT scan and MRI, either free of cost or at affordable rates, for patients in need of such investigations was discussed by a large number of doctors. One neurologist gave the example of a patient suffering from paraparesis, who could not afford to have an MRI done from the market. This patient could be provided an MRI in the hospital only after certification from a medical board. This process would take a minimum of two weeks, by which time permanent nerve damage would have set in. In another case, a child with a diagnosis of hydrocephalus could not undergo a surgical intervention, because his family could not afford to have a CAT scan done. Consequently, the child was given drug treatment instead of the treatment of choice, i.e. a shunt operation. Another physician discussed the use of exploratory laparotomy as a diagnostic aid in the absence of a CAT or MRI scans. In the face of difficulties in obtaining results through medical investigations, several doctors underscored the importance of the clinical examination in the diagnosis.

Since many hospital could not provide low-cost prosthesis and other implants to poor patients, several orthopaedic doctors lamented that they were forced to provide patients suboptimal treatment. Some rehabilitation

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[4] In the other two cases, both the mothers and infants were saved through non-operative procedures.

specialists also said that in the absence of specialized equipment and facilities in the hospital, they were not really able to help severely handicapped persons, such as those suffering from quadriplegia. One doctor at the India centre said in this regard:

*I can recall hundreds of such patients since 1980, when I got involved in rehabilitation work. There have been a number of young and old patients. Apart from telling the prognosis, we can not really help. So far, in my life out of say fifty or sixty quadriplegic patients, I have been able to help only one: because he had the means to go and get some gadgets. Still, he is not very satisfied because of the absence of basic infrastructure. So, I must say that there may be many patients, whom we cannot treat at all in rehabilitation. We are not able to give them much support. They require motorised wheelchairs. They require other additional features at home, such as control units. Only then can they make their lives better. They have good brains, but their extremities and joints are weak. So, although we can definitely help them, we are not able to do so* (Rehabilitation Specialist, male).

The absence of aftercare facilities and community care programmes for the management of chronic mental illness was discussed by a couple of psychiatrists. It was pointed out that shortages of psychotropic drugs in the hospital for maintenance therapy resulted in frequent relapses in patients. A psychiatrist at the Myanmar centre discussed the functioning of halfway homes. These were unlicensed private establishments run by unskilled staff, where families could leave their ailing relatives. In the absence of community mental health initiatives to rehabilitate chronic mental patients after discharge from the hospital, this psychiatrist stressed the need for registration and medical supervision of such establishments. The need for more psychiatric social workers to follow up chronic mental patients in the community was also emphasized by more than one psychiatrist.

Shortages of life-saving equipment, such as ventilators, oxygen and dialysis machines, were also discussed. One doctor discussed the case of a child, who went into respiratory depression after a lumbar puncture. In the absence of adequate supply of oxygen in the ICU, it was not possible to save the child. Another physician was of the opinion that respirators should be provided in the general ward and not only limited to the ICU.

The shortage of medical facilities was not only discussed in the context of drugs, investigations and life-saving equipment, but several interviewees mentioned the scarcity of basic materials like linen, gloves, soap and even water in hospitals. Other doctors observed that it was not only lack of adequate equipment that was responsible for the low quality of care but also negligence in following procedures related to hygiene and sterilization. They pointed out that needles and syringes were at times not properly autoclaved, and their reuse was not an uncommon practice. Improper autoclaving of operating instruments, it was pointed out, could result in major post-operative complications.

Furthermore, some interviewees also noted that it was not only a question of shortage of equipment, but also poor maintenance of existing equipment. For instance, it was pointed out that repair of broken machines took a long time. One doctor said that the endoscopy machine in the hospital had been out of order for the past one year. In the face of such problems, one surgeon said that he preferred to use his personal operating kit, instead of the instruments provided by the hospital.

In addition to obtaining drug samples from pharmaceutical companies for the treatment of patients who could not afford to buy the required medicines themselves, physicians described other methods that they had devised to help patients. One physician at the Myanmar centre said that he asked for charity for the treatment of very poor patients, admitted in the ward, from other ward patients, who were relatively better off. Another paediatrician at the Indonesian centre said that he often paid for the treatment of critically ill children, whose families were too poor to undertake such expenditure. Several doctors said that they tried to look for alternative sources of funding, but added that their efforts were hampered by paucity of time.

In the face of massive shortages of facilities, some doctors wondered whether it was legitimate to channel these limited resources for the treatment of patients with very poor prognosis. This issue has already been discussed in the context of end-of-life decisions in the section on saving life in Part One. Another doctor questioned the practice of treating dependants of doctors, given the limited hospital facilities, the so-called professional etiquette discussed earlier in the section on access factor network in Part Two.

Thus, it can be seen that shortage of medical facilities was discussed in terms of shortages of drugs, investigation procedures, blood and other life-saving equipment. The problems of long-term management of chronic conditions like functional psychosis and mental and physical handicaps were also discussed. Some interviewees mentioned strategies they had devised to cope with these material constraints. Using drug samples provided by pharmaceutical companies and arranging donations for poor patients were mentioned.

## Shortage of manpower

Heavy workloads and rapid turnover of patient populations were discussed by a large number of interviewees. On the one hand, a general shortage of hospital personnel (ranging, from nurses to super-specialists) was mentioned. A few doctors discussed the impact of this general shortage of trained personnel on emergency care. For example, several interviewees said that the care of accident victims brought to the casualty was found to be a daunting task, especially if there were no relatives to provide nursing care. Medical emergencies may also result in doctors performing tasks for which they are not adequately qualified. For example, one orthopaedic surgeon recounted a case, when after having reconstructed the bones of an accident victim, he was also forced to put together the blood vessels in the absence of a vascular specialist on hand to perform this task.

On the other hand, the issue of shortage of trained personnel was discussed in the context of specific services. A couple of participants pointed out how the shortage of female staff adversely affected the treatment of female patients, who refused to be physically examined by male doctors. For instance, one ENT doctor said:

*In the ENT examination room, there should be one nurse to examine the lady patients. We are not able to do this. In front of everyone, we have to examine the patient. This, I say, is an ethical problem. But for the shortage of manpower, we have not been able to do so* (ENT Doctor, male).

Given the low patient-nurse ratio in the hospitals, a few doctors pointed out that in the absence of an adequate number of nurses to provide nursing care in the wards, the assistance of relatives became an intrinsic part of hospital treatment.

Shortage of paramedical staff, such as occupational therapists and social workers, was also discussed. For instance, some psychiatrists and orthopaedic specialists pointed out that in the absence of adequate number of trained personnel, it was not possible to implement community-based health and tertiary-level prevention programmes. In the absence of doctors being able to provide individualized care to all patients, a number of respondents reiterated the need for more social workers and counsellors to provide detailed, yet simple, explanations to patients about the disease and treatment options available to them. The role of social workers was felt to be of paramount importance in suicide prevention and genetic counselling programmes.

The issue of shortage of trained manpower was not only discussed in quantitative terms, i.e. inadequate number of personnel, but some interviewees felt that the quality of services provided by staff was also an important criterion of evaluation. Several doctors admitted that the pressure of work at times made them brusque and impatient in their interactions with patients. They pointed to the stress experienced by both doctors and patients in the OPD, a situation in which frayed tempers were not an uncommon occurrence. Some interviewees also commented upon the brusque manner of nurses and orderlies towards patients. Since these factors could have adverse consequences on medical compliance, even leading to the exacerbation of the disease in some cases, several interviewees underscored the need for better communication between patients and all categories of hospital staff.

The theme of shortage of manpower was also discussed in the context of doctor-doctor interaction. Some doctors, for instance, raised the issue of medical procedures being performed by under-qualified personnel, such as radiographers performing radiological examinations under the supervision of radiologists. The doctors, who brought up this issue, were of the opinion that doctors should adhere to their chosen field of specialization. Thus, one paediatric surgeon said that, ideally he should only practise paediatric surgery even though he had received formal training in general surgery, and was technically qualified to undertake other types of surgical interventions. This issue was discussed more in the context of private practice.

Other doctors observed that the system of collaboration between different specialists was not properly institutionalized. For instance, one doctor pointed out that a bone cancer patient should ideally be

simultaneously provided individualized services of an orthopaedic surgeon, oncologist, pathologist and psychologist. However, in day-to-day practice the treating physician generally managed patients more or less single-handedly.

In the context of heavy workloads and rapid turnover of patient populations, interviewees pointed to shortages of all categories of medical staff. The need for more paramedical, nursing and emergency care staff was stressed. Interviewees pointed out that quality of care was dependent both on availability of adequate number of qualified personnel and harmonious client-professional interaction.

## The wider health care system

While interviewees contextualized their discussions on the ethical dilemmas encountered in clinical practice primarily with reference to the centres where they were practising, some doctors broadened the ambit of discussion by referring to features of the wider health system, such as the perceived quality of services in the public and private sectors. The issue of timely and proper referral of cases was also discussed at length by a large number of interviewees. During analysis, issues concerning the wider health care system were grouped together under the rubric of infrastructure. The discussion on infrastructure takes on an added meaning, since the field centres, where the present interviews were carried out, are all tertiary-level referral health care facilities situated in large cities.

Many interviewees said that there was an over-utilization of referral centres by people for minor health problems, which could easily be managed at other city and district hospitals. Although shortage of trained personnel and facilities in district hospitals was a major problem, some respondents were of the opinion that people did not have faith in doctors working in these facilities. They pointed out that there was some truth in this popular assessment, because qualified medical personnel preferred working in larger cities, where remuneration was higher and career options better. As one doctor said:

*Basically, people usually tend to come to this institute or to any institute in the Capital City. In the zonal hospitals, services are given but people don't have faith. There may not be any surgeon available, and facilities may not exist. Lastly, if the surgeon is available, he may not be a properly trained surgeon* (Gastroenterologist, male).

In the wake of the burden put on referral centres to treat minor health problems, some respondents stressed the need for more rigorous screening procedures to ensure that the specialized facilities of referral centres were not entirely used in the management of health problems that could easily be taken care of at district or peripheral hospitals near patients' homes. A couple of doctors felt that, under such circumstances, referral centres should have discretionary power to refuse treatment in order to avoid misuse of resources. One doctor, however, said that if he refused to treat a patient and referred him to a doctor in a hospital nearer his home, he felt this might arouse unnecessary suspicion in the patient, who might ask, "Why is this doctor not treating me? What type of disease do I have?"

Examining the problems in health infrastructure from another perspective, a number of doctors pointed out that due to the absence of a well-structured inter-hospital referral system, cases in need of specialized services of referral centres often reached such facilities too late. This often occurred, it was felt, because the physician of first contact did not make an appropriate and timely referral. The issue was discussed at some length by an obstetrician at the India centre in the detection of foetal abnormalities. She said that by the time patients reached the antenatal clinic, it was often too late to perform a medical termination of pregnancy.

Inadequate networking between various hospitals in the health system could result in treatment delay. For instance, one doctor pointed out how he was unable to provide some gadgets to an outstation patient suffering from paraplegia, because the equipment had to come from another hospital after due certification by a medical board. The entire process resulted in a delay of over two months causing unnecessary hardship to the patient and his family.

Examining the interface between private practice and the public health system, several doctors noted the absence of proper coordination between private clinics and larger government hospitals. A paediatrician said that he often came across cases of neonatal jaundice in which obstetricians in private clinics did not immediately refer the cases to the Children's Hospital. He accounted for the delay in referral by doctors in the private sector to the profit motive.

The role of pharmaceutical companies in health also came up for discussion. Several doctors pointed out how pharmaceutical companies were co-opting medical professionals into prescribing more expensive drugs, whose efficacy was more or less the same as the less expensive drugs.

The limitations of the health infrastructure were discussed in a large number of interviews. Inadequate budgetary outlays for the health sector were cited as a major obstacle to the delivery of optimum health care. Many doctors said that the absence of compulsory health insurance was a serious limitation of the health system. Since the expenditure for health care has to mainly come from personal savings, several informants stressed the need for a national health security system to help patients in procuring the treatment they needed.

Several suggestions were put forward by interviewees to improve the functioning of the health care system in general. Some doctors said that hospitals should have greater autonomy in decision-making, and should be shielded from the machinations of politicians and bureaucrats. To reduce the dependence of hospitals on state funding, interviewees felt the need for more collaboration with NGOs, especially for fund-raising. Furthermore, several doctors said that even in government hospitals, free treatment should not be available to all and sundry. There should be a proper screening system in place to determine patients' eligibility for availing of free hospital services. In order to reduce the burden on referral centres, interviewees underscored the need to involve paramedical staff in a big way to manage priority health problems in the community and at the PHC level.

In their discussions of geriatric cases, a couple of interviewees said that since care of the elderly was not a priority in health policy, NGOs should be encouraged to work in the area. Similarly, other doctors reiterated the need for institutions in the SEA Region to house terminally ill patients, such as those in the last stages of cancer or AIDS. Since hospitals were too overburdened to handle such cases, and the families of these patients were unable or unwilling to look after them at home, the need for hospices managed by paramedical staff to provide nursing and other medical care was stressed.

Many doctors felt that the health infrastructure was deficient in the provision of emergency care and reiterated the need for more trauma care services. Some interviewees said that in the absence of well-equipped ambulance services, emergency cases were most often transported to the hospital by relatives. Even in hospitals, there were hardly any trauma care centres to provide emergency care to accident victims.

Thus we have seen that limitations of the wider health care system, such as the over-utilization of referral centres for treatment of minor health problems, lacunae in inter-hospital referral system, shortage of paramedical personnel to assist in chronic care, etc. were discussed. Suggestions to improve health infrastructure, such as encouraging autonomy in the functioning of health institutions, collaboration between public hospitals and NGOs, etc. were made.

## Misuse of resources and over-treatment

In the face of shortages of medical equipment, facilities and manpower in hospitals, any overuse or misuse of such limited resources could be considered a serious matter. Table 23 shows the indexing frequency of discussions on misuse of resources and over-treatment by centre.

*Table 23:* **Pattern of indexing frequency of "Misuse of resources" and "over-treatment" by centre**

| | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
| | | | | | | | Overall freq. |
| Misuse of resources | | | | | | | |
| INT | None | Very High | Low | Low | None | None | Very Low |
| TXT | None | Very High | Low | Medium | None | None | Very Low |
| Over-treatment | | | | | | | |
| INT | None | High | High | High | Very High | Low | Low |
| TXT | None | Medium | Medium | Very High | High | Very Low | Low |

While misuse of resources emerged as a significant topic of discussion only at the India centre, it was not at all mentioned at the Bangladesh, Nepal and Sri Lanka centres. At the Indonesian and Myanmar centres, it was sparsely discussed. While over-treatment was not at all discussed at the Bangladesh centre, it was mentioned in a large number of interviews at the other centres, except Sri Lanka. Discussions on over-treatment were most frequent and extensive at the Myanmar and Nepal centres, followed by the India and Indonesian centres.

Some interviewees discussed even minor incidents of misuse at length. A surgeon, for instance, recounted how some very expensive medicines had been bought by the hospital for the treatment of a patient. However, before the medicines could be procured, the patient had recovered and was discharged from the hospital. Another case requiring the same expensive medicines was admitted some time later and the same medicines were again procured after a great deal of difficulty, without taking account of the fact that the earlier batch had not been utilized. Again, the second batch was not used. By the time the matter came to light, both the batches of expensive medicines had expired due to perceived faulty management by the hospital administration.

Some doctors were concerned about the judicious use of concessions and subsidies provided for the ill and the disabled by the state, such as free railway travel for those suffering from leprosy in India. These doctors reiterated the need for sound criteria to determine eligibility, so that scarce resources were not wasted. One doctor brought up the issue of issuing sickness leave certificates to staff members, even for minor conditions.

The futility of medical management of mental retardation was brought up by some rehabilitation experts. Doctors said that they found it difficult not to accede to the requests of the parents of such children for some kind of medical treatment. In such cases, it was pointed out that the best treatment was for the doctor to counsel the parents. The same questions were posed by some neurologists in connection with the prolongation of life of moribund patients. The use of time, energy and resources only resulted in providing sub-human survival, since many such patients could be kept alive indefinitely on life support systems.

The attempt to balance optimum use of resources in a situation of scarcity is illustrated in the following excerpt, wherein an ophthalmologist is wondering whether or not to continue treatment of a child suffering from cancer with very poor prognosis. She elaborated her dilemma as follows:

*I admit that I might be wrong, because the patient has the right to survive anyway. Yet, on the other hand, we also know that the patient's prognosis was quite unfavourable. The problem now was whether it was right to let this dying child have the funds, or wouldn't it be better and more effective to.... That's where the dilemma lies. Is it ethical, therefore, to say that the money would be better given to other children, for getting food, for attending school, so that they would be healthier than to assist the child, who would die?* (Ophthalmologist, female).

Interviewees discussed the issue of over-treatment in a variety of situations. It was discussed in the context of abuse of investigations, medication (especially antibiotics) and surgery. Firstly, over-treatment and the side-effects of medicines came up in the discussions on management of multiple medical problems in a single case, as, for instance, treatment of a geriatric patient having an ulcer and also suffering from renal failure. One psychiatrist discussed toxicity arising out of overuse of psychoactive drugs in the management of chronic mental illness.

Over-treatment was also discussed in the context of surgery. One surgeon described a case where he was forced to remove the normal appendix. The provisional diagnosis was appendicitis, but after making a gridiron incision, the surgeon found that while there was pus in the pelvic cavity, the appendix was normal. However, he decided to remove the appendix. He said that if another doctor later examined the patient, he would think that the appendix had been removed because of the gridiron incision.

Over-treatment was also discussed in the context of the technology-driven movement in medicine. For instance, the question was raised as to how much the patient should be investigated, when a fairly accurate diagnosis can be made on the basis of a clinical examination and some baseline investigations. A cardiologist at the India centre wondered whether such procedures as cardiac catheterization, coronary angiography and angioplasty were really necessary in routine treatment, in a situation where a large

number of patients sought treatment for conditions like unstable angina. He asked whether it was fair to have the limited number of hospital beds occupied by patients undergoing these sophisticated procedures.

From another perspective, one gynaecologist described how she was forced to accede to a patient's request to remove the uterus because the patient wanted to start hormone replacement therapy (HRT). The doctor said that although medically it was indicated only partially, she performed the prophylactic hysterectomy at the insistence of the patient, who was very keen to begin with HRT.

Some doctors discussed over-treatment in the context of private practice. They referred to the practice of patients being seen more often than was required in order to get more fees. Prolonging the hospitalization of patients for the same reasons was also mentioned. One doctor said that because of the positive value attached to injections in the eyes of a large number of patients, he often did give injections in order to retain the patients in his private practice. He added that he realized this was a medically incorrect practice, but he was forced to resort to it so that he did not lose his patients to other doctors. He also said that he knew that the overuse of injections facilitated the spread of infections such as hepatitis B and HIV.

The themes of misuse of resources and over-treatment were discussed in connection with specific case illustrations. Over-treatment was specifically discussed with regard to abuse of investigations, medicines (particularly antibiotics) and surgery. These concerns were discussed both in the context of medical practice in the public and private sectors.

## Conflict and conflict-solving

Shortage of material resources was only one important factor in clinical decision-making. In their descriptions of ethical dilemmas in day-to-day practice, interviewees alluded to areas of conflict, which challenged their functioning as responsible physicians. Disagreements with colleagues, teaching duties and vested interests were some of the factors mentioned by clinicians, which raised ethical concerns. Two models of conflict resolution were proposed to manage such conflicts, viz., (a) legal regulation and (b)

standardization of procedures by professional associations. The themes of conflict and conflict solving will be discussed under the following headings:

➢ Doctor-Doctor Conflict

➢ Teaching Responsibility

➢ Vested Interests

➢ Methods of Conflict-Solving

➢ Legal Regulation of Medical Practice

➢ Establishment of Professional Standards of Practice

## Doctor-doctor conflict

In addition to voicing technical disagreements with reference to differential diagnosis, necessary investigations and the optimum line of treatment, interviewees also discussed a range of other issues involving dissent among colleagues. These disagreements were, in turn, connected with larger issues of professional hierarchy, multi-disciplinary treatment, information management and the public-private interface in medical practice. We have grouped these themes under the general rubric of doctor-doctor conflict. Table 24 presents the centre-wise indexing frequency of discussions on doctor-doctor conflict.

*Table 24:* **Pattern of indexing of "Doctor-doctor conflict" by centre**

|  | Variation Among Centres | | | | | |  |
|---|---|---|---|---|---|---|---|
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** |  |
| INT | Very Low | Medium | Very High | Low | Low | Very Low | High |
| TXT | Very Low | Low | Very High | Low | Very Low | Very Low | High |

The above table shows that discussions of doctor-doctor conflict were most frequent at the Indonesian centre. At the other research centres, it was a comparatively less frequent topic of discussion, while remaining high from an overall perspective.

When asked to provide examples of some ethical dilemmas encountered in routine practice, a number of interviewees chose to discuss doctor-doctor conflict in the context of technical dilemmas around diagnosis and treatment. For instance, a pulmonologist described a case referred to him by a colleague with a diagnosis of heart abnormality. Upon examination, he found that the patient was actually suffering from lung cancer, which, due to delay in diagnosis, had metastasised beyond repair. The doctor attributed the deterioration in the patient's condition to a faulty diagnosis by the treating physician. In another case, a doctor described the case of a child, who was treated for asthma for several years, but a detailed examination revealed that the patient was actually suffering from a heart abnormality. In the light of such misdiagnosis and the consequent delay in making appropriate treatment available to patients, several physicians recommended the institutionalization of a practice of second opinion.

A number of doctors discussed the problem of inter-collegial confidentiality in the context of doctor-doctor conflict. The question posed was what one should do, when one sees a case, which has been, in one's opinion, wrongly managed by a colleague? The dilemma expressed by interviewees, who brought up the issue was whether one should cover up for the colleague, or one should directly inform the patient that he has received suboptimal treatment. In his attempts to balance the competing demands of not bringing harm to the patient and maintaining a good rapport with a colleague, a paediatrician at the Indonesian centre described his dilemma in this connection as follows:

*You see what happens sometimes is that you see patients, who have been seen by other consultants. And they come with the prescriptions. Now, the question is that the prescriptions, which were given to the patients, have many drugs, which may not be needed by the child, which you know for a fact. Now, the question is whether you will tell the mother, 'Don't give the medicines, it will harm the child!' If you tell that, then your personal relation with the patient and with your colleague might be adversely affected. Now, you know that these drugs are not doing any good for the child; they should*

*not be used. But somebody has prescribed them. So, should you tell the mother that these drugs are very bad, don't use them. Then immediately, you think that by doing that, you are in opposition to your colleague. It is a difficult situation. What I do is that I tell the mother that probably these medicines were written, when the other physician saw the child first. But at present, I don't think these medicines are required. So, you can stop all of them now and give only what I am now writing. That is what I do* (Paediatrician, male).

In another case, the doctor, however, said that he did tell the patient that the treatment of the other physician was not optimal, but in a manner that the colleague was not blamed. In connection with post-operative complications associated with surgery to treat facial paralysis, a doctor at the India centre said that he told the patient:

*I did not say that the damage was not there. Damage was there, and I told the patient the same thing, I told the patient the absolute truth. But I did not try to blame the other doctor. I said that even we come across such situations, since this is a very well know complication, which can happen in anybody's hands. So, I didn't hide the truth. And at the same time, I said it in such a manner that the person was not directly held responsible for the mishap* (ENT Specialist, male).

In yet another case, a paediatrician justified his decision not to inform the mother of a patient that her child had been over-medicated by the other doctor on grounds of the parent's lack of education. He, however, said that he would have explained to her everything, if she had been literate, and had directly asked him why the child had not improved, despite having been on medicines for so long.

In a case of possible misconduct, a psychiatrist said that he did not take any action, when a female patient and her family complained to him against the misconduct of his colleague. The colleague was accused by both the patient and her family of sexual molestation. Although it is not clear from the interview, whether the doctor believed that his colleague was guilty or not, he chose not to make the matter public. In addition to preserving his relationship with the colleague, he speculated that the patient's version might be at a variance with the real situation, since psychosis leads to a loss of touch with reality and a possibility of counter-transference in the psychotherapeutic relationship.

Interviewees pointed out that the need to ensure a good professional relationship among colleagues was necessary for a number of reasons. The practices of medical consultation, second opinion and the system of referral are all dependent on ongoing professional communication. For instance, one interviewee noted that the need to avoid criticising a colleague is in the patient's interest, in the context where a family doctor refers a patient to a specialist for a consultation. Overt expression of differences of opinion between the specialist and the primary caregiver was perceived to hold the effect of eroding the patient's confidence in the latter.

Furthermore, tarnishing the reputation of colleagues in front of patients could backfire on the second physician. A few physicians said that they desisted from changing the medicines prescribed by their colleagues for fear of being accused of promoting brand medicines of a particular company.

With increasing sub-specialization in medicine and the tendency to go in for multidisciplinary treatment protocols, a number of doctors said that it was at times difficult to decide which specialist should treat which disease condition. A couple of doctors, for instance, wondered who should be the primary physician of a patient suffering from a malignant tumour in the ovary: a surgeon or a gynaecologist.

A surgeon at the Indonesian centre raised the issue of the norms of appropriate consultation. He cited a pneumothorax case referred to him by a pulmonologist for necessary surgical intervention. However, the referring physician enjoined the surgeon not to use the suction method. The surgeon was of the opinion that the referring physician should not attach any preconditions, which would hamper the freedom of judgement of the second doctor. Hinting to involved financial gains, he also said that he was unable to articulate his objection to the pulmonologist, because the professional medical culture did not permit overt expression of dissent:

*A:        Yes, in my opinion...this [treatment] had resulted in a fairly long delay. To me...  the problem of having to follow any suggestions is not a good thing. It would better if I could tell explicitly... but I do not want to.*

*Q:        As a matter of fact, you could...I mean you could communicate, but in this case you did not do that.*

A:        I *did not do that.*

*Q:      What are the factors involved in making your consideration...whether because you looked to seniority, physician factor itself, or other factors?*

*A:      In my opinion, it was a factor...er...I think I was the most senior. Also, from the viewpoint of scientific authority, I think they would listen. Perhaps the factor was economic considerations which immensely affected my deed.*

*Q:      Ideally... you could in fact have undertaken an intervention which had yielded a better result.*

*A:      Yes.*

*Q:      In addition to the quality of care  provided for the patient...er...What do you think is the best way to resolve this problem? With respect to the domination...or scientific authority, as you felt that you were dictated in this case...*

*A:      Well, I would say that the consultation should not be attached with...er...conditions. I think it was because my  culture did not permit me to make a direct communication... which put me in difficulty and prevented us from performing what we think to be the best thing.* (Surgeon, male)

The issue of conflict between doctors of different specialities was graphically described in the case of surgery and anaesthesiology by a surgeon and an anaesthetist respectively. The case was of a patient suffering from duodenal perforation with septicaemia. The surgeon and anaesthetist accused each other of trespassing into each other's respective fields of specialization. Justifying her decision to undertake a laparotomy, the surgeon accused the anaesthetist of undue interference. She said:

*Since gangrene developed, we decided to do laparotomy. So, we informed the anaesthetist. The anaesthetist came and asked, whether peritonitis was certain, whether this condition needed surgery, and she also asked to reconfirm the condition. In that way, the anaesthetist took part in the surgical field. Instead of planning to give anaesthesia to this chronic bronchitis and heart case, she created hindrances in laparotomy. But, laparotomy was done later, because of gangrene. Causes of gangrene were multifactorial, but one of the causes was the disagreement between the doctors, and the anaesthetist taking part in the other expert's field leading to delay in operation. We must take responsibility in our own field* (Surgeon, female).

On the other hand, in addition to commenting on what she saw as the high-handed treatment of anaesthetists by surgeons in general, the anaesthetist justified her decision to question the surgeon's diagnosis. She said:

Confirmation of the diagnosis is the surgeon's field. We neither supersede nor interfere in their field. But since the risk of the emergency operation is so great, we want the operation to be done only if the diagnosis is certain. In those cases, the patients came with different presentations and we have little time to do the optimization. Complications can arise at any time during the operation and also immediately afterwards during the post-operative period. So considering these facts, we should take the risk only if the diagnosis is certain. Sometimes in cases of presumed appendicitis, when we examine these cases, the guarding as well as rebound tenderness is not so prominent; so we think that the diagnosis is not so certain. As they are surgeons, we have no right to contest the diagnosis. But we must tell them our opinion. So, when we say that the case is not sure, and that they should take second opinion, they are not satisfied about it (Anaesthetist, female).

The role of status hierarchies among doctors in relation to doctor-doctor conflict were also discussed by some interviewees. A junior physician, for instance, said that he was forced to discharge a patient suffering from kala-azar at the behest of the senior consultant, even though he felt that the patient had not recovered sufficiently.

Interviewees felt that formal modalities should be worked out to deal with divergent opinions among colleagues, without bringing harm to patients. They felt that encouraging better communication between colleagues was a way of reducing doctor–doctor conflict at various levels i.e. between juniors and senior doctors and between various specialists and subspecialists. The need for a clear-cut delineation of authority between general practitioners and front-line physicians and specialists was also underscored by a few interviewees.

Interviewees discussed a range of situations involving dissent among colleagues. These disagreements were connected with larger issues of professional hierarchy, multi-disciplinary treatment, information management and the public-private interface in medical practice. Doctor-doctor conflict

was specifically discussed with reference to the medical consultation, second opinion, and the referral system. The need to ensure a good professional relationship among colleagues was stressed.

## Teaching responsibility

Some interviewees referred to the conflict experienced by them between delivering optimum patient care and their academic responsibilities as teachers. This issue was mainly discussed in the context of time management. Some senior doctors said that they found it at times difficult to balance their duties as treating physicians, teachers and researchers. The pattern of indexing frequency of teaching responsibility is given in the following table.

*Table 25:* **Pattern of indexing of "teaching responsibility" by centre**

|  | Variation Among Centres | | | | | |  |
|---|---|---|---|---|---|---|---|
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** |  |
| INT | Very Low | Very High | Low | Very Low | Low | None | Very Low |
| TXT | Very Low | Very High | Very Low | Low | Low | None | Very Low |

Discussions on teaching responsibility were most frequently indexed at the India centre. The topic was not indexed at all at the Sri Lanka centre, and discussions on teaching responsibility were sparse at the other research centres. At the overall level, it was not a frequently discussed issue.

Although the interviewees who brought up this issue said that patient care took precedence over training, there were situations when both had to be given equal priority, even if it was at the cost of violating the patient's autonomy. Expressing his dilemma in discharging his responsibilities as a physician and teacher, a dermatologist at the India centre described how patients could be manipulated into not refusing to be examined by students. He said:

*Another situation is where the patient has an illness that is not very common, and you want residents in training to have a look at the patient. It becomes a little ticklish. Do you actually overtly take the patient's permission to let others examine, or do you mention to the patient that you will ask some colleagues to come in, and take it for granted that she will not object? And only if she herself explicitly says no, then you stop others from coming in. Most of the times, we take a bit of a liberty with the patient, when we say that I'm going to ask a couple of my colleagues to have a look at you. Then you are careful not to mention the sex of your colleagues, when you make the statement, because if you say male doctors will come and have a look at you, she is more likely to say no. So we say, I am going to ask one of my colleagues to come and have a look, and you don't even ask if it is OK with the patient, because there again, there is a possibility she might refuse. You know that it requires somebody with a lot of confidence to say I do not want that. There again you see the situation, where someone has come to you for assistance, and they will not want to offend you by not letting you do something that you think is right. But they are not given much of a choice* (Dermatologist, male).

Other interviewees pointed to the unwillingness of some patients to cooperate with junior doctors. In addition to wanting only senior doctors to be attending on them, a few interviewees said that it was a frustrating experience for patients to repeat their medical history each time they were asked. On the other hand, one respondent said that, while patients have a right to treatment, they are also obliged to assist in training.

How best to fulfil their mandate as teachers without bringing harm to patients was discussed by some doctors. A few doctors wondered whether it was right to admonish a student doctor in front of patients and their relatives. For instance, if a junior doctor under the supervision of a senior doctor was performing a minor surgery on a patient under local anaesthesia, the patient might unnecessarily become anxious and confused at hearing the exchange between the two doctors. The patient might think that an incompetent doctor was managing him.

A couple of interviewees discussed their functions as teachers in the context of consumer rights and the increasing number of medico-legal cases. A doctor, for instance, noted that bedside discussions among doctors have become more restrictive, because of their apprehensions about how patients might react. He felt that this was compromising on academic responsibility.

Interviewees discussed how they tried to balance their duties as treating physicians, teachers and researchers. They described how they managed the conflicts arising out of these multiple functions in day-to-day clinical work.

## Vested interests

The interviews in this study were conducted in public hospitals. Some of these hospitals also have separate beds for private patients. Furthermore, some of the interviewees were also engaged in private practice outside the research centres. The issue of vested interests was discussed by some interviewees in the context of this public-private interface in medical practice. Table 26 presents the centre-wise indexing frequency of discussions on vested interest.

*Table 26:* **Pattern of indexing frequency of "vested interests" by centre**

|  | Variation Among Centres | | | | | |  |
|---|---|---|---|---|---|---|---|
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** |  |
| INT | Very Low | Very Low | Very High | Low | None | None | Low |
| TXT | Very Low | Very Low | Very High | Low | None | None | Low |

As in the case of doctor-doctor conflict, discussions on vested interests were most frequent at the Indonesian centre. The topic was not at all indexed at the Nepal and Sri Lanka centres, while discussions on vested interests at the other research centres were scanty.

A number of interviewees criticized the practice of colleagues treating cases falling out of their area of specialization and claiming specialization where they did not have it. While consultation and second opinion were considered to be legitimate practices for both doctors and patients, it was, however, felt that a doctor should not see a patient without the consent of the primary treating physician.

Respondents also criticised doctors working in private hospitals for not making timely referrals to government hospitals when they were unable to manage a case. They said that the tendency to hang onto the patient for as along as possible in order to make profit was highly objectionable.

While respondents were opposed to medical men functioning as businessmen, those in support of private practice were of the opinion that a balance should be established between the welfare of patients, the interests of hospital management and doctors' personal incomes. Thus, a few interviewees said that doctors with higher expertise and longer work experience had a right to demand a higher fee for the same procedure in comparison to their junior counterparts.

As in the case of recommending investigations outside the hospital and prescribing medicines that had to be purchased from the market, some doctors expressed anxiety at making referrals to doctors in the private sector. They feared arousing suspicion in patients to the effect there was a prior financial arrangement between them and the private practitioners.

A number of practices to enhance personal income were enumerated by some interviewees. For instance, the practice of doctors working in public hospitals taking jobs in many private hospitals resulted in their spending less time in the public hospital during working hours. Describing the situation, a doctor at the Indonesian centre said:

*Now, we could perform that one job outside, but we should not necessarily do another job there as well. Thus, perhaps we should select when to do a job that takes a lot of time. Perhaps, it should be done outside our working hours at the hospital. And perhaps the private hospitals should look for other physicians, who would be able to perform within those hours. It could be a financial loss, but we must be able make a proper decision, so that it won't result in any harm to our main hospital. But at the same time, it would still guarantee that we could have an appropriate compensation outside (*Radiologist, female).

Referring to the cost-sharing system prevalent in certain public hospitals in Myanmar, an anaesthetist decried the tendency of some surgeons in presenting a surgical case as a routine case and not as a private case, so as to avoid sharing profits with other members of the medical team.

Other doctors mentioned the practice of some of their colleagues functioning as patrons (or clients) of particular pharmaceutical companies. This practice was deplored by those who brought up the issue, because it was felt that personal interest superseded objective assessment. The sponsorship of

medical seminars, conferences and research by pharmaceutical companies was also discussed in a couple of interviews, pointing to the risk of unwarranted influence on clinical decision-making stemming from these activities.

The theme of vested interests was discussed in the context of a range of practices in the public and private sector that were considered to be objectionable by the interviewees. Although working in the private sector was not considered wrong by participants, they felt that since the profit motive was a driving force, doctors had to show extra self-restraint.

## Methods of conflict-solving

Table 27 presents the centre-wise distribution of discussions around the theme of establishment of professional standards of practice.

*Table 27*: **Pattern of indexing frequency of "Establishment of professional standards of practice"**

|  | Variation Among Centres | | | | | |  |
|---|---|---|---|---|---|---|---|
|  | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** |  |
| INT | Very Low | Very Low | Very High | Very Low | None | Very Low | Medium |
| TXT | Very Low | Very Low | Very High | Very Low | None | Very Low | Medium |

Discussions on professional regulation of medical practice were a major topic of discussion at the Indonesian centre. It was discussed at the other centres relatively less frequent and was overall a topic of moderately frequently discussion.

## Establishment of professional standards of practice

The need to expand the functioning of professional medical associations, not only to reduce doctor-doctor conflict and protect doctors against prosecution, but also to improve the quality of medical care, was discussed by many interviewees. Underscoring the need for such bodies, a doctor at the Indonesian centre said:

*Whether it is a body of organizational profession, or a scientific council, I am extremely aware that the need for such a body has been pressing: so we can draw up a standard procedure on diagnostic interventions, on therapy, contraindications, etc. There should be a competency standard, and it should be clear with respect to the indications and contraindications. Sometimes, we perform an intervention, which is, in fact, a shortcut. We perform an intervention with insufficient examinations. This is what I have seen, and I think that all professions require that there be guidelines. These guidelines may not be comfortable, but they could safeguard us, particularly from prosecution (*Pulmonologist, male).

Such a formal organization, that would supervise professional conduct and establish criteria of professional competence, it was suggested, should be charged with a number of functions. A large number of interviewees felt the need to establish a formal Standard of Procedure (SOP). The SOP, it was argued, should cover both technical and ethical issues in medical practice. The need to formalize the informed consent procedure has already been discussed in Part One. Given the gap between formal guidelines and their actual implementation in day-to-day practice, it was pointed out that the SOP should not be too rigid, but should be able to accommodate to the diverse contexts in which physicians practice.

Some interviewees reiterated the need to establish formal norms of consultation and second opinion. Others felt that there was a need to streamline the consultation process between different hospitals, e.g. between district and referral hospitals.

The role of manpower and medical equipment and facilities was also discussed in connection with the establishment and implementation of the SOP. Given the relative shortage of facilities and manpower at district hospitals, some interviewees were of the opinion that the SOP at the district level should be simpler in comparison to that being implemented in the city hospitals. One senior doctor at the Indonesian centre expressed his opinion in this connection:

*I think at the faculty, each department should have its own standard [of procedure]. They have published the books and we have all read them. They*

*are the standard guidelines that we must cling to. Usually, the standards of the faculty are already there. But in teaching students, I always say that not all of them would be practising here. Not all of them will be stationed at the University or in the big cities. Certainly, there will be many who will be stationed in small towns. So, they may not get the expensive medication, other than the standard ones. There might be adrenaline or aminiotilin that they could use. At present, these medications have been abandoned at teaching centres. Yet, in the district they are still a major modality of treatment. Students have to know about them. We also used them in the past. It is only now that we have more sophisticated ones* (Physician, male).

Some interviewees made distinctions between different standards of procedure depending upon their ambit of application. While the general standard of procedure was discussed with reference to the health care system in general, some respondents spoke of a professional SOP operating at the level of the profession. Yet others referred to the hospital standard of procedure in the context of specific health care facilities. A cardiologist made a distinction between standard of service, standard of profession and standard of management.

Although there was a consensus among interviewees on the establishment and implementation of SOP, some interviewees pointed out that this formalization should not be at the cost of self-regulation among colleagues. For instance, one doctor said that if a colleague was performing too many abortions, he should be reminded that his practice was questionable. The matter should only be taken up at a more formal level, if he continued with the practice without paying heed to the subtle reprimand.

It was also felt by some interviewees that the situation with regard to the standardization of procedure was more favourable in the Western countries.

The need to expand the functioning of professional medical associations, not only to reduce doctor-doctor conflict and protect doctors against prosecution, but also to improve the quality of medical care, was discussed by many interviewees. The need for a Standard of Procedure (SOP) that would regulate professional conduct and establish criteria of professional competence, was stressed.

### Legal regulation of medical practice

Medico-legal cases were discussed by a number of interviewees in a range of situations from rape cases to the involuntary treatment of psychiatric patients. One doctor stressed the need to establish medico-legal wards in general hospitals to handle cases brought in for treatment by the police. An endocrinologist at the India centre bemoaned the absence of formal legal guidelines for the treatment of gender identity disorders. Medical practice and the law were also discussed by a few doctors in the context of domestic violence, especially dowry-related violence in India.

A large number of doctors underscored the need for legal guidelines to regulate professional practice, especially in connection with ethical issues. Some doctors, working in countries where abortion is illegal, pointed out that they faced a dilemma in performing procedures of medical termination of pregnancy. A doctor at the Sri Lanka centre said that although abortion was permitted, when it was a question of saving the life of the mother, it was technically illegal when performed to terminate an abnormal foetus. Although such operations were performed, legal action could be taken against such doctors. On the other hand, another doctor at the Indonesian centre said that he might refuse to perform an abortion, when asked by a patient who desperately wanted to terminate the pregnancy, but there would always be other doctors willing to undertake the procedure in order to make money. With the expansion and consequent commercialization of the medical profession, other interviewees felt that there should be more stringent legal restrictions on competition, although the nature of such restrictions was not explicitly delineated.

Thus it can be seen that legal regulation of medical practice was discussed in connection with different themes. For instance, the matter was discussed in counties where abortion was still illegal. The need for regulation of competition in the private sector was stressed.

## Decision-making under resource constraints

In this section, interviewees' evaluation of clinical decision-making will be examined in terms of a set of categories that carry relevance for discussions on ethical dilemmas in clinical practice. During the analysis of interviews, one set

of categories that emerged was connected with the nature and process of decision-making, One question raised was whether the decision taken was typical or not; and if it was typical, in what sense was it so. The second question was whether the interviewees had discussed the case with colleagues or not; and if it had been discussed, what was the nature of the discussion. Given another case under similar circumstances, would the interviewee repeat the same decision?

It was also found that clinical decision-making at times entailed an element of compulsion. This compulsion could be in the nature of a doctor forcing a decision upon another doctor, a doctor imposing a decision on a patient, or relatives forcing a decision on a patient.

Finally, another important dimension of clinical decision-making was concerned with agency, i.e. the person who was identified by the interviewee as the central actor in the ethical dilemma.

These aspects of decision-making will be discussed in this section under the headings:

➢ Elements of Decision-Making

➢ Agency in Decision-Making

## Elements of decision-making

In this section, we will initially examine three selected aspects of decision-making. We will analyse the responses of interviewees to such questions as to whether the decision made was typical, whether it was discussed with colleagues, and whether the interviewees would repeat the decision under similar circumstances in the future.

### *Typical case*

As seen in the following table, a majority of the interviewees said that the ethical dilemmas that they had described were perceived by theme to be typical in nature. While, on an overall average, the typicality of cases used to illustrate ethical dilemmas was considered very high, at the Indonesian centre, the number of perceived typical cases was comparatively low.

*Table 28:* **Pattern of indexing of "typical cases" by centre**

| | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
| | **BAN** | **IND** | **INO** | **MMR** | **NEP** | **SRL** | |
| TYP | Medium | High | Low | Medium | Medium | Medium | Very High |
| NOT TYP | Medium | Very High | Medium | Very High | Very High | High | Medium |

Note: TYP = typical cases, NOT TYP = Not typical cases

Since there were no questions in the interview guide to probe what precisely constituted the typicality or a-typicality of a decision, we can only infer from the responses how interviewees interpreted the question. It appears that typical was most frequently interpreted by the respondents to refer to the frequency of occurrence of the problem under discussion. Thus, many interviewees said that shortages of medical equipment and facilities were a typical feature of the hospital settings in which they were practising. For instance, a surgeon said that he was forced to plan an operative procedure on a patient suffering from an abdominal lump without the requisite pre-operative investigations, because neither could the hospital provide them free of cost nor could the patient afford to have them done from the market. This, in his opinion, was a typical situation.

Other respondents interpreted typical in terms of the occurrence of a particular disease condition, such as the high incidence of spinal injuries in the population. The same disease condition could be interpreted as typical in one centre and atypical at another centre. For instance, a doctor at the Myanmar centre said that they were getting two to three HIV seropositive cases a week, which was in his opinion quite typical. On the other hand, a doctor at the India centre said that they did not get many such cases, and the problem was, according to him, not so typical.

Several psychiatrists gave examples of cases that posed ethical dilemmas, which they felt were not so typical. For instance, one psychiatrist at the Indonesian centre cited the case of a young girl who told him that she had been involved in prostitution. The doctor wondered whether he should pass this information onto the father but he feared the consequences of such a move for the patient.

*Discussion with colleagues*

A large number of interviewees affirmed that they had discussed the ethical dilemmas that they had described, with colleagues. The pattern of indexing of this theme is given in table 29 below.

*Table 29:* **Pattern of indexing of "Discussion with colleagues",
no. of interview documents by centre**

| | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
| | BAN | IND | INO | MMR | NEP | SRL | |
| Discussed with colleagues | Medium | High | Low | Medium | High | High | Very High |
| Not Discussed with colleagues | None | Medium | Medium | Very High | High | None | Very Low |

There were no cases where colleagues had not been consulted at the Bangladesh and Sri Lanka centres, while at the other centres, the incidence of not discussing with colleagues was also very low. However, differences in the indexing pattern of the same theme interview-wise and text unit-wise suggest that, as in the case of typical cases, the responses were more concise though lacking in density. This despite the fact that many interviewers did explicitly probe into the nature of the discussion that the interviewees reported to have had with colleagues.

The ward and teaching rounds and case conferences were cited as occasions for such discussions, when cases were regularly reviewed. Furthermore, some respondents said that the practices of consultation and second opinion also provided opportunities for discussions with colleagues. Some respondents pointed out that multidisciplinary treatment at referral centres required close and constant interaction between various members of the treatment team.

A few doctors referred to disagreements among colleagues and the impact of this on clinical decision-making. Thus, one anaesthetist at the Sri Lanka centre said:

*There is one case I remember. This patient was admitted to the Intensive Care Unit after snakebite with respiratory paralysis, and he was on ventilator. I can't remember exactly for how long, but quite a long time. And there was no response. Brain death tests were carried out. There were three consultants at the ICU at that time. We discussed this patient and wondered what to do. One of us was in favour of switching off the ventilator, because it had been a long time and brain death tests were positive. But other two of us were not in agreement. So, we decided to keep her on for some more time. And it was about one or two weeks later, the child recovered* (Anaesthetist, female).

Another doctor at the Nepal centre described a case of a child suffering from retinoblastoma, in which his decision to do surgery was influenced by his colleagues. He said:

*Initially, I had certain reservations about operation, but some colleagues thought we should go ahead and do it. I was not favourably disposed to doing the operation, which is, you know, a fairly extensive destructive surgery. But I gave in and said that okay this is one thing that we can offer to the child at no great cost to us and to the family. So, although I was initially not favourably disposed, I listened to the advice of others and said okay we can go ahead and do it* (Ophthalmologist, male).

Several interviewees said that although group discussion was the norm in the case of hospitalized cases, it was not always the case in the OPD. The rush of patients and paucity of time made it difficult to consult colleagues for each and every case.

Some participants pointed out that discussions on ethical dilemmas, especially in the context of doctor-doctor interaction, could be discussed at the level of the professional association. This was brought up in the context of discussions on doctors practising outside their chosen field of specialization.

A couple of doctors said that the issue of withholding a cancer diagnosis from a patient was such a routine practice that they did not discuss it with their colleagues. Others said that the issue was controversial, and they did bring up the matter with their colleagues. A few doctors said that they only

discussed difficult cases with their colleagues. One doctor said that he chose not to discuss the case of a female leprosy patient with colleagues, because her husband did not want his wife to be examined by other doctors. He said:

*Generally we do tend to discuss the decisions with other colleagues. Normally, when you call other colleagues in, usually you ask the patient's permission. You ask the patient: do you mind discussing with other doctors? But this particular patient's husband was very emphatic, and refused to have his wife examined by so many doctors. He didn't want many people to get involved in this* (Dermatologist, male).

However, the study was not carried out in such a way as to bring light on local interpretations of what would count as a 'discussion' (as different from 'information', 'sharing', 'mentioning', etc.) or what was the nature of discussions, or what types of ethical dilemmas were discussed (or not) in what ways. Looking at the results we have on this issue, we believe that there is a risk of bias similar to what Bernard calls 'deference effect' on this particular issue, leading to an over-reporting of issues 'discussed' with colleagues.[5]

### *Repeat decision*

When asked whether they would repeat the decision taken if other circumstances were similar, practically all of the participants answered in the affirmative. This is presented in the table given below:

*Table 30:* **Pattern of indexing of "repeat decision" in no. of interview documents by centre**

| | Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|---|
| | BAN | IND | INO | MMR | NEP | SRL | |
| Repeat Decision | Low | Low | Very Low | Medium | Low | Very High | High |
| Not Repeat Decision | None | Very Low | Low | High | Very High | None | Very Low |

[5] Bernard, H. Russell: Research Methods in Anthropology, Second Ed., Sage, 1994

While repeating decision (affirmative) was discussed in a large number of interviews at the India and Nepal centres, the corresponding decline in terms of number of text units shows that the issue was not discussed in great detail. Caution should be observed in interpreting the table. Looking at Myanmar as an example, the 'Medium' value is relative to the other centres on 'REP'; it is NOT relative to the MMR value for 'NOT REP'. Only the overall frequency indicates that 'REP' is much more frequent than 'NOT REP'.

Most of those who answered in the affirmative, when asked whether they would repeat the decision, however, qualified their answer by adding that they would follow a case-by-case approach, since no two cases could be truly identical. One neurologist said that he always kept the case as an index. There were some participants, who took a more ambiguous position by saying "might be", when this query was posed to them.

A large majority of the interviewees said that the ethical dilemmas, which they had delineated, were typical in nature. They interpreted typical and atypical categories primarily in quantitative terms, i.e. the frequency of occurrence of a given phenomenon (rather than thinking in qualitative typologies and referring a case to a certain type irrespective of its frequency). Again, a majority of interviewees affirmed that they had discussed the cases they had described with colleagues. They pointed out that clinical decision-making involved teamwork and the ward and teaching rounds offered ample opportunities for discussions. A majority of interviewees expressed satisfaction with the decisions they had taken. And they asserted that they would repeat the decision, if presented with a similar case under similar circumstances

### *Forcing a decision*

Three categories were inferred during analysis in connection with forcing a decision, *viz.,* a doctor forcing a decision on another doctor, a doctor forcing a decision on a patient and relatives forcing a decision on a patient. The relative indexing frequency of these categories is given in Table 31:

*Table 31:* **Pattern of indexing of "forcing a decision" by centre**

| | BAN | IND | INO | MMR | NEP | SRL | |
|---|---|---|---|---|---|---|---|
| | Variation Among Centres | | | | | | |
| | BAN | IND | INO | MMR | NEP | SRL | |
| **Doctor forcing a decision upon a doctor** | | | | | | | |
| INT | Very Low | Very High | Very High | Very Low | None | None | Very Low |
| TXT | Very Low | Very High | High | Very Low | None | None | Very Low |
| **Doctor forcing a decision upon a patient** | | | | | | | |
| INT | Very Low | High | Medium | Very Low | Low | Very Low | Medium |
| TXT | Very Low | Very High | Medium | Very Low | Low | Low | Medium |
| **Relatives forcing a decision upon a patient** | | | | | | | |
| INT | Very Low | Very High | Medium | Very Low | Low | Low | Low |
| TXT | Very Low | High | Low | Low | Very Low | Low | Low |

While discussions on a doctor forcing a decision on another doctor were uniformly sparse or even non-existent at some centres, discussions on a doctor forcing a decision on a patient was much more frequent and showed more variation. The theme was discussed very often at the India centre, moderately at the Indonesian and Nepal centres and very little at the remaining centres. Again, there was more discussion on relatives forcing a decision on a patient at the India centre with much less discussion on the theme at the other centres. Overall, issues of somebody forcing a decision on somebody else were much more frequently perceived in relation to ethical dilemmas in India, followed by Indonesia, than in the other centres. The study does not show, whether this reflects differences in actual decision-making processes across the centres, or differences in perception of the ethics of decision-making, or (as would be most likely) both.

*Doctor forcing a decision on another doctor*

The issue of doctor forcing a decision upon another doctor was most often discussed in the context of a senior doctor imposing a decision on a junior doctor. This issue should be seen in the light of the issue of discussing ethical dilemmas with colleagues. It is noteworthy that while doctors generally said that they did discuss issues with colleagues, this was not so for issues where there was a conflict. Conflicts were generally kept hidden, and there seemed to be a general avoidance of open confrontation on disagreements between doctors across the centres.

*Doctor forcing a decision on a patient*

Far more numerous than the doctor forcing a decision on another doctor were instances wherein a doctor was perceived to be forcing a decision on a patient. For instance, a surgeon at the Myanmar centre recounted the case of patient suffering from closed abdominal injury, who was not immediately given analgesics to ease the pain. Although a doctor's primary duty is to help the patient, the surgeon said that treatment was withheld to observe the patient and ascertain the exact diagnosis. If the patient was immediately medicated, then the signs and symptoms of the underlying disease would have been masked, and the patient's condition might have worsened in the long run. The doctor said that he had discussed the case with colleagues and that he would repeat the decision under similar circumstances.

The issue of a doctor forcing a decision on a patient came up in a number of themes, ranging from withholding confidential information from the patient to treatment delay and refusal due to the non-availability of a vacant bed. Long waiting lists were also cited by many doctors as a major factor contributing to treatment delay.

In an emergency situation the patient has no choice and must submit to the decision of the treating physician. For instance, a doctor at the Indonesian centre described a case where he removed the respirator from a patient, because he felt that he had to choose who would be given the limited medical facilities. He said that he had to choose between maintaining a patient on life support, whose prognosis was very unfavourable, and making the limited medical facilities available to someone else in a similar situation, who had higher chances of recovering. He said:

*It was the patients, who could not be admitted (to the ICU) and later would die, that I should care for. And it happened that there was a patient with sepsis, who could, in fact, recover by being cared for in the ICU, but as the place was occupied by this patient with such a bad prognosis; it means that we wiped out the opportunity. I had emphasized that. It turned out the patient died in twenty minutes after he was removed. The patient's family then complained to me, and I said that I was responsible in this respect. Two factors I took as my guidance. Firstly, the circulatory letter from the Pope, and second was that by maintaining his life, we shut out the chances for others (Gastroenterologist, male).*

The issue of a doctor forcing a decision upon a patient also came up in the context of patients receiving suboptimal treatment due to shortages of medical supplies and facilities. For instance, a doctor at the Bangladesh centre cited the case of a patient suffering from puerperal sepsis, who was forced to stop breast-feeding her child. The treating physician justified her decision on the following grounds:

*A patient came to me with complaints of temperature and foul smelling discharge. She had a delivery five days back. She had also undergone vaginal swab culture sensitivity and the report was that there was a profuse growth of E.coli, which was sensitive to only ciprofloxacin. But the patient was so poor that it was not possible for me to advise her to take ceftriaxone from outside. I had to give her ciprofloxacin, though I knew that ciprofloxacin ideally should not be given to a lactating mother. So, I think it is a type of ethical dilemma. I had to stop breast-feeding, as I know that ciprofloxacin can cause some cartilaginous abnormality, if taken during lactating period (Gynaecologist, female).*

A few doctors also discussed the issue of a doctor forcing a decision on a patient in the context of teaching responsibility. Delineating his dilemma between his responsibilities as a physician and as a teacher, a dermatologist said:

*Sometimes, there is a dilemma between one's responsibility to one's patient vis-à-vis the responsibility towards students in the department. A four-month-old baby was brought to me this morning with a condition called acrodermatitis. She has lesions around the mouth, hands and feet and on the buttocks. She was not particularly uncomfortable but this is where we normally*

*see the patient, advise them. We try to ensure that they spend the least time in the department. But there is also our duty to train the doctors, who are working with us, to recognize and treat disorders. So, this involves some extra waiting on the part of patients and also the discomfort of being examined more than once. This is what I subjected this patient to in the morning, so that my colleagues would have a chance to see it, to learn from it. There is a dilemma between what is best for the patient, and subjecting the patient to some discomfort. It should make no difference to his illness or his treatment, unless the patient is extremely ill and would be actually harmed by waiting or by being examined by more than one person. There are few situations when that happens. We put them through this extra examination, because in order to better provide patient care, we have to train people to become good physicians* (Dermatologist, male).

The issue of a doctor forcing a decision on a patient is closely linked to the issue of patient autonomy. While patients in many cases were seen to be submitting to the decisions of their doctors and families, there were a few cases where patients made informed choices, and the doctor had to observe the patient's right even though the decision was not the best treatment option. For instance, a surgeon at the Indonesian centre described the case of a severely diabetic patient requiring amputation, who instead decided to get discharged from the hospital and go to what he termed a witchdoctor.

A gynaecologist at the India centre described another case, where the wishes of the patient were honoured. She said:

*I had a post-operative case, who had a vulvar dysplasia. And there was a doubt of malignancy. So, we did a biopsy that showed a carcinoma. Now, this lady was not at all willing to undergo a second surgery. She said, 'No, I just do not want to have the second surgery'. She was already seventy plus [years of age], and she said that she had no symptoms. She argued, 'There was a little growth, which you have already removed, so why should I have second surgery?' So there was a problem convincing her, because once we have found a cancer, then she needs a little more radical surgery, rather than just leaving her in the follow-up. She is medically fit. But I could not convince her that surgery will not harm her. She said since in any case she did not have much life left, so why mutilate her body. Then, we took a decision not to undertake any intervention* (Gynaecologist, female).

### *Relatives forcing a decision on a patient*

The issue of relatives forcing a decision on a patient has been discussed in the context of barriers to treatment from the relatives' side. The issue also came up in the context of withholding confidential information wherein families prevail upon the doctor not to reveal the diagnosis to the patient. The theme also came up in the context of end-of-life decisions, when the family insists on keeping the patient on life support even though the doctors have arrived at a consensus to let the patient die.

A number of examples were provided by interviewees from which the role of relatives in imposing a decision on a patient can be inferred. For instance, a physician at the India centre described the case of a family, who refused to have their ailing relative be kept in the ICU. The reason for this unwillingness was that another family member had died sometime ago in the ICU of the same hospital. This, according to the doctor, resulted in delay and deterioration in the patient's condition, before the family members were persuaded to change mind. Some doctors cited instances of patients being forcibly discharged from the hospital by relatives in order to take them to perceived witchdoctors and other folk healers. One doctor cited the case of a patient scheduled for amputation whose relatives had him discharged at the last moment in order to seek a second opinion. The doctor said that he was very frustrated in this case, because deciding to undertake an amputation was in itself a very difficult decision, a treatment option of last resort.

Several gynaecologists discussed the role of relatives, especially the woman's in-laws, in medical treatment. One doctor at the India centre mentioned how women, suffering from infertility, were forced to seek treatment, because of their families insistence that they produce children, even if it meant endangering their life.

In some cases there was an overlap between doctor forcing a decision on the patient and relatives forcing a decision on the patient. This was most often observed in the case of end-of-life decisions, when both parties agreed to euthanasia. An agreement between doctor and relatives could also occur in the choice of a treatment modality, which the patient opposes. For instance, a surgeon described the case of a patient suffering from severe diabetes, who categorically refused to undergo an amputation even though he was fully aware that it was a matter of life and death. The family gave consent and the amputation was performed in the face of stiff opposition from the patient.

The overlap between a doctor forcing a decision and relatives forcing a decision on a patient was also observed in cases of involuntary hospitalization of psychiatric patients. A couple of psychiatrists pointed out how they were at times forced to admit patients, because they were a management problem for their families rather than because their illness required them to be isolated from society. As one psychiatrist at the Myanmar centre said in connection with one such case:

*Because the patient had no mental illness, and I wonder whether it was fair or not for the individual patient. The patient did not want to be hospitalized and I had to decide against his will for the benefit of the family* (Psychiatrist, male).

In the absence of other viable alternatives, this doctor said that he would repeat his decision in a similar case in the future.

The issue of doctor forcing a decision upon another doctor was most often discussed in the context of a senior doctor imposing a decision on a junior doctor. The issue of a doctor forcing a decision on a patient was discussed in connection with a number of themes, ranging from withholding confidential information from the patient to treatment delay and refusal. The theme was also discussed in the context of end-of-life decision and teaching responsibility. The issue of relatives forcing a decision on a patient was discussed in the context of barriers to treatment from relatives' side. The issue also came up in the context of withholding confidential information and end-of-life decisions.

## Agency in decision-making

Interviewees were directly asked whom they considered the main persons in the ethical dilemma that they had themselves described. The interpretation of the question was very much left to the interviewees to decide. This generated a multiplicity of interpretations, which makes comparative analysis difficult. Inter-interviewer variation is also to be considered in this connection. While some interviewees interpreted central agency in terms of causative factors responsible for the problem, others interpreted it in terms of those directly affected by the problem, i.e. patients and relatives. Yet others castigated the

entire health care system, which was held responsible for many problems occurring in clinical practice. Some interviewees even interpreted it in terms of areas for improvement. Often, several factors together were identified by interviewees as central in the ethical dilemma under discussion. It is these heterogeneous responses which will be examined in greater detail below. Table 32 shows the indexing frequency of agency by centre.

*Table 32:* **Pattern of indexing of identification of various types of "Central Agency" by centre (interview documents)**

| Variation Among Centres | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | | **Overall freq.** |
| **DR Self** | | | | | | |
| Very Low | Very High | Very Low | Low | Very Low | None | Low |
| **DR other** | | | | | | |
| Very Low | Very High | Very Low | High | None | None | Very Low |
| **Staff (Other than physicians)** | | | | | | |
| Medium | Very High | Very Low | Medium | High | None | Very Low |
| **Patient Self** | | | | | | |
| Low | Very High | Very Low | Medium | High | None | Medium |
| **Patient's Relatives** | | | | | | |
| Very Low | Very High | Very Low | Low | Medium | None | Medium |
| **Other** | | | | | | |
| High | Low | Very Low | Low | Very High | Medium | Medium |
| **Nobody** | | | | | | |
| Very Low | Very Low | None | Low | None | Very High | Very Low |

The above table shows that discussions on the doctor him/herself as the central agent were highest at the India centre and entirely absent at the Sri Lanka centre. Discussions on other doctors as central agents were again highest at the India centre, followed by Myanmar. There were no discussions on this topic at the Nepal and Sri Lanka centres. Other staff as central agents were also highest at the India centre, followed by Bangladesh and Myanmar. This topic was absent at the Sri Lanka centre. Discussions on the patient as the central agent in the creation of the ethical dilemma were very frequent at the India centre, frequent at the Nepal centre and moderately frequent at the Myanmar centre. A similar pattern of indexing frequency was observed in connection with patient's relatives being perceived as central agents. The topic of others as central agents was most frequently discussed at the Nepal and Bangladesh centres. Lastly, nobody being perceived as central agents was the general picture only at the Sri Lanka centre.

### *Doctor as central agent*

Doctors considered themselves to be central actors in a range of tasks in routine clinical work, ranging from deciding the course of optimum treatment for individual cases to switching off life support systems in the case of end-of-life decisions. Underscoring the decision-making role of the clinician, a doctor at the India centre said:

*Again, I think the central person is the doctor. Because the patient and the family members very often will not bother about it, once we look. We say to them, 'Look, this is the problem and this is what needs to be done.' They usually then accept it: and they will go away. Then, there will be another case with a similar or another problem. Again, the treating doctor becomes the central figure* (Neurologist, male).

Some doctors considered themselves to be central agents of the ethical dilemma in cases involving information management, wherein a patient was not informed about his diagnosis. One physician said that even though he was withholding the diagnosis of cancer from a patient at the behest of her family, yet he felt he was the central person in this ethical dilemma. Other doctors, however, were of the opinion that patients were central agents in such cases, because they were the ones who were most affected by the decision. One doctor said that the central person was the one who was legally authorized to give consent for an operative procedure. This would most often be the

patient, but it could also be the guardian in the case of a legally incompetent person, such as a child.

A number of doctors said that they considered themselves to be central persons involved in cases of treatment refusal. One doctor said that when it came to deciding who got the limited quantity of blood in the hospital emergency, it was he who decided who would be treated and who would not be. Even when it was a case of refusing treatment due to non-availability of a hospital bed, some doctors still regarded themselves as central agents They said that they felt helpless, angry, and at times guilty at not being able to discharge their duties as responsible physicians, due to material constraints.

Doctors also held themselves to be responsible in cases of misdiagnosis. For instance, when a patient with a provisional diagnosis of inflamed appendicitis was opened and it was found that the actual diagnosis was pus in the pelvic cavity, the operating surgeon said that he was the one who had to decide whether to have the normal appendix removed or not.

Some interviewees also considered themselves to be central actors when it was a question of self-perceived acts of omission. For instance, a psychiatrist recounted the case of a mentally ill patient, who was sexually molested on her way to the hospital. Subsequently, she went to the police to file a case on her own, but no action was taken. The psychiatrist felt guilty because he had not had a social worker accompany the patient, when the latter went to the police station. He felt that the police would have taken some action, if the patient had been sent with a hospital staff. In another case, a doctor felt bad because he had not been able to accede to the request of a renal patient for an interview. But before he could see her, she had died in the ward. Thus, it appears that some interviewees were more likely to identify themselves as central figures in ethical dilemmas, wherein they expressed themselves to be emotionally affected.

In addition to stressing their central role in all matters related to diagnosis and treatment, a few doctors also said that they considered themselves to be playing a decisive role in clinical research. They underscored the important task of balancing the interests of patients and the aims of research protocols, especially with regard to the implementation of informed consent procedures.

### *Other doctor as central agent*

In cases where, in addition to themselves, interviewees also identified someone else as central to the ethical dilemma under discussion, the second person was most often another doctor. Consequently, in certain cases of doctor-doctor conflict, the dyad doctor-doctor was identified as the central agency. Thus, one physician described how he differed with the opinion of a colleague in the treatment of leukaemia in a child, who was also suffering from Down's Syndrome. While the treating physician felt that using aggressive chemotherapy was not a viable treatment option, his colleague disagreed. However, they had to take a joint decision. The treating doctor felt that both of them were central in this dilemma, because they had to come to some sort of consensus on the course of treatment. Some doctors pointed out that in the context of multidisciplinary treatment, it was not a single doctor but a treatment team that played a decisive role. Consequently, if some complication occurred, no one individual could be held responsible, because providing treatment was a joint exercise.

### *Other staff as central agent*

In other cases, interviewees made a distinction between situations in which they and other colleagues were involved, and those in which other staff members or hospital administration in general were identified as central agency, without any direct involvement of the interviewees. A few interviewees identified the lower-level staff and trade union activities as playing a central role in treatment. Thus, one psychiatrist described how he was forced to prematurely discharge several ward patients because of an impending strike. Other doctors said that they were often forced to refuse treatment or provide only suboptimal treatment, because some important component of treatment was not available in the hospital. For instance, an orthopaedic surgeon described how he was forced to make a referral to another hospital in the case of a child requiring bone grafting, because the hospital tissue bank did not have any bone tissue to supply. In yet another case, a psychiatrist recounted the case of an alcoholic male patient, who was abusive with the staff at the community de-addiction clinic to such an extent that the latter were contemplating refusing treatment. In this situation, the psychiatrist felt that the central agency was the clinic staff, who had to decide on what to do with the patient.

### *Patient as central agent*

Despite the determinative role assigned to families in medical decision-making, a large number of interviewees showed respect for the autonomy of patients by assigning them the role of central agency. As one doctor said:

*Without the patient the dilemma does not arise* (Physician, male).

In cases of medical termination of pregnancy, the patient was usually considered the central agent. In one pregnancy-related case, the doctor identified the mother and unborn child as the central persons. This was in connection with the case of a female leprosy patient in the early months of her pregnancy.

Examining the role of poverty in medical treatment, some doctors said in cases where patients could not afford treatment, the ethical dilemma revolved around their financial incapacity. In yet other cases, where patients were fearful of undergoing surgery or other medical procedures, central agency was attributed by the interviewees to patients' emotional vulnerability. In another situation, where a patient was unable to undergo an urgent investigation in the hospital due to a long waiting list, the doctor felt that the patient was the central agent, because it was he who needed the investigation on a priority basis.

### *Relatives as central agency*

Relatives were identified as central figures in a range of situations. In the case of treatment of children, their parents, especially the father, were mainly identified as the principal actors. For instance, when the family could not afford to buy the medicines required for their child suffering from meningitis, the paediatrician felt that poverty of the family was the major obstacle to treatment of the child. Similarly, a number of doctors identified relatives as central in connection with disclosure and withholding of confidential information. In case of families' refusal to take home psychiatric patients after discharge, some psychiatrists felt that relatives were the main persons involved in such cases.

In a case of a woman, who had conceived within three months after delivery, a doctor at the Indonesian centre felt that the husband was the central figure, because he had failed to use condoms. In another case the husband was considered to be the main actor, because he was not giving permission for medical termination of pregnancy, even though its continuation was a threat to the life of the mother.

As already mentioned the responses of interviewees regarding agency at times showed an overlap between different factors. For instance, in their inability to offer optimum treatment to patients, several interviewees said, that they considered themselves central actors, but equally important in this dilemma were other factors, such as shortages of hospital facilities and heavy workloads. On the other hand, a cardiologist felt that all three parties, viz., doctor, patient and relatives were equal partners, since they all had stakes in decision-making. Examining the complexity of the situation from the perspective of agency in the disclosure of a cancer diagnosis to a patient, a surgeon at the India centre said:

*I think the central person involved in the dilemma is the patient himself. He does not know what's happening. His relatives are very keen that he is not told what is happening to him. He has come here with a lot of hope. I can't give him any hope, and I feel very bad telling him that I can't do anything. So, I will end up telling his relatives, or I have already told the relatives. But if he asks me straight on my face: am I going to live? Am I going to die? Do I have a cancer? I will tell him what it is. But if he doesn't, then I will probably end up only telling his relatives. So, the key person, I think, involved in this dilemma is the patient himself. Well, the dilemma affects me, but essentially in all these situations, it is the person who is going to be affected by the dilemma, who to my mind is the central person. Two weeks, three weeks, four weeks down the line, I will have other patients with the same kind of problem, and six years later probably I will get used to this. But for the patient and for the family, this is the one dilemma; for them this is central and so they are the focus of the dilemma* (Surgeon, male).

Describing the shift in the central person(s) from clinician to family, a paediatrician said:

*I feel it's the clinician who has ethical dilemma. However, when it comes to the cost, and if we disclose the information to the parents... We tell them that the treatment is available but they will not be able to afford this treatment, then the whole thing gets shifted to the parents. It's only before disclosing that the clinician is in a dilemma, to do it or not to do it. But once you have passed on the information to the parents, then the parents are the ones who suffer. In fact, if they are not able to afford it, they feel guilty that despite the availability of treatment, they are not able to afford it* (Paediatrician, female).

### *Other as central agent*

When interviewees either attributed agency to persons or factors not covered by other categories, such cases were during analysis grouped together under the general rubric of other. General poverty, inadequate attention to health problems by the State, paucity of hospital beds and other medical equipment and facilities were cited as major factors in doctors' inability to make available the best possible treatment to patients. These issues came up more often in the context of end-of-life decisions and the management of various types of handicaps, such as paraplegia and quadriplegia.

It can be seen that six components were identified in the interviews as constituting the category of central agency. More often than not, interviewees felt that no factor in isolation was central to the ethical dilemmas under discussion, since there was considerable overlap between the different central agency categories. Also, the concept of agency was understood very differently both among interviewees and among centres, pointing to a need for more research to better understand this aspect of health ethics.

## Summary

### *Institutional constraints on clinical practice*

Four constraints at institutional level were identified in the interviews. These were shortages of medical equipment and facilities, manpower and blood. Deficiencies in the wider health infrastructure were also discussed in this connection.

*Shortages of medical equipment and facilities*

This topic was discussed in the context of shortages of drugs, investigation procedures, and blood and other life-saving equipment. The problems of long-term management of chronic conditions like functional psychosis and mental and physical handicaps were also discussed. Some interviewees mentioned strategies they had devised to cope with these material constraints. Using drug samples provided by pharmaceutical companies and arranging donations for poor patients were mentioned.

*Shortage of manpower*

In the context of heavy workloads and rapid turnover of patient populations, interviewees pointed to shortages of all categories of medical staff. The need for more paramedical, nursing and emergency care staff was stressed. Interviewees pointed out that the quality of care was dependent both on availability of adequate number of qualified personnel and harmonious client user-provider interaction.

*Comments on wider health care system or infrastructure*

Limitations of the wider health care system, such as the over-utilization of referral centres for treatment of minor health problems, lacunae in inter-hospital referral systems, shortage of paramedical personnel to assist in chronic care, etc. were discussed. Suggestions to improve health infrastructure, such as encouraging autonomy in the functioning of health institutions, collaboration between public hospitals and NGOs, etc. were made.

*Misuse of resources and over-treatment*

This issue was discussed in connection with specific case illustrations. Over-treatment was specifically discussed in connection with abuse of investigations, medicines (particularly antibiotics) and surgery. These concerns were discussed both in the context of medical practice in the public and private sectors.

### *Conflict and conflict-solving*

Disagreements with colleagues, teaching duties and vested interests were some of the factors mentioned by clinicians, which raised ethical concerns. Two models of conflict resolution were proposed to manage such conflicts, *viz.*, legal regulation of medical practice and the standardization of procedures by professional associations.

### *Doctor-doctor conflict*

Interviewees discussed a range of situations involving dissent among colleagues. These disagreements were connected with larger issues of professional hierarchy, multidisciplinary treatment, information management and the public-private interface in medical practice. Doctor-doctor conflict was specifically discussed with reference to medical consultation, second opinion, and the referral system. The need to ensure a good professional relationship among colleagues was stressed.

### *Teaching Responsibility*

Interviewees discussed how they tried to balance their duties as treating physicians, teachers and researchers. They described how they managed the conflicts arising out of these multiple functions in day-to-day clinical work.

### *Vested interests:*

The theme of vested interests was discussed in the context of a range of practices in the public and private sectors, that were considered to be objectionable by the interviewees. Although working in the private sector was not considered wrong by participants, yet they felt that since the profit motive was a driving force there, doctors had to show extra self-restraint.

### *Legal regulation of medical practice:*

Legal regulation of medical practice was discussed in connection with different themes. For instance, the matter was discussed in centres where abortion was illegal. The need for regulation of competition in the private sector was stressed.

### Establishment of professional standards of practice

The need to expand the functioning of professional medical associations, not only to reduce doctor-doctor conflict and protect doctors against prosecution, but also to improve the quality of medical care, was discussed by many interviewees. The need for a Standard of Procedure (SOP), that would regulate professional conduct and establish criteria of professional competence, was stressed.

### Appraisal of decision-making under resource

Constraints: Some selected features of clinical-decision-making are discussed in this section. These themes are covered under the headings (a) Elements of Decision-Making (b) Agency in Decision-Making.

### Elements of decision-making

Typical Case: A large majority of the interviewees said that the ethical dilemmas, which they had delineated, were typical in nature. They interpreted typical and atypical categories primarily in quantitative terms, i.e., the frequency of occurrence of a given phenomenon.

### Case discussed with colleagues

Again, a majority of interviewees affirmed that they had discussed the cases they had described with colleagues. They pointed out that clinical decision-making involved teamwork, and they noted that ward and teaching rounds offered ample opportunities for discussions.

### Repeat decision

A majority of interviewees expressed satisfaction with the decisions they had taken. And they asserted that they would repeat the decision, if presented with a similar case under identical circumstances.

### Doctor forcing a decision on another doctor

This issue was most often discussed in the context of a senior doctor imposing a decision on a junior doctor.

### *Doctor forcing a decision on a patient*

The issue of a doctor forcing a decision on a patient came up in a number of themes, ranging from withholding confidential information from the patient to treatment delay and refusal. The theme was also discussed in the context of end-of-life decision and teaching responsibility.

### *Relatives Forcing a Decision on a Patient*

The issue of relatives forcing a decision on a patient was discussed in the context of barriers to treatment from relatives' side. The issue was also discussed in the context of withholding confidential information and end-of-life decisions.

### *Agency in decision-making*

Six types of central agency were identified in clinical decision-making in the interviews. More often than not, interviewees felt that no factor in isolation was central to the ethical dilemmas under discussion, since there was considerable overlap between the different central agency categories. Inter-interviewer variation and differing definitions of the notion of agency is likely to have affected results on this issue, limiting possibilities for comparative analysis.

### *Doctor, self as central agency*

Doctors considered themselves to be central agents in a number of clinical tasks, including deciding the optimum course of treatment, information management, treatment refusal and end-of-life decision.

### *Doctor, other as central agency:*

In cases where, in addition to themselves, interviewees also identified someone else as central to the ethical dilemma under discussion, the second person was most often another doctor. This issue came up in cases of doctor-doctor conflict,

*Staff, other as central agency*

Interviewees made a distinction between situations in which they and other colleagues were involved, and those in which other staff members or hospital administration in general was identified as central agency, without any direct involvement of the interviewees.

*Patient, self as central agency*

A large number of interviewees assigned patients the role of central agency. As one doctor said: *Without the patient the dilemma does not arise.*

*Relatives as central agency*

Relatives were regarded as central agency in a range of situations. For instance, parents were considered as central actors in the treatment of children by a number of paediatricians.

*Other as central agency*

When interviewees either attributed agency to persons or factors not covered by the other categories, such cases were during analysis grouped together under the general rubric of other. General poverty, inadequate attention to health problems by the Government, paucity of hospital beds and other medical equipment and facilities were cited as major factors in doctors' inability to make available the best possible treatment to patients.

## Conclusion

As mentioned in the introduction, the current research project emerged from the realisation that teaching and training in health ethics is not sufficiently developed in the SEA Region, and that the training that is given in some institutions may be completely unrelated to the clinical realities that meet the medical students after leaving the class. This initial perception was strongly supported by the findings of the study in terms of interviewees' comments on training in health ethics.

Most interviewees felt that there was hardly any connection between the little training that they had received or acquired and the day to day work. They said that they had been taught such elementary things like not examining a female patient without the presence of a third person, not consuming alcohol before undertaking an operation and not having a sexual relationship with a patient. Many respondents stated that they were ignorant about the basic principles underlying medical ethics.

Describing the hiatus between theory and practice in the case of revealing a cancer diagnosis to the patient, a doctor said:

*There's a lot of difference between what we were taught theoretically and what we are doing practically. So many cases you have to manage and you have to leave aside the theory aspect and you have to think of the social problem, of the ethical problems we face. So many times we have to tell a lie. Because according to the Hippocratic oath, you are not supposed to lie. But then, for the patient's wellbeing there are many situations not only me, there have been other doctors also. So for the patient's sake we have to lie* (Gynaecologist and Obstetrician, female).

The intention in terms of utilisation of the current research findings is to work towards bringing together the worlds of health ethics and clinical practice in the SEA Region, with the hope to build and strengthen not only the role of health ethics in medical curricula but also the application of locally and regionally acceptable ethical principles in clinical practice.

## The contextual approach to ethics

This study has been unconventional in two ways. Firstly, we tried not to define ethics and ethical dilemmas in any precise or constricting ways beforehand. We were looking, as it were, for value conflicts in clinical practice. One reason for this approach was that the history of medical ethics as a discipline is as Western as biomedicine itself and the question of cultural variation of (what may be locally understood as) ethical values and dilemmas may be suppressed if categories of ethics are imposed on the interviewees. In short, we were interested in local perceptions, definitions and examples of what may constitute ethical dilemmas. Only at a later stage, we determined to

what extent the issues raised would fit into established categories such as "informed consent", or whether we had to create new categories, such as "withholding information" and "assessment of patients", or alternatively, whether we had to split existing categories such as "doing harm" into the more context sensitive categories of "social harm", "mental harm" and "physical harm".

Secondly, we have tried to avoid the traditional tendency in much health ethics literature to discuss values out of context. While we would like to repeat the limitations of any interview study, namely that it describes what is reported to happen and not necessarily what actually happened, the study has been successful in showing the importance of contextual issues for the occurrence of dilemmas. This does not only come out as a strong message from the study as such. It was also mentioned as an issue by many interviewees. Some said that although they had the necessary training, they were hindered from applying these principles in routine practice For instance, several doctors said that they were unable to give individualised attention to patients due to shortage of time and massive workloads. However, the overwhelming contextual constraint that leads to ethical dilemmas for the practitioner is financial, either in terms of available equipment and/or available manpower at the institution or in terms of available funds from the patient's side, as in the following example.

*I want to pay attention to the problem of costs, because I think it is connected with ethics. And during the education, we have not learnt about this, whereas in practice when a patient asks us how much he will have to pay, I think it would be difficult for us to answer. We never learned about this during the education, whereas in our daily practice, we would always be asked, "Doc, how much it would be?" after we performed an examination. At times, we looked first whether she (the patient) wore a bracelet or not, by what kind of car she came. We might ask, "Where do you work?"* (Surgeon, male).

While resource constraints in health care delivery are universally present, the study indicates that in developing countries practitioners may often have to deny very basic treatments to poor patients in urgent need of treatment or have to give sub-optimal treatment. Issues of equity and justice in resource allocation, while universally recognisable, come out in the narratives of the interviewees with an almost inhuman strength.

In addition, the context of the overall educational level of a society is seen to be a strong influencing factor in generating ethical dilemmas. We find a disturbing tendency to accept illiterate and uneducated patients on par with mentally impaired or otherwise not fully autonomous individuals. The rude facts of time pressure and shortage of manpower, perhaps combined with lack of sensitivity and communication skills among medical professionals as has been documented in many studies around the globe, maximises the disadvantage of the illiterate and uneducated patients, especially in terms of understanding what the physician says. This barrier may often lead to information not being provided and/or informed consent not being obtained. In addition, non-adherence to a particular treatment regime may often be the result, since the patient and his/her relatives may not have understood the treatment to be taken nor the reasons for taking it for a given duration.

A third important contextual issue, which also has to do with autonomy, is the role of the family. There is a tendency to place the concept of patient autonomy in the overriding framework of family decision making. This implies that the patient may or may not be informed of a condition or treatment decision, depending on a consultation between the physician and the relatives, which again may be linked to the doctor's assessment of the patient's social support. The question of patient autonomy is not merely an issue of whether or not an individual has been informed. The issue has to be understood in the context of the role of the family. However, that should also not be construed as an argument for not respecting the rights of the individual patient as an autonomous being.

## Teaching medical ethics

The focus on the context of the medical dilemmas leads to the question: "If the overall economical, social and cultural factors are so important for the occurrence of ethical dilemmas, then what will be the effect of teaching health ethics?"

Of course, teaching in health ethics does not address the root causes of the determining contextual issues, such as massive social inequalities or high levels of illiteracy. These are problems that must be addressed at different levels. What the teaching in health ethics should do is to prepare medical

students for the nature of ethical dilemmas they should expect to find in their daily work. Especially, the strengthening of health ethics in medical curricula should address the following four issues:

➢ The teaching should be contextually relevant, taking into consideration issues of poverty, illiteracy, the organization of the health care system, decision-making processes and other such issues, as illustrated in this document.

➢ Teaching should be based on case illustrations from the medical settings where students would be working. In the current study, a total of 382 cases of patients that were linked to ethical dilemmas were identified. These cases have not been systematically analysed in the current volume but provide an additional analytical dimension that will be elaborated further. They are systematically being reviewed for inclusion in the teaching modules to be developed for the SEA Region.

➢ Integration of health ethics into the various standard disciplines of medicine should be encouraged and teaching modules should be developed in such a way that integration is facilitated.

➢ Open discussions among colleagues of cases raising ethical issues should be strongly encouraged. Currently, a tendency may be seen to mistake ethical doubts with professional incompetence, and the hospital hierarchy may also not encourage discussions on issues, which often have no right or wrong answers. The integration of teaching and training in health ethics could be used as an opportunity to develop a forum for open discussion of such issues.

Let us conclude with a return to the opening remarks. Ethics has gained importance and urgency in the recent past due to a number of reasons... So has the need for research in ethics. We believe that, at least for the WHO SEA Region, the current study represents a first step towards a contextually sensitive exploration of ethical values involved in clinical decision making. However, it is a first step in three senses.

Firstly, the current data warrants more in/depth analysis. We have tried here to provide a synoptic view of the material, and to focus more on breath than depth. The next phase of the work with the material should compensate for this shortcoming.

Secondly, research is required focusing on other disciplines, such as nursing, and different levels of care, such as primary and tertiary care in the public and private sectors. The study could even be expanded to include other systems of medicine, such as Ayurvedic, Chinese or traditional systems.

Thirdly, the current project has been limited to exploring context exclusively through an interview study. Research involving more context-sensitive methods is required, especially ethnographic methods such as participant observation.

We hope the current project inspires such initiatives in the future.

**Annex 1**

## INTERVIEW GUIDE

Interview guide for semistructured first time interview with physician regarding ethical dilemmas faced by the clinician.

*Assumptions:* The interview is carried out with a physician with nobody else present. The interview is tape-recorded. The interviewer restates the purpose that has already been explained to the interviewee by the Principal Investigator, i.e. that the data are to be used for subsequent development of health ethics teaching material, the purpose of the tape recorder, the confidentiality of information and separation of name from data, etc. Each answer is open for follow-up questions to make the informant expand and/or explain any answer, i.e. the purpose of this guide is to support the interviewing process without losing sight of the open-ended and exploratory nature of the study.

The first interview may be introduced similar to the following:

"Usually, decisions making in clinical medicine is fairly straightforward, in the sense that there is one decision that is correct. This is the decision to do what is medically indicated in the situation. Sometimes there may be disagreements about what is medically indicated, but those disagreements are often about factual matters, such as whether one or another treatment will produce the best results for that patient. Sometimes, however, decision making in a case involves disagreements about values. In other cases, you may think that what is usually done is nevertheless not what is the right thing to do. These are the types of cases we are interested in this study, and these are the cases which raise ethical issues. Often in these cases you have the feeling that there is not one correct answer, but you still have to choose."

To simplify the explanation of the above, the interviewer may rephrase the definition in accordance with her/his experience from earlier interviewing. Visual tools may be used to explain the distinction between an ethical and a purely technical dilemma, similar to the table shown below:

| Dilemmas In Clinical Practice | |
|---|---|
| NOT topic for this interview: | TOPIC FOR THIS INTERVIEW |
| Medical/technical dilemmas, like "What is the best treatment option in this case" (there may be <u>one</u> correct answer) | Ethical dilemmas, Involving values Decisions that bothered you in your heart, that made you feel uncomfortable Issues, where there is NOT <u>one</u> correct answer |

(1) Now, before we start talking about ethical dilemmas, I would appreciate if you could briefly tell me what is your specialisation or special area of work?

(2) Could you please briefly describe the main tasks you have been involved in today?

(3) Thinking over the tasks that you have been involved with today, can you think of any situations where you have encountered cases which raise ethical issues? Could you describe the case, and why you think this case raises an ethical issue?

(If yes: The interviewer should probe into the ethical dilemma reported by the physician to obtain as detailed a narrative as possible. Obtain the patient's data, i.e. *age, sex, principal diagnosis, length of stay, prognosis and, if discharged, discharge disposition*, then proceed from question no 5 to fill in possible gaps)

(If no: Please proceed to question no 15)

(4) What were the options you had when you took your decision? Please explain, why you preferred this decision over the other(s).

(5) Is this a typical ethical dilemma, i.e. one that you have experienced often, or is it unusual? (If typical, ask about earlier cases, probe into the what ways they were different/similar)

(6) Did you discuss your decision with your colleagues (if yes, probe into the nature of the discussion)

(7) Why did you think that this was a difficult case?

(8) Would you make the same decision again, given that other circumstances were similar?

(9) Do you see any factors in the clinical setting that changed this particular case from an ordinary case to a case that raises ethical issues (such as shortage of manpower, shortage of medical supplies, economical capacity of patient, etc.)?

(10) Do you think that the decision made was the right thing to do, and if not, why do you think that the right thing was not done in this particular case?

(11) Do you see anyone in particular as being the central person or persons involved in the ethical dilemma in this case? (You may prepare alternative explanations like "who is the ethical dilemma evolving around?" or " Who acted in such a way that this case turned into an ethical dilemma?")

(12) What do you see as the *outcome* of this ethical dilemma/issue (Probe into 1. case-specific outcome and/or 2. outcome of the general ethical issue, and explore what the outcome actually was (for a case), generally is, and what outcome/consequences the doctor would like to see in future)

(13) Now, you have described in some detail one case you encountered today. Are you able to think of any other ethical dilemmas, you have faced in your work today?

(14) Are you able to think of any ethical dilemmas, you have faced in your work during the past four weeks?

(If yes: Proceed to question no. 5, skipping question nos. 14 and 15)

(If No: Proceed to question no. 17)

(15) Now, you have described in some detail one case you encountered during the fast four weeks. Are you able to think of any other ethical dilemmas, you have faced in your work today? (If yes, proceed to question 5, skipping questions 14 and 15)

The following questions are for the first interview only (however, they should appear in the header information on transcripts of all interviews)

(16) What is your designation at the hospital

(17) In which age group do you belong - below 35 yrs. / 36-50 yrs. / above 50 yrs.?

(18) What is your level of experience in years in clinical medicine - less that 5 yrs. / 6-15 yrs. / more than 15 yrs.?

(19) Have you received formal training in medical ethics? -If yes, how do you see the relationship between what you learned and the day-to-day clinical work?