

07FN-6102

142P

**DOCTOR PATIENT AND FAMILY : A REVIEW OF  
LITERATURE WITH SPECIAL REFERENCE TO  
TERMINAL ILLNESS**

*Dissertation submitted to the Jawaharlal Nehru Universtiy  
in partial fulfillment of the requirements  
for the award of the Degree of  
MASTER OF PHILOSOPHY*

Ms. (SUJATA) SIL

CENTRE FOR THE STUDY OF SOCIAL SYSTEMS  
SCHOOL OF SOCIAL SCIENCES  
JAWAHARLAL NEHRU UNIVERSITY  
NEW DELHI-110067,  
INDIA  
1994

CSSS

SSS  
JNU



जवाहरलाल नेहरू विश्वविद्यालय  
JAWAHARLAL NEHRU UNIVERSITY  
NEW DELHI - 110067

Centre for the Study of Social System  
School of Social Sciences

Date :

CERTIFICATE

Certified that the dissertation entitled "DOCTOR, PATIENT AND FAMILY: A REVIEW OF LITERATURE WITH SPECIAL REFERENCE TO TERMINAL ILLNESS" submitted by Ms. Sujata Sil in partial fulfilment of eight credits out of the total requirements of twenty-four for the award of the degree of Master of Philosophy (M.Phil.) of this University. This dissertation has not been submitted for any other degree of this University or any other University and is her original work.

We recommend that this dissertation may be placed before the examiners for evaluation.



(Prof. K.L. Sharma)  
Chairperson



(Dr. Dipankar Gupta)  
Supervisor

## ACKNOWLEDGEMENT

I express my sincere respect and gratitude to my supervisor, Dr. Dipankar Gupta, who initiated me into this fascinating field of study. His unflinching help, constructive criticism and timely guidance as well as moral support were instrumental in the completion of this dissertation.

I gratefully acknowledge my indebtedness to all the Faculty members of my Centre for their help and suggestions.

I thank Prof. Bela Dutt Gupta, Member, State Planning Board, Government of West Bengal, for her critical comments and thoughtful exposition which helped me in my field of study.

I also thank Prof. Swapan Kr. Pramanik and Dr. Bula Bhadra, my teachers at the Dept. of Sociology, Calcutta University. Their constant encouragement has been a great source of inspiration for my work.

My sincere thanks are due to Mou, Pankaja, Ananya and many other friends for patiently bearing me whenever I stayed back in P.G.W. Hostel for my library works. At the same time, I acknowledge my indebtedness to Sreekala, Richa and Mohita, my hostel-mates, for helping me in all sorts of matters throughout this time. Participation in debates and discussion with them helped me to evolve my ideas.

My indebtedness are certainly due to my parents who sowed the first seed of inquisitiveness in my mind and helped me to look at this world with an open mind.

I would like to specially thank my typists, for their painstaking efforts in producing this dissertation in time.

Finally, I thank my beloved husband, for being an unwearying support all throughout my work.

A handwritten signature in cursive script, appearing to read 'Sujata Sil'.

(SUJATA SIL)

## CONTENTS

	Page No.
<b>CHAPTER I</b> INTRODUCTION	1-38
<b>CHAPTER II</b> CARE OF THE ELDERLY	39-62
<b>CHAPTER III</b> CARE OF THE CANCER PATIENT	63-97
<b>CHAPTER IV</b> CHILDREN WITH CANCER	98-129
<b>CHAPTER V</b> CONCLUSION	130-142

# **CHAPTER I**

## **INTRODUCTION**

Health is presently reaffirmed as "a state of complete physical, mental and social well being and not merely the absence of disease or infirmity, is a fundamental human right and that the attainment of the highest possible level of health is a most important social goal whose realisation requires the action of many other social and economic sectors in addition to health sector".<sup>1</sup> This implies the importance of studying health and related problems from sociological aspects.

During recent years, the problem of death has brought forward and discussed to an increasing extent. As a consequence, there is a growing demand for proper care of the dying have been proposed.

Caring for the patient starts with the interaction between doctor and patient. It is only recently that attempts are being made to study this interaction systematically. My work is also another attempt to study this relationship in a specific situation, i.e. when the patients are terminally ill. Terminally ill patients interested me because of their basic difference with non-terminally ill patients. Non-terminally ill patients come to the doctors to get back their ill health. They enjoy the status of patient

---

1. "Primary Health Care - Declaration of Alma Ata"; The Lancet; 1978; ii; pp.1040-41.

for a definite period of time and go back to normal life once again after the completion of treatment. Terminally ill patients also go to the doctors to cure their physical problems. But at a certain stage of the treatment process, it becomes obvious to both the doctor and patient that there is no hope for life anymore. This is expected to lead to certain differences between the doctor-patient relationship in terminal cases and that of non-terminal cases. This is my one point of interest. Along with the doctors, the family of the patient also takes part in the treatment process. And for terminally ill patients, they become inseparable part of the caregiving process. How the family adjusts and functions with the terminal illness of one of its members and as well as contributes to the patient's caregiving process is my main interest.

There is a growing recognition of the fact that every aspect of the sub-system of medicine is open to influence from the wider social system.<sup>2</sup> Sociologists are becoming more and more interested in medicine, just as in other aspects of social life, such as religion or economy. It is understood that both the doctor and patient are products as well as prisoners of this social system. Thus, the study of

---

2. Minocha, A.A. Some Aspects of Social System of an Indian Hospital; Delhi; Delhi University; 1974.



doctor-patient relationship becomes more meaningful when social perspectives, along with the clinical perspectives, are taken into consideration.<sup>3</sup>

Another sub-discipline of sociology, viz., sociology of profession looks at medicine as a profession. Before entering into the debate on doctor-patient relationship, it is necessary to spare few pages on how the sociology of profession distinguishes health professionals from other so-called non-professional occupations and what is its idea of professional-client relationship.

#### **MEDICINE AS A PROFESSION**

"Medicine as a profession has had its measure of public esteem in every society" -- This is how Venkataratanam has started the "Introduction" of his book "Medical Sociology in an Indian Setting".<sup>4</sup> He has considered doctors (or medicine-men in his own words) as professionals. What is a professional? And what is a profession? For lay people, a professional is simply a person who takes money for doing what other people do for free, e.g., playing football, music,

- 
3. Patrick, D.L. & Scambler, G.(ed.) Sociology as Applied to Medicine; Balliere Tindall; 1982.
  4. Venkataratnam, R. Medical Sociology in an Indian Setting; Madras; Mcmillan; pp.1,; 1979.

tennis and even sexual activity.<sup>5</sup> But for sociology of profession, it is something more than that. Actually, the question of what constitutes the essential characteristics of a profession has been rendered complex by the claim put forth in recent times by a multitude of occupational groups adopting to professional status.<sup>6</sup> Following Baber,\* we can identify four general attributes of professional behaviour - (1) generalised knowledge (2) primary orientation to community interest (3) internalised code of ethics (4) rewards which primarily symbolise work achievement.<sup>7</sup>

Though doctors possess all these attributes of professionals, they are nevertheless still different from other professional groups. This is clearly evident in McCormick's writings. In his opinion, "Medicine is different from most other professionals not by virtue of the length of training (which is extremely long) or the depth of knowledge but by its code of behaviour and by its concern with people rather

---

5. Moline, J.N. "Professionals & professions : a philosophical examination of an ideal"; Social Science & Medicine; Vol.2; No.5; pp.501-508; 1986.

6. Cox, C. & Mead, A.(ed.) A Sociology of Medical Practice; Collier-Mcmillan; London; 1975.

\* There are many other sociologists who have defined profession. But I find Baber to be the most systematic one and he is quite often quoted by other writers also.

7. Baber, B. "Some problems in the Sociology of Profession"; Daedalus; 92; 4 (1963); 671.

than buildings, structure or accounts. This involvement with people shared with priests, nurses, teachers, social workers and to some extent with lawyers. It is not characteristics of architects acturies accountants and engineers".<sup>8</sup>

The mode of interaction with clients (i.e., patients) also distinguishes doctors as a professional group from other professionals. Other professionals can do without taking interest in other aspects of the client's life except the problem for which the client has come to him. But for the doctor, it is necessary to know the other aspects of his client's life as he deals with the life and death situation of the client in the true sense. This enables the doctor with a special kind of autonomy on his decisions as well as assign an "altruistic" responsibility on him which no other professional groups need to, or even expected to bear. On the other hand, this leads the doctors to enjoy a higher social esteem in comparison to other professional groups.<sup>9</sup>

Talcott Parsons has also pointed out several features of the physicians' role which are responsible for their great importance. First, he notes that caring for the sick is a functionally specialised full-time professional activi-

- 
8. McCormick, J. The Doctor: Father figure or Plumber; London; Croom Helm; pp.13; 1979.
  9. Jones, R.K. & Jones, P.A. Sociology of Medicine; The English Universities Press Ltd.; 1975.

ty. This position is achieved through developing a minimum standard of technical proficiency. The high technical competence required of the doctor also implies a specification of function. Moreover, the doctor is expected to maintain a stance of affective neutrality, i.e., whether he dislikes or likes a patient should have no bearing on how he deals with the case. He is expected to approach the patient in objective and scientifically justified terms. Finally, the ideology of the profession emphasizes the welfare of the patient and the doctor is expected to put the patient's welfare above his personal interests.<sup>10</sup>

Medicine acquired professional status in India under an act of the legislature and the professional body, viz., the Indian Medical Council enjoys statutory recognition.<sup>11</sup> In recent times, there is a growing trend among doctors to shift their site of work to organisational structures. They are thus becoming "salaried professionals" or "professionals employees". But this transformation has left its effects and some reflections upon the ethical and social service aspect of doctors.

---

10. Parsons, T. The Social System; The Free Press; New York; 1951.

11. Rajagopalan, C. Some critical reflections on the revealing outlook of professions in India. In Lal, S.K. et.al.(ed.) Reading in the Sociology of the Profession; Gian Publishing House; Delhi; 1988.

## PROFESSIONAL - CLIENT RELATIONSHIP

Professions are incomplete without clients. They are complementary to each other. Hughes defines "professions (as a type of occupation) as a social role defined by the nature of the relationship between the professionals and their clients".<sup>12</sup>

Reeder considered professional-client relations in the context of certain structural changes in society. In the developed societies, there has been a shift from curative to preventive types of services. The second feature of societal change concerns the growing sophistication of bureaucracy. The third refers to the development of consumerism. The consumerism manifests itself most prominently in terms of expression of satisfaction and dissatisfaction with that system in varying forms. The processes involved in consumerism influence and are influenced by social structural changes and the implications for changing roles and relationship of clients and professionals. Reeder differentiates between "consumers" and "clients" by mentioning that as a client an individual delivers himself into the hands of the professional who presumably is the sole decision-maker

---

12. Hughes, E.C. Men & Their Work; Free Press; New York; 1951.

regarding the nature of the services to be delivered. On the other hand, when the individual is viewed as a consumer, he is a purchaser of services.<sup>13</sup>

As the doctors are different from other professional groups, in the same way the patients also differ from other clients. As the doctors need to deal with other aspects of the client's life, the doctor-patient relationship tends to become more informal and intimate than any other professional client relationships.<sup>14</sup>

The term "client" should be used cautiously for a patient in the Indian context. It has different connotations here from what it has in other countries. For example, in a country like USA where the payment system is direct, the situation is of a different order. It is somewhat similar to the case of patients visiting private practitioner in our country. In case of general hospitals, the treatment in most of the hospitals is free of cost or the payment is made by the patients on the basis of their income. When the treatment is free, they do not directly hire the services of the

---

13. Reeder, L.G. "The patient-client as a consumer: some observations on changing professional client relationship"; Journal of Health & Social Behaviour; 1972; 13(4); 406-412.

14. Advani, M. Doctor-patient relationship in Indian Hospitals; Sanghi Prakasan; Jaipur; 1980.

professionals by the state, as in a welfare state, the state takes up the responsibility of proper medical care of the people. But the patients are 'clients' in the sense that some agency is paying for the professionals and it becomes the responsibility of the professionals to provide proper medical care to them. The patients are dependent on the professionals and are not really customers who can freely bargain in exercising their choice.<sup>15</sup>

#### **BECOMING A PATIENT**

When the patient's definition of his illness becomes crystalised and he seeks professional help for his problem, it can be said that he is entering the "sick role".<sup>16</sup> The analysis of sick-role will help us to understand the characteristics of doctor-patient relationship easily. It has been said that Parsons' conceptualisation of the sick-role is the single most important contribution to the sociology of health because it offers the most systematic and consistent framework for analysing the socially necessary behaviour of

---

15. Tuckeett, D. (ed.) An Introduction to Medical Sociology; Tavistock Publications; 1976.

16. Miele, R.L. "Pathways to patienthood: sick role and labelling perspectives"; Social Science & Medicine; Vol.22; No.1; pp.35-40; 1986.

sick individuals in western and other societies, though this has not been adequately examined in India.<sup>17</sup>

The concept of the "sick role" is an ideal-type, in the sense that it is a theoretical model that attempts to depict the patient's behavioural orientations when he seeks medical care, but is not itself a description of empirical reality. It thus constitutes a perspective for viewing patients' behaviour, although it does not necessarily describe accurately what the patients' behaviour will be.<sup>18</sup>

Parsons argues that being sick is a role as well as a condition, in that there are institutionalised expectations of the sick and associated with them are particular sentiments and sanctions. He believes that there are four aspects to these institutionalised expectations as they affect the sick: (1) The sick are allowed "exemption from social-role responsibilities" and this requires that others accept the idea that they are suffering from an illness condition. Parsons notes that the physician serves as a "court of appeal" in legitimising sickness. He further suggests that exemption from normal responsibilities is not only a right,

---

17. Nagla, M. Professionals & their clients: A study of doctor-patient relationship. In Lal, S.K. et.al. (ed.), Readings in the Sociology of the Professions; Gian Publishing House; 1988; pp.296.

18. Mechanic, D. Medical Sociology; Free Press; New York; 1968.



but also an obligation, in that others may insist that a person withdraw from his usual social roles because of sickness. (2) The sick person is also exempted from 'responsibility' for his condition in that he is not usually expected to be able to get well by his own decision or will. Thus, it is assumed that he needs help, and this assumption serves as a bridge to the acceptance of 'help'. (3) The patient is 'expected to want to get well'. (4) He is expected to 'seek technically competent help; and to 'cooperate' with the helper in trying to get well. Parsons suggests that once a patient has called in a physician, he assumes the obligation to cooperate with him in getting well.<sup>19</sup>

Parsons does not imply that these steps always go together or that they do not vary. Indeed, he is alert to various contingencies that may affect conformity to institutionalised expectations, such as severity of the patients' conditions. Parsons formulation has been of great use to medical sociologists, but there is a tendency to regard it as unimodal. Only recently have studies been undertaken which reveal that social status affects the process of defining who is to be regarded as sick. This growing theoretical sophistication is reflected in Gordon's study.<sup>20</sup> In essence, he found that the poorer or more uncertain the

---

19. Parsons, T. Op.cit.

20. Gordon, G. Role Theory and Illness; New Haven; College and University Press; 1966.

prognosis, the greater the tendency to define someone as sick. Beyond that, however, there was an inverse relationship between socioeconomic status and the importance of physical incapacity as a factor in defining someone as sick. Upper socioeconomic groups used a wider range of conditions for the definition of sickness, lower socio-economic groups were more likely to limit the conditions to some kind of physical incapability. However, there were no differences among the socio-economic groups regarding the way a sick person should be treated once he had been placed in that role.<sup>21</sup>

Gordon also found evidence for a condition which he called 'impaired role'. In the sick role, the prognosis is likely to be serious and uncertain and there is a consistent tendency to treat the sick person as dependent. In the impaired role, health is impaired but the prognosis is not serious, and there is a tendency to encourage the ill person to fulfill his personal and social responsibilities even though he is also encourage to seek medical care.<sup>22</sup>

The sick role is also a useful concept in analysing certain reactions of institutions or societies. Mechanic has

---

21. Ibid.

22. Ibid.

listed a number of these. In time of war, admission to the sick role may become more stringent, especially in the army under combat conditions. The needs of the combat unit take precedence over individual needs, except when the individual soldier is incapacitate. Moreover, experience in recent wars has shown that when a soldier goes back to a base hospital, thus reinforcing his sick role, it is more difficult to get him ready for combat again than if his sick role is minimised by keeping him near the front lines.

#### **THE SOCIAL ROLE OF THE PATIENT**

For the functionalists, the patient is a deviant individual. Traditionally, functionalists have located a sociology of illness within the field of social control as illness is conceived to be "dysfunctional" for the social system, upsetting its equilibrium. The essential reason for the patient being called a deviant is not obscure : A patient is by definition an individual whose incapacity thwarts his performance of the social roles with which he is normally charged. It is thus eminently reseasonable to believe, with Parsons, that a society cannot long afford an endemic or epidemic taking of the patients' role, that society must construe this role as undesirable, temporary and basically disruptive. With the possible exception of certain severe

congenital defects, no one is "born" a patient. The role is usually temporary only loosely circumscribed by accepted definitions of its content, and ascribed to the individual rather than achieved by him. It is not consciously sought by many persons in society, although the secondary gains of illness - especially the security of a protected dependency - may lead some persons to an unconscious desire to be ill. In a society which is marked by an interdependent series of highly complex social roles, the patient is under particularly heavy pressure to regain capacity.<sup>23</sup>

#### **THE SOCIAL ROLE OF THE PHYSICIAN**

The role of the physician centres on his responsibility for the welfare of the patient in the sense of facilitating ability. The primary definition of the physician's responsibility is to "do everything possible" to forward the complete, early and painless recovery of his patients. Indeed, having defined the patient as a social deviant, it is natural to think of the practitioner first as an agent of social control. He is implicitly charged by society with the job of returning the affected person to full functioning, of reversing the tide of withdrawal so that the patient may again

---

23. Parsons, T. Op.cit.

take up the threads of social obligations. That is, the physician is the symbol of the well and normal, of the non-ill encountering the ill.<sup>24</sup>

Viewing chronic illness as a variation or sub-type of the sick-role, its distinguishing characteristics depart from the "model" in crucial respects. First, chronic illness by definition is not temporary, so that role-expectations predicted on the assumption of the temporary nature of illness (for example, motivation to get well) are clearly inapplicable without respecification. Also, since many chronic patients are ambulatory, incapacity for the performance of other roles is more often partial than total. Indeed, while the Parsonian view of the sick role implies that it is the patient's dominant role for the duration of his illness, in the case of the ambulatory chronic patient, this assumption is often unwarranted. Hence, the degree to which illness produces alienation or insulation from norms of the 'well' population, is itself a problem for investigation. Similarly, norms prescribing permissive treatment and exemption from role obligations in the event of acute illness may require respecification when prolonged adherence of the

---

24. Ibid.

patients' alters.<sup>25</sup> It is equally applicable to the case of terminally ill patients also.

#### **THEORETICAL VIEWS OF DOCTOR-PATIENT RELATIONSHIP**

Parsons noted at the beginning of his formulation that illness is "partly biologically defined" and that the "state of the organism as a biological system" is related to the social systems of medical practice. Szasz and Hollender, both physicians, saw more extensive behavioural implications of organic symptoms which they incorporated in a model, of doctor-patient relationships based on a three-fold typology.<sup>26</sup>

(i) *Activity-passivity*. Here the orientation is one in which the physician is active and the patient is passive. It has originated in, and is entirely appropriate for emergencies (severe injuries, marked blood loss, delirium or coma). The patient is more or less completely helpless and the physician does something to him. Treatment takes place regardless of the patient's contribution.

- 
25. Kassebnum, G.G. & Baumann, B.O. Dimensions of the sick role in chronic illness. In Jaco, E.G. (ed.), Patients, Physicians and Illness; The Free Press; 1972.
26. Szasz, T.G. and Hollender, M.H. "A contribution to the philosophy of medicine: the basic models of the doctor-patient relationship"; Archs intern. Med.; 97; 585-592; 1956.

(ii) *Guidance-cooperation*. This model usually underlies the doctor-patient relationship when the circumstances are less desperate than those described above. It applies to most acute disorders and especially to those of an infectious type. Although the patient is ill, he is still keenly aware of what is going on, and he is capable of following directions and of exercising some judgement. Moreover, when the approach is geared at this level, the patient is expected to look up to his physician and to obey him.

(iii) *Mutual participation*. This approach is often useful for the management of chronic illness in which the treatment programme is carried out by the patient with only occasional consultation with a physician (i.e. diabetes mellitus, myasthenia gravis, psoriasis, etc.). According to this model, the physician helps the patient to help himself. Since it requires a complex psychological and social organisation on the part of the patient, it is rarely appropriate for children or for people who are mentally deficient, very poorly educated, or profoundly immature. Its prototype is the relationship of adult to adult (with one having specialised knowledge that the other needs).

With respect to the doctor-patient relationship, there are two other competing theories - the consensus model of Parsons and the discrepancy model of Friedson. The first assumes a harmonious relationship where the physician is leading and patient is following, the physician's role is characterised by high status and control vis-a-vis the patient. There is a normative pattern of trust. The physician will be alternative to the needs of the patient and will act in the patient's interests. The patient has to cooperate and to do everything the doctor advises to become healthy as quickly as possible.<sup>27</sup> The discrepancy model argues in contrast that there is an inherent discrepancy between the expectations of the patient and what the doctor can really offer.<sup>28, 29</sup> Only a part of the physician's control is used to advance the patient's interest. The physician also uses control to maintain his institutionalised authority.<sup>30, 31</sup> It is assumed that illness is less objective

---

27. Parsons, T. Op.cit.

28. Friedson, E. Patients' View of Medical Practice; Russell Sage Founations; New York; 1961.

29. Friedson, E. Profession of Medicine: A study of the sociology of applied knowledge; Dodd, Mead and Company; New York; 1970.

30. Hughes, D. "Control in medical consultations: organising talk in a situation where coparticipants have different competence"; Sociology; 16; 359; 1982.

31. Waitzkin, H. "Information giving in medical care"; Journal of Health & Social Behaviour; 26; 81; 1985.



than has been thought. The reactions of the environment, including the physician, are very important in the process of health and illness. Consequently, the discrepancy model emphasizes the interactional and dynamic aspects of doctor-patient conversation. Both theories postulate an asymmetrical relation between doctor and patient, where the doctor is the leading party, who structures the medical conversation and gives advice while the patient gives biographical information regarding the complaints. The latter theory stresses the process of negotiation as a result, at least partly, of the interactional process between doctor and patient. This implies that the patient is also regarded as an active party in the interaction.<sup>32</sup>

A third theoretical view of the doctor-patient relationship is worth mentioning, i.e., the patient-centered approach. The relationship is an essential part of the patient-centred approach, which acknowledges the patient as a person with unique needs and a life-history.<sup>33</sup> In the doctor-patient relationship, patient-centredness will be expressed when the physician is actively interested in the

---

32. Meeuwesen, L.et.al. "Verbal analysis of doctor-patient communication"; Social Science and Medicine; Vol.32; No.10; pp.1143-1150 ; 1991.

33. Stewart, M. "What is a successful doctor-patient interview? A Study of interactions and outcomes"; Social Science & Medicine; 19; 167; 1964.

patient's point of view. This is in contrast to the illness-centred approach, in which the physician is exclusively focussed on the illness or disease, at the cost of loss of interest in the patient as a person. Especially, in case of psychological complaints a patient-centred approach may be more appropriate. In reality, however, there are strong indications that the illness-centred approach is still predominant.<sup>34</sup>

#### **FACTORS AFFECTING DOCTOR-PATIENT RELATIONSHIP**

Different studies on doctor-patient relationship have revealed that there are some factors which affect this relationship in general.

Friedson has described some of the influences that clients (i.e., patients) and other practitioners may have on the work of a particular doctor.<sup>35, 36, 37</sup> He argues that al-

---

34. Gandhi, R.S. An interactionist approach to the sociology of illness and medicine and its relevance to the Indian situation. In Gupta, G.R.(ed.) The Social & Cultural Context of Medicine in India; Vikas Publishing House Pvt. Ltd.; 1981.

35. Freidson, E. "Client control and medical practice"; American Journal of Sociology; 65; 374-382; 1960.

36. Freidson, E. "The sociology of medicine: a brief report & bibliography"; Current Sociology; No.3, pp.10-11; 1961-62.

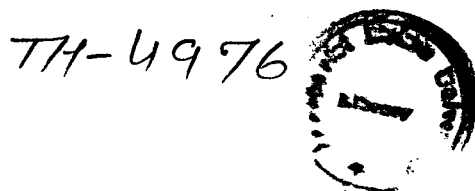
37. Freidson, E. & Rhea, B. "Processes of control in a company of equals"; Social Problems; 11; 119-131.

though the physician practising by himself may share knowledge, identity and loyalty with other doctors, he is dependent on the patient for his livelihood. Patients usually evaluate the physician by non-professional norms which may be influenced by the patients' cultural background and the lay referral process. Thus, the physician, if he is to satisfy his patients, must to some extent perform in accordance with patient expectations, which may require him to behave in a fashion contrary to professional expectations.<sup>38</sup> Among urban patients, the first visit to the physician is often tentative. Whether the patient will return or follow the physician's advice depends on his evaluation of how the physician performed his role and the character of the doctor-patient interaction as it develops.<sup>39</sup> Moreover, often the patient discusses with others the behaviour of his physician and treatment prescribed in order to ascertain whether he is receiving proper attention. Thus, the patient often communicate expectations to the doctor and subtly attempts to influence how the doctor will deal with him.

---

38. Robins, L & Wolf, F.M. "Confrontation and politicians strategies in physician-patient interactions"; Social Science & Medicine; Vol.27; No.3; pp.217-221; 1988.

39. Davis, M. "Variations in patient's compliance with doctor's advice: an empirical analysis of patterns of communication"; American Journal of Public Health; 58; 1968.



The cues patients use to estimate the doctor's competence, however, may not reflect his technical abilities and knowledge, as these cannot be assumed by most patients. Instead, they usually reflect the doctor's interest in the patient, his willingness to give time to hear the patient's complaints, and similar indications of concern that are important to the patient.<sup>40</sup> The doctor's willingness to make home calls may be seen as an index of his interest, his confidence and authority may be perceived as an indication of his expertise and a rapid diagnosis and treatment plan may be viewed as evidence of his competence.<sup>41</sup>

Physicians and patients often operate within quite different assumptive worlds and often lack awareness of the extent to which their assumptions are different. Various studies show that medical information among patients is considerably less adequate than most physicians expect<sup>42</sup> and obviously physicians often fail to appreciate why patients are really seeking their help. Medical practice inevitably

---

40. Oeandami, A. Medical Profession: A Sociological Exploration; New Delhi; Jainsons Publications; 1985.

41. Calnan, M. "Images of general practice : perceptions of the doctors"; Social Science & Medicine; Vol.27; No.6; pp.579-586; 1988.

42. Pratt, L. et.al. "Physician's views on the level of medical information among patients"; American Journal of Public Health; 47; 1277-1283; 1957.

requires changing patients stereotypes and expectations, as well as treating their symptoms.<sup>43</sup>

The success of doctor-patient relationship is in large part attributable to the extent that doctor and patient share common frames of reference. Doctors from certain ethnic groups practice predominantly in areas where members of their own ethnic groups reside. This may be in part attributable to the opportunities available for practice to the ethnic practitioner but it may also be related to the fact that patient and doctor who share particular cultural traits relate to one another more easily.<sup>44</sup>

The age of the patient also plays an important role in deciding the quality of doctor-patient relationship. Our society tends to worship youthfulness at present and to equate aging with mental and physical deterioration. Physicians also do not differ significantly from the lay public in their orientation to age. Rather, sometimes physician anticipates that his therapeutic ministrations may be less effective in the elderly patients. Old age, with its accumu-

---

43. Hall, J.A. & Dornan, M.C. "What patients like about their medical care and how often they are asked: a meta-analysis of the satisfaction literature"; Social Science & Medicine; Vol.27; No.9; pp.935-939; 1988.

44. Liberson, S. "Ethnic groups and the practice of medicine"; American Sociological Review; 2; 233-246; 1964.

lated physical insults to the body, is often associated with a decreased resiliency, a diminished reserve, a lessened ability to bounce back from a new assault.<sup>45</sup>

A second variable is the estimate of "social worth" placed on the patient by the culture, both in general and specifically, and by the doctor in charge. A president or a famous film star will certainly receive more attention than any common people. This is narrated very clearly by Oommen. He also mentioned that the interest of professionals whether it is rooted in cancer orientations or genuine scholastic orientations, determined the quantum and quality of patient-care, independent of the amount of attention the cases deserved or desired.<sup>46</sup>

The physical characteristics of a patient may also result in variation in receiving attention from the attending physician. Attractive female patients are always found to receive more attention than unattractive patients.<sup>47</sup>

---

45. Lasagna, L. Physician's behaviour toward the dying patient. In Brim, O.G. & others (ed.) The Dying Patient; Russell Sage Foundation; 1970.

46. Oommen, T.K. Doctors & Nurses: A Study in Occupational Structures; Delhi; Mcmillan; 1978.

47. Hadjistavropolous, H.D. et.al. "Are physicians' ratings of pain affected by patients physical attractiveness?" Social Science & Medicine; Vol.31; No.1; pp.69-72; 1990.

The approach of the doctor to the patient is also affected by the disease from which he suffers. AIDS, for example, arouses the image of hopeless, horrible disease. There are lots of confusion regarding it. So, usually all the hospital staffs, including the doctors, avoid AIDS patients as it still defy treatment.<sup>48</sup>

Byrne and Long made a study on the verbal behaviours exhibited by the general practitioners in the consultation in U.K. In their opinion, the deficiencies in the doctor-patient relationship are not true fault of the doctor. He is both a product and a a prisoner of his medical education, which has made no attempt to provide him with behaviours suited to enable him to cope with psycho-social problems.<sup>49</sup>

There are two other significant elements in modern medicine which also have a bearing on this relationship. Firstly, the growth of specification has resulted in changing the doctors role from a "know-all" and "cure-all" generalist to a specialist in a narrow field rendering the relationship more impersonal. Secondly, modern medicine is increasingly being practised in the context of organisa-

---

48. Das, S. & Mistry, H. "Doctors attitude towards patients of AIDS and other transmissible diseases"; CARC Calling; Vol.4; No.1; pp.34-37; 1991.

49. Byrne, P. & Long, E.L. Doctors Talking to Patients; Her Majesty's Stationary Office, London; 1976.

tions, such as hospitals in which a number of functionaries, as members of a team, play important roles in the treatment process.<sup>50</sup>

#### **DOCTORS AND TERMINALLY ILL PATIENTS**

This brings us to the main object of our research, viz. the doctor-patient relationship in terminally ill cases, which is not fully elaborated in sociology of medical profession or in the studies which looked at doctor-patient relationship. We have found a considerable number of factors which affect the pattern of interaction between doctor and his patients. This issue becomes more sensitive when it comes to the question of interaction between doctors and terminally ill patients.

Though frequently we use "dying" to mean "terminally ill", not all dying patients go through protracted terminal illness. This can extend to a period of weeks or months proceeding death, in which serious attempts at cure have been given up and treatment is palliative.<sup>51</sup> To some extent, terminal illness is a creation of modern medical science, its occurrence requires sure knowledge both of the fatal

---

50. Madan, T.N. Doctors & Society; Vikas Publishing House Pvt. Ltd.; 1980.

51. Herzlich, C. & Graham, D. Health & Illness; Academic Press Inc. Ltd.; 1973.



course of the illness and also of the ineffectiveness of available treatment, except in the control of pain.

Noyes and Clancy have distinguished the "dying role" from the "sick role". They have used the word "dying" to mean terminal illness. In their opinion, the person in a dying role has rights similar to the sick person, but his duties differ. First, it is important for dying person to desire to remain alive. He may relinquish unrealistic hope of recovery but must retain the "will to live" unless subjected to extensive suffering or disability. Second, the dying person transfers his healthy social roles to others on a more permanent basis than is the case with the merely sick person. The person who fails to execute a will or participate in decisions regarding the future of his business or family may become an object of disapproval. Third, the dying person has an obligations to avail himself of the necessary supports to life and to cooperate in their administration. Fourth, the dying person is expected to accept the curtailment of freedom and loss of privileges imposed by caregivers. And, finally, and perhaps more conventionally, dependency is encouraged in the dying role.

The relationship of doctor and terminally ill patient is unique in one sense, that is, in other cases, patients come to the doctors to get back their lost health. They go back to the social system and play out the full quota of social roles after the treatment. On the other hand, the

terminally ill patients do not have any hope to go back to their earlier position in the society. Doctors only help them to make their last days a bit better, or at best, give them a new locus in the system.

With terminally ill patients, doctors too know that they cannot "succeed" in the sense they do with other patients. This attitude will certainly leave some impact on their interaction with the dying patients which is totally different from their interaction with non-terminally ill patients. I wish to examine this aspect of the interaction of doctor and terminally ill patients through the following chapters.

#### **TELLING THE TRUTH TO THE TERMINALLY ILL PATIENTS**

Until just a few years ago, it was thought that telling the truth to a patient with terminal disease would harm that patient.<sup>52</sup> Since telling the patient his diagnosis was to pronounce upon him a hopeless sentence of doom, it was therefore thought preferable to conceal his fate from him. Recent surveys of physicians' attitude toward truth-telling have shown that a small number never tell patients their diagnosis and prognosis, a larger number of them do, but the majority indicate a flexible attitude. The largest group

---

52. Brim, O.J. (ed.) The Dying Patient; Russell Sage Foundation; 1970.

discusses the diagnosis depending on the type of patient, patient attitude, personality so on.<sup>53</sup>

Telling the truth to the dying patient is primarily aimed at two purposes - to reduce uncertainty and to provide a basis for action. These two functions are inextricably related. The patient's trust in the physician is vital for his effective treatment. A moments reflection will show that in serious illness situations, there is never quite enough information to entirely eliminate uncertainty about the right thing to do, or about the future. Then the patient's anxiety may be alleviated by trust in physician. The patient, like all others, has a need to act and this need is aided by the doctor's help in decision making. When a patient trusts a doctor, he, in part, gives his uncertainty over to his physician, relinquishing it to him in trust.<sup>54</sup>

Moreover, we must recall that modern medical requires a partnership between physician and patient\*. In the case of

---

53. Novack, D.H. et al. "Change in physician's attitude toward telling the cancer patient"; Journal of American Medical Association; 41; 897-980; 1979.

54. Muyaji, N.T. "The power of compassion, truth-telling among American doctors in the care of the dying patients" ; Social Science & Medicine ; Vol. 36; No.3; 1993.

\* Nowadays media is making a considerable portion of medical knowledge available to the general people. So, doctors no more can enjoy their full autonomy over their knowledge and exercise their power at their own discretion. Patients, with the help of legal rules, are compelling the doctors to change their autocratic attitude and come down to the level of the patient and share a partnership regarding the treatment process.

chronic illness or long-term disease, patients themselves must actively comply with treatment, from taking potent medications correctly to following dietary or exercise regimens. However, only an informed patient who feels himself a partner in the process will willingly participate fully. Thus, physician must determine how much information the patient requires, what information the patient wants and how much information is needed in order to make the patient an effective partner in his care.<sup>55</sup>

It is also true that no piece of information should be imparted unless the physician is prepared to answer the question raised by the patients. The process of imparting information is not complete until all facts, possible consequences and alternative action have been specified to the degree that the patient desires. This is important because it is also the patient's right to receive no information. Social, even absolute denial is a powerful tool the mind uses to protect itself.<sup>56</sup>

In treating patients who are generally alert but are dying of a progressive illness, such as cancer, the physi-

---

55. Bensing, J. "Doctor-patient communication and quality of care"; Social-Science & Medicine; Vol.32; No.11; pp.1301-1310; 1991.

56. Blanchard, C.J, et al. "Information and decision making preferences of hospitalization adult cancer patients." Social Science & Medicines; Vol.27; No.1; pp.1139-1145; 1988.

cian must be especially sensitive to their need for relief from pain and suffering, Aggressive treatment in response to this need is often justified even if under other circumstances the risk of such treatment would be medically undesirable. For such treatment might even result in respiratory depression. The level of care to be provided should reflect an understanding between patient and physician and should be reassessed from time to time. In many cases, neither intensive care nor emergency resuscitation is desired by the patient and his family. There may be a wish only for comfort, with general medical treatment given solely to provide relief from distress.<sup>57</sup>

#### **STATEMENT OF THE PROBLEM**

For my own convenience, I have classified terminal patients into three categories - (1) geriatric patients (2) cancer patients (3) Children with cancer. I wish to go through specially on terminal care to see :

- (i) how the patient accepts his approaching death
- (ii) how the doctor looks at the problem
- (iii) how the relatives of the patient react to the problem.

---

57. Still, A.W. & Todd, C.J. "Role ambiguity in general practice : the care of patients dying at home" ; Social Science & Medicine; Vol.23; No.5; pp.519-525; 1986.

I also wish to examine whether there is any particular pattern of interaction which may help the doctors to interact with the terminally ill patients, which can satisfy the patient and whether there is any difference in doctor's attitude in attending the non-terminally ill patients and terminally ill patients.

### **DYING AND TERMINAL ILLNESS**

Dying, as a Dickens character once remarked is a very funny business, and by 'funny' he meant 'funny peculiar' rather than 'funny ha ha' although a certain type of gallows of humours may help to relieve the more peculiar side of it.<sup>58</sup> Dying is not only a funny business but, even under the best management, it is an awkward business and none of the participants seem quite to know what to say or what to do.

Dying is like adolescence, a transitioned period that, unless ritualised and routinised within a cultural setting, is liable to generate anxiety and maladjustment not only in the individuals under-going the experience but equally in those connected with it. Like adolescents, the dying are in-between people who are in the process of change and, therefore, not easily categorised. They are marginal individuals

---

58. Anthony, J.E. & Couperneik, C. (ed) The Child in his Family; The impact of disease & death; Vol. 2; John Wisley & Sons; 1973.

belonging neither to life nor to death but occupying a psychological limbo where they are imbued with group attributes devoid of idiosyncracies.<sup>59</sup>

It is illuminating to start with the question when does dying begin? In one sense, this question does not even become relevant until death has occurred, because people often recover from a life - threatening condition. Although logic might be on the side of suspending the classification of 'dying' until the event of death, we seldom wait this long. A lot of feeling, thought and behaviour are organised around the judgement that a person either or is not 'dying'. This judgement is not so easy to make as it might appear. Even person in the situation may have a different concept of what 'dying' is and also a different perspective of observing and interpreting the factor.

As Kastenbaum puts, dying usually begins as a psychological event.<sup>60</sup> Four common pragmatic modes of defining the onset of dying are explored:

1. Dying begins when facts are recognised.
2. Dying begins when the facts are communicated.

---

59. Armstrong, D. "Silence & truth in death & dying"; Social Science & Medicine; Vol.24; No.8; pp.651-657; 1987.

60. Kastenbaum, R.J. Death, Society and Human Experience ; The C.V. Mosby Company.

3. Dying begins when the patient realises or accepts the fact.
4. Dying begins when nothing more can be done to preserve life.

As judgements about dying are made within psychological contexts, often there are lags, miscommunications and disagreements. A person may be considered terminally ill by some people and not by others. Differences in treatment are often related to classification of the person as dying or not dying, as are differences in how the affiliated persons feel about himself.

Whatever the circumstances in which 'dying' is thought to begin, there is a high probability that the final course will be seen in a medical facility of some type. This leads to a completely different type of doctor - patient relationship which I am going to discuss in the following chapters.

Only in recent years, the word "terminally ill" has come into use as a label for people with a fatal disease. The shortcomings of a label are those aspects of it that create stigma and cause the labelled person to be treated as less than human. There have been efforts to clarify terms important to discussion of terminal illness. Ramsay suggests



the following distinctions<sup>61</sup>:

Terminal Illness		
Diagnosis of fatal disease	Imminently dying	Virtually dead

In his scheme, the period of terminal illness, which can last for minutes or years, extends from the time of the diagnosis until the person dies. When it appears that the person is about to die ( is imminently dying), then new considerations about what to do become appropriate. The concept of a "virtually dead" person enters into discussion of life-prolongation, transplantation and other issues in which the moment of death - by no means a clearly defined event - is an important considerations.

There are two distinct aspects of terminal illness that must be understood.<sup>62</sup> First, the person is going through, a process of dying", which means that known pathological condition is progressing and eventually will lead to almost certain death. Terminal illness brings into focus a number of new fears, concerns and hopes and evokes some particular kinds of responses from persons.

---

61. Ramsay, P. The Patients are Person ; New Haven ; Yale University Press ; 1970.

62. Purtilo, R. Health Professional/Patient Interaction ; W.B. Saunders Company ; 1978.

Second, the person is going to "be dead". The death event creates its own outlooks, concerns and fears, many of which are deep-seated. While much attention in recent years has been devoted to the subject of "dying", for most people the concept of death remains a great mystery and as such is still a taboo topic.

#### IMPACT ON SOCIOLOGY

We can recall once again here that this paper can fall on both sociology of profession and sociology of medicine - two sub disciplines of sociology. So, the impact of this paper on the field of sociology can better be understood through the discussion of its impact on both of these sub-disciplines.

Profession is not a new concept, yet the sociology of profession as a distinct subject sub-field has come into prominence only recently.<sup>63</sup> The attention of the scholars was drawn to the systematic study of work, occupations and professions with the rise of industrial urbanism in Western Europe.<sup>64</sup>

---

63. Dingwall R. & Lewis, (ed). The Sociology of the Professions ; The Macmillan Press Ltd. ; 1983.

64. Cockerham, N.C. Medical Sociology ; Prentice Hall ; 1987.

This exercise deals with one of the profession, viz.. medicine. Generally doctors are treated with higher social prestige than any other professions because of their special kind of responsibilities to their patients' lives. The present work once again focuses attention to this aspect and discusses how the doctors change their 'curing role' to "care-giving role" according to the need of the situation. The paper also examines how far the doctors deviate from the classical concept of professions in real life. The most significant contribution of this paper to the field of sociology of profession is that it shows how the changes in behaviour of the doctors can influence their interaction pattern with their patients (specially terminally ill) and makes them "successful" doctors in spite of their patients' death.

Sociology of medicine once again is divided into two separate but closely interrelated areas : sociology in medicine and sociology of medicine.<sup>65</sup> Sociology in medicine can be characterised as applied research and analysis primarily motivated by a medical problem rather than sociological problem. The sociology of medicine on the other hand has a different emphasis. It may be characterised as research

---

65. Mathur, I. Interrelation in an Organisations ; A Study in Sociology of Medicine ; Jaipur ; Aalekh ; 1975.

and analysis of the medical environment from a sociological perspective.<sup>66</sup> The present paper falls in this category as it tries to analyse how the social factors play an important role in the doctor's relationship with terminally ill patients. This paper also explains all the points of views of doctor, patients and patients' relatives to the incident of the death of the patient and how do they perform their roles in this situation to make the dying patient's last day a bit better. Through this discussion the idea of "hospice" has also come out which is rather unknown in India.

---

66. Straus, R. "The nature and status of medical sociology" ;American Sociological Review ; 1957; 22; pp. 200-204.

## **CHAPTER II**

### **CARE OF THE ELDERLY**

Geriatric care, includes that period of life that ends an ongoing process. At what moment the geriatric patient becomes a dying patient is not clear. While one phase of life typically shades almost imperceptively into the next, an awareness of fatal illness may begin at some point.<sup>1</sup>

It is easy to understand why persons, as they age are likely to become patients (in the sense of undergoing treatment for disease or injury). Elderly persons are likely to hurt. Hurt here means, to suffer or cause to suffer physically or mentally.<sup>2</sup> Even cursory examinations reveal that old people have a combination of physical and mental problem that cause pain and suffering. Although these problems may be of recent origin, they often have antecedents in early life. Yet aged persons are reluctant to ask for help. They may need encouragement to accept treatment and a role as a patient.<sup>3</sup>

- 
1. Marshall, J.R. The dying patient. In William, R. (ed). Topics in Aging & Long-Term Care; William & Wilkins; 1981.
  2. Gaitz, C.M. Aged patients, their families and physicians. In Usdin, G. And Hofling, C.J. (ed). Aging: The Process and the People; Brunner/Hazel, Inc.; New York; 1978.
  3. William, E.I. Issues in general practice. In Elford, R.J. (ed). Medical Ethics & Elderly People; Churchill Livingstone; 1987.

## PATIENT'S EXPERIENCE OF LOSS

Central problem associated with becoming a patient is that experience entails loss.<sup>4</sup> The loss may be in the form of decreased physical or mental function. For old people, it is both ways. With age, they become physically as well as mentally weak. Many older people, deprived of meaningful family, friendship or occupational ties and experiencing the stigma of old age, are convinced that they are no longer worthwhile. Like the physically disabled person, they also experiences cognitive dissonance. For them, things have changed. Many older people feel they are relics from another era, whose only use is to be displayed for the entertainment of the present generation.<sup>5</sup>

Retirement posses a threat to the former self-image (and subsequently, to the self-esteem) for many older men and women.<sup>6</sup> For most, retirement not only involves a substantial reduction in income but also signals the end of a whole identity. It is indeed a type of 'little death'.<sup>7</sup>

- 
4. Purtilo, R. Health Professional/patient Interaction; W.B. Saunders Company; 1978.
  5. Rao, V.A. & Girinathan, V. "Mental illness in patients aged 50 and over"; Indian Journal of Psychiatry; 14:319; 1972.
  6. Karl, C.S. et.al Aging and Health; Biologies and Social Perspective; California; Addison - Wesley; 1978.
  7. Deasi, K.G. & Naik, R.D. Problems of Retired People in Greater Bombay; Bombay; TISS.

Hospitalisation is also traumatic for almost everyone.<sup>8</sup> First, usually it quite significantly disrupts an individual's personal life as well as the lives of his family, occupational associates and friends. In addition to the disruption, the patient is often aware that entering the hospital signals the end of an increasing failure to cope with illness. This psychological defect can be as deleterious to the patient's welfare as the physical manifestations of the illness itself. The disruption and some of defeat that usually accompany the patient's admission are made greater by the fact that the person is placed in the middle of a mysterious hospital world. In the strangeness of this other-world that is vaguely associated with sickness and dying, he is robbed of both home and privacy.<sup>9</sup>

The loss of home and privacy is rooted in the far more basic loss of independence.<sup>10</sup> Hospitalised patient's reactions to this loss are easily discernible. The patient outside the hospital setting also experiences a loss of independence. He may be too weak to carry on simple daily

- 
8. Pathak, B. Our Elderly; Some Effects of Aging in Indian Subjects; Bombay; Medical Research Centre.
  9. Gillick, M. et.al. "Adverse consequences of hospitalisation in the elderly"; Social Science & Medicine; Vol.16; No.10; pp.1033-1038; 1984.
  10. Cowdry, E.V. Care of the Geriatric Patient; St. Louis; The C.V. Mosby Company; 1983.



activities. The loss of independence is thus of consequence to the old person; self-respect and the power to command the respect of others depend on it.<sup>11</sup>

The older person's assumption that he is different and is, therefore, no longer worthwhile as a human being sometimes manifests itself in a variety of ways. All these things ultimately contribute to create a stress in those people's mind which, again, in its own course, affects the condition of health. Coping with the stress is a major factor for the betterment of lost health. We all develop elaborate coping mechanisms for dealing with stress and the three common ones seen among the old people are (1) extreme defensiveness (2) false jocundity and (3) withdrawal.<sup>12</sup> Yet a fourth group becomes frankly dependent giving up all efforts at coping. The older person's interaction in this case is based on ambivalence and thus does not enhance his self-esteem.

#### **PATIENT'S ATTITUDE TOWARDS DYING**

The aging person usually begins to disengage himself from enjoying life processes prior to the actual terminal

---

11. Prasad, R. Problems of Aged in India. In Sharma, M.L. & Dak, T.M. (ed.) Aging in India: Challenge for the Society; 1987.

12. Bhatia, H.S. Aging and Society: A Sociological Study of Retired Public Servants; Udaipur; Arya's Book Centre; 1983.

illness.<sup>13</sup> In denying the importance of the processes and in turning away, he prepares for the eventual isolation and aloneness, that is, death. This decreased human interaction, a by-product of the aging process, appears to be a mutual withdrawal by both the aged person and society.<sup>14</sup>

Older patients seem to be less fearful of death in comparison to the younger ones.<sup>15</sup> Though they may not talk readily of it, when they do, their attitudes are more likely to be excepting and favourable, often reflecting an attitude of expectant waiting. Some elderly look forward to death as a pleasant occurrence or relief.<sup>16</sup> There are a number of reasons for the apparent greater acceptance of death.<sup>17</sup> As death becomes more imminent reality, the aged may engage in some anticipating socialisation for dying (perhaps with the help of age peers). Having reached their

- 
13. Biswanathan, R. Medical Problem of Old Age, Bombay; CTL; 1969.
  14. Bergner, M. Ermini, M. and Stahelin, H.B. (ed) Crossroads in Aging; Academic Process; London; 1988.
  15. Kalish, R. Death and dying in social context. In Benstock, R. and Shans, E. (ed). Handbook of Aging and The Social Sciences; New York; Van Nostrand Reinhold; 1976.
  16. Riley, H. and Foner, A. Aging and Society Vol. I. Inventory of Research Findings; New York; Russell Sage Foundation; 1968.
  17. Kalish, R and Reynolds, D. Death and Ethnicity : A Psychocultural Study; Los Angels; University of Southern California Press; 1976.

'expected age' they may feel also that they are living on borrowed time, making death seem less unfair. Finally, problem associated with aging and process of disengagement may diminish the value of life. Religious beliefs also seen to modify a person's view of death in a positive manner. Thus, contrary to what are might expect, the elderly as a group are not more fearful of death.

Other older people can be invaluable source of support against death and dying. Studies of age segregated settings indicate that, they facilitate discussions of death, allowing the aged to come to grips with their own feelings and achieve an acceptance of death which does not require denial.<sup>18,19</sup> Age peers serve as role models of how to 'face up' to death, how to react appropriately to death of others and how to die in a 'good' or signified way.

The stage of depression is a special problem among the elderly for the incidence of depression is increased substantially among this age group and it is very difficult to separate a significant clinical depression from a more

---

18. Hoschild, A. The Unexpected Community; Englewood Cliffs; New Jersey; Prentice-Hall; 1973.

19. Marshall, U. "Socialisation for impending death is retirement village"; American Journal of Sociology; 80; 1124-44.

common stage in the process of dying.<sup>20</sup> This is an important distinction for the treatment and outcome of each is different. Even geriatric patients themselves may not be able to help for there is often an implicit belief of the patient (and at times of doctors too) that feeling bad is a normal part of aging process and must be endured. Thus, elderly patients frequently tolerate unhappiness, suffering and lethargy in an almost philosophic context -- it's part of growing old.<sup>21</sup>

And, finally, it appears that elderly patients more often achieve a stage of acceptance of their ultimate fate.<sup>22</sup> It is not clear whether they progress to this phase more easily than younger patients or are just more accepting. Resignation is not to be misconstrued as acceptance. Many older patients give up their wish to live due to physical deterioration or due to a lack of quality in their contacts with people or surroundings. Despair is not acceptance.

- 
20. Breemhar, B., Visser, A.Ph., Kleysieh, J.Y.V.H. "Perception & behaviour among elderly hospital patients; description & explanation of age differences in satisfaction, knowledge, emotions and behaviour". Social Science & Medicine, Vol.31; No.12; pp.1377-1990; 1990.
  21. Kohli, D.R. Challenge of Aging. In Sharma, M.L. & Dak, T.M. (ed.): Aging in India: Challenge for the Society; 1987.
  22. Haug, H.R., Wykle, M.L. & Namaz, K.H. "Self care among older adults". Social Science & Medicine, Vol.29; No.2; p.171; 1989.

## DOCTOR'S ATTITUDE TOWARDS THE DYING PATIENT

Medical professionals seldom handle dying patients well.<sup>23</sup> Management of dying patients is often based on unexamined beliefs and dogmatic misconceptions. Personal interactions with the patient gets filled with perfunctory rituals, awkward reassurances and intellectualized jargon when the fact of approaching death becomes obvious to all. The result of these maneuvers is an increasing emotional distancing between doctor and patient at a time when it is most needed.<sup>24</sup> Sociological field studies have demonstrated striking changes in staff behaviour such as, doctors make rounds less often or with more haste, nursing staff terminate their procedures and enter the patients' room less frequently, or the patient may be moved to a single room further from the nursing station. Effectively, the still living patient is treated as if he is already dead, a 'non-person'.<sup>25</sup>

This failure to render appropriate, effective and sustained care to the dying patient has multiple causes.<sup>26</sup>

---

23. Marshall, J.R. Op.cit.

24. Hazel, R. Social & Medical Problems of Elderly; London; Butchison; 1965.

25. Smith, D.W. et.al. Care of the Adult Patient; Medical Surgical Nursing.

26. Goldberg, E.M. Helping the Aged: A field experiment in social work; George Allen & Unwian Ltd.; 1970.

Some are general. By training and tradition, medical professionals are dedicated to the maintenance of life. They see themselves as implacable foes of the many causes of physical death and experience its arrival as a defeat. Beyond this too narrow conceptualisation of their role, they have had little or so formalised training or formulated ethic to guide them in administering to the dying and in seeing that the patient and his family yield to death only on most favourable human terms. The practicality of time limitations for both nurses and physicians also cause them to place a lower priority on those whose days are clearly numbered. Perhaps most importantly, medical staff, as representatives of our society, share in general, denial of the reality of dying, even to an exaggerated degree. It has been seen that physician (and perhaps nursing personnel) have an above average fear of death when compared with their patients and general public. The more anxiety produced by the dying, the more apt the staff member is to shun or relate poorly to the terminal patient.<sup>27</sup>

There are also general attitudes related to the geriatric dying patient, that could interfere with appropriate

---

27. Lowy. L. Social Work with the Aging; Harper & Row publishers, Inc.; New York; 1979.

care.<sup>28</sup> While an aversion to death, the belief that it is wrong or at least premature, is a source of anxiety concerning younger patients, it may be mitigated or absent when dealing with elderly patient. Also, it can be natural, the reasonable last stage in the longitudinal process of living.

There are adverse implications, however, to the too ready acceptance that all elderly patients are appropriately ready for death. It may lead the medical team member to join society (as opposed to their profession) in viewing their patients' death as relatively less important. This belief, often fairly conscious, may allow the physicians and the staff easy rationale for abandonment of these patients, avoidance of personal contacts, nonconfrontation of their own ambivalent feelings or acceptance of deaths which could have been postponed.<sup>29</sup>

'Though perhaps only experience -- the many encounters of seeing it through with dying patients will adequately prepare one for terminal care, there are principles which are helpful. To render effective care, in those last days, it is not necessary to be a psychiatrist, nor does it follow

---

28. Barser, M.L., Evans, R.Y., Hartzman, C. & Lomas, J. "Aging & health care utilisation: new evidence on old fallacies"; Social Science & Medicine; Vol.24, No.10, pp.851- ; 1987.

29. Pai, M.S. Senior Citizens and their Care. In Bose, A.S. & Gangrade, K.D. The Aging in India: Problems & Potentialities; New Delhi; Abhinav Publications; 1988.

they are more proficient. First, one must try to understand the patient in terms of what has been. By joining a patient who is attempting to put his life into perspective, one can more easily empathise. One can comprehend the pain of immobilisation for a person who was hitherto active or recognise the sense of loss of one has, who has lived through roughly three generations in the same house and is now removed to a hospital or nursing home. It is empathy, not sympathy, which is the critical attitude for this process.<sup>30</sup>

By fully understanding that the feelings a person experiences in the process of dying are actually aspects for their grief for themselves, therapeutic measures became clearer.<sup>31</sup> The patient needs to talk outward expression of feelings and thoughts will facilitate the work of grieving. By an attitude of non-critical acceptance, particularly of negative affects, the physician can help the patient objectify his turmoil and with time move toward some level of acceptance of the situation. The terminally ill consider death as a possible outcome and welcome the chance to talk about their feelings. The fact of sharing this fear with the

---

30. Nandlal, D.S. et.al. Aging Problems in the Structural Context. In Sharma, M.L. & Dak, T.N. Aging in India: Challenge for the Society; 1987.

31. Thomson, M.K. Care of the Elderly in General Practice; Edin.; Churchill Livingstone; 1981.



doctor is in itself therapeutic and promotes more confident communication between patients and doctors.<sup>32</sup>

Reassurance from the doctor is most important for the dying patient. Unfortunately, glib reassurances like, "Don't worry about that, things will turn out all right" are too often used in those moments instead of listening for the precise nature of the fear.<sup>33</sup> It is often stated that people do not fear death but the process of dying. By spending more time with the patient, the doctor becomes friendly and then only he can come to know about the nature of the fear. Perhaps, the greatest fear that patients have concerning their prognosis is the dread of being left alone. This is a very real fear and one likely to occur in the hospital, particularly when the staff runs out of procedures for the terminally ill patient. When these moments are anticipated and the patient is reassured of human contact, either professional or familial, it puts the patient into better situation.

Psychotropic drugs are rarely helpful for the dying patient and are of insignificant advantage compared to the

---

32. Cramond, W.A. "Psychotherapy of the dying patient"; British Medical Journal; Vol.3, pp.389-1970.

33. Anderson, F. Practical Management of Elderly, Blackwill Scientific Publications; 1976.

comfort of human contact in the patient's last days.<sup>34</sup> Though pain control may be needed, heavy radiation is not doing any favour to the dying patient. Most often tranquilizing medications are given for staff anxieties rather than the patient's. As the doctors want to avoid meeting the dying patients, they adopt this method. Most of the doctors tend to forget that large number of dying patients retain a fairly high quality of mental functioning and are aware of their immediate environment and of words spoken in their presence. This strains relationship of the doctor and patient. Where spoken communication is no longer possible, then just one's presence and occasional physical contact remain powerful messages.<sup>35</sup>

Persons inexperienced in attending dying patients are often troubled by a fear that the patients will ask if they are dying. What should be said? This very seldom happens, particularly among older patients. If it does, the answer is, of course to be compassionately truthful.<sup>36</sup> There is no evidence to support that talking about death hasten its arrival or makes dying more painful. There is much to the

- 
34. Tinker, J. & Rapin, H. Care of the Critically Ill Patients; Berlin; Springer Verlag; 1982.
  35. Ayres, S.M. & Giannelli, S. Care of the Critically Ill; N.Y. Applieton; 1967.
  36. Kolker A. & Ahmed, P.I. (ed), Aging; Elsvier Science Publishing Co. Inc.; New York; 1982.

contrary. A patient almost always knows the answer by the time this question is asked directly.

#### **OLDER PEOPLE AND THEIR FAMILIES**

While the nature of family relationship has changed in many ways because of modernisation and industrialisation, the family is still a major source of primary relationships, providing long-lasting, intimate, emotional ties with others.<sup>37</sup> Thus, the extent to which older people are embedded in a system of family relationship has a great potential impact on the aging experience, process of dying and death.

The death of an old person, who is performing the role of grandparent successfully will have a different impact on the family members than an old person who is already detached from his family. Equally, in the former case, family member will take more active participation in the old man's treatment process till his death than in the later case. In families, where the grandparents are closely attached, their death is expected to bring an impact on the grandchildren's mind, specially regarding the development of the concept of death. It will be better to discuss how people slowly socialise them with the expected age role as this socialisa-

---

37. Landsberger, B. H. Long-Term Care for the Elderly; Croom Helm Ltd.; 1985.

tion process becomes important for the quality of care for the elderly on the family members' part.

There is a stereotyped notion that socialisation and personality formation are confined to childhood, producing a relatively finished product. There are, however, numerous situations, which may lead to socialising experiences in adulthood.<sup>38</sup> Additionally, adults move through sequences of roles and statuses during the life cycle which require meeting changing expectations.

Adult socialisation is particularly relevant to 'role transfer' which combines the strain of leaving old commitments with the need to adjust to new tasks and expectations. One of the most basic problems of older people is that they are not socialised into 'old age'.<sup>39</sup> Adult role transition typically involves an increase in responsibility and independence. Changes associated with aging, however, are more likely to represent a loss of responsibility and increased dependence. Consequently, there is little motivation to deny it. One consequence of this may be uncertainty and alienation, although, it also implies greater freedom, which may

---

38. Brim, O.Jr., Wheeler, S. Socialisation after Childhood; New York; John Wiley; 1966.

39. Rosow, I. Socialisation to Old Age; Berkeley University of California Press; 1974.

be a positive aspect of aging.<sup>40</sup> There is also little role continuity in the shifts associated with aging. The aged are left to make their own adaptation, since modern cultures do little to prepare them for the positions occupied by older people. It may be more appropriate to speak of 'role exit' for older people, since they do not really take on new roles. When role exits are involuntary, there may be feelings of shame and betrayal with the implied social rejection.<sup>41</sup>

A final family role available to older people is that of grandparent. Grandparenting is a potentially important source of gratification and responsibility since it is one of the few new roles open to older people. Grandparents can be an important source of assistance during the family emergencies. The most extensive study of the grandparent role was conducted by Neugarten and Weinstein, through interviews conducted with 100 grandparents in Chicago.<sup>42</sup> It found that most prevalent meaning of the grandparenting role is a source of 'biological renewal' (it's through my grand-

---

40. Ward, R.A., The Aging Experiences: an Introduction to Social Gerontology; J.B. Lippincot Company; 1979.

41. Blaue, Z. Old Age is a Changing Society; New York; New viewpoints, 1973.

42. Neugarten, B. & Weinstin, K. "The Changing American grandparent". Journal of Marriage and Family; 26; 199-204.

children that I feel young again) and/or 'biological continuity' with the future (it's through the grandchildren that I see my life going on into the future on its carrying on the family line).

Reported 'styles' of grandparenting again reflect a relative lack of involvement. The most frequent style was a 'formal' one, reflecting a 'proper' role which clearly separated parental and grandparental functions. While minor services and indulgences were allowed, care was taken not to 'interfere' in childrearing. Two other roles are prevalent: 'fun-seeking', emphasising informality, playfulness and mutual satisfaction and 'distant figure', largely confined to ritualised family gatherings. The 'parent surrogate' was confined to the grandmothers and very few functioned as a 'reservoir of family wisdom.

The degree of involvement with other family members certainly has some impact on the process of dying of an elderly. If the old person is too attached to his family members, he may not be able to accept the forthcoming death with courage. He may be scared of losing all his favourite relations and may not allow him as well as the caregivers and family members to deal with the situation properly. But sometimes, when the elderly person is already detached from his family, he looks forward to death with hope for an

'happy ending' to his not-so-happy life. This attitude helps them to accept death calmly and both the caregivers and family members find it easy to go through the situation. But there is a possibility that this detachment from the family may lead to a depression for which the older person may find the family members and caregivers guilty for any kind of discomfort he is facing. This makes the situation worse.

#### **DOCTOR, PATIENT AND PATIENT'S FAMILY**

Care for the elderly demands a comprehensive approach.<sup>43</sup> It requires that health care professionals become familiar with community resources and options for care. The health care professionals often becomes the liaison between the elder, family friends, and health care sources during critical transitions. The ease and ability with which the health care professional can balance and negotiate community resources, to the benefit of the patient is often directly tied to the survival of that individual.

The problem of old age tend to be multiple rather than single.<sup>44</sup> Reduced mobility due to osteoarthritis or to more

---

43. Kleh, J. Community and medical resources. In O'Hara-Devereaux, M., Andrus, L.H. Scott, C.A. & Garg, M.I. (ed). Eldercare: A practical guide to clinical geriatrics; Grune and Stratton, Inc.; 1981.

44. McCormick, J. The Doctor: Father figure or plumber; Croom Helm; London; 1979.

easily remediable disorders such as corns and bunions, coupled with failing sight and hearing, transform minor tasks such as homework and shopping into major undertakings. Falls are no longer trivial accidents but likely to lead, especially in women, to broken wrists and, more seriously, broken hips, social contacts are diminished, in part by not being able to get about, but also by the death and enfeeblement of contemporaries. Paradoxically, those who are becoming deaf are often intolerant of noise and failing sight may make reading either difficult or impossible.

Minor degrees of urinary incontinence are common and the resultant problems of laundering clothes and bed linens, of protecting chairs and dealing with smell are quite disproportionate to the seriousness of the disorder.<sup>45</sup>

Leaving aside physical diseases, such as failing hearts, chronic chest disease, enlarged prostates and cancers, the most serious problem of this age is failing mental powers. Some degree of failure of memory, especially for recent happenings, is almost universal. In minor degree, this means nothing more than predictable responses to given cues, the same often told reminiscence. But it may well result in the endless repetition of the same question no matter how often an answer is provided.<sup>46</sup>

---

45. Ibid.

46. Ibid.



One of the results of unable to recall events is a sense of being out of touch, of being unsure about things in general. Initially this is most distressing and is often followed by unjustified suspicion, amounting sometimes to paranoia. Things which are mislaid have been stolen things which have been misunderstood are seen as deliberate attempts to mislaid. It is easy to overlook the extent of mental failure and the casual caller, even the doctor, nurse or health visitor, may be deceived by outward appearances. The true extent of the failure may only become apparent if hospital admission or some other move to a different and strange environment becomes necessary.<sup>47</sup>

Whether he leaves home or not, the patient in terminal illness remains a part of his family and they have to go through the same journey together.<sup>48</sup> Families provide their elderly relatives with significant assistance. This network includes family members (spouses, parents, brothers, sisters, inlaws, etc) friends and neighbour.<sup>49</sup>

---

47. Gupta, P. & Vohra, A. Problems of psychiatric morbidity in the Aged". In Sharma, M.L. & Dak, T.M. (ed.) Aging in India: Challenge for the Society; 1987.

48. Jecker, N.S., "The role of intimate others in medical decision making". The Gerontology; Vol.30; No.1; pp.65-71; 1990.

49. Julras, S. "Caring for the elderly: The partnership issue". Social Science & Medicine; Vol.31; No.1; pp.763-771; 1990

Research on families and older adults has consistently demonstrated that families , especially adult children, are the predominant service and health care providers to the inpaired elderly.<sup>50, 51, 52</sup> To say 'adult children' is usually to mean adult daughters. Three factors are usually cited to explain why daughters have dominated as primary caregivers - their traditional assumption of nursing tasks, their stronger emotional tie to their family of orientation and the fact that they have more flexible free time in their role as homemakers than do their male counterparts in their occupational roles. In fact, the familial obligations did not diminish the global assistance provided by women, but reduced the global maintenance provided by men caregivers.

Various studies have shed some light on certain psycho-

- 
50. Horowitz, A. Sons. & Daughters as caregivers to older parents: differences in role performance & consequence. Gerontologist; Vol.25; No.6; pp.612-617; 1985.
  51. Fisher, L.R. Elderly parents and the caregiving role: an asymmetrical transition. In Peterson, J. & Quadagno, J. (ed). Social Bonds in Later life; Aging & Independence; Sage; Beverly Hills, CA; 1985.
  52. Stoller, E.P. "Parental caregiving by adult children"; Journal of Marriage & Family; 5; 851-858; 1983.

logical difficulties<sup>53, 54</sup> as well as health problems<sup>55</sup> experienced by caregivers. Adult children caregivers may find themselves at a point in their lives where they long for freedom and fewer familial responsibilities. But this aspiration is frustrated by caregiving obligations. The relationship with the elderly relative often creates many problems, particularly, because of an asymmetrical reciprocity in exchange, a role reversal or a mutual misunderstanding.

The situation may be more taxing when younger family members are called upon to provide aid with 'marital household services' (such as providing meals and cleaning) to their formerly independent parents or relatives. The potential for family conflicts is heightened as the balance of independence and dependance needs in older member shifts.<sup>56</sup>

- 
53. Hausman, C.P. "Short-term counselling groups for people with elderly parents"; The Gerontologist; 19; 102-107; 1979.
  54. Cattanachx, L. & Tebes, J.K. "The nature of elder impairment and its impact on family caregivers' health and psychosocial functioning"; The Gerontologist; Vol.31; No.2; pp.246-255; 1991.
  55. Silliman, R.A. & Sternberg, J. "Family caregiving: impact of patient functioning and underlying causes of dependency"; The Gerontologist; Vol.28; pp.377-382; 1988.
  56. Cantor, M.H. The informal support system: its relevance in the lives of elderly. In Borgatte, E.F. & McCluskey, N.G. (ed), Aging & Society; Beverly Hills, CA; Sage Publication; 1990.

Retirement and bereavement, decline in physical capacities and societally imposed lessening of authority may each serve to shift this balance, thereby disrupting the homeostasis of the family system. Families who are flexible, prepared to take on new tasks vis-a-vis older members, while still providing them with a meaningful role, will contribute positively to the elderly person's health and well-being.

Some relatives feel guilty that the old person has had to come to hospital for his last illness and blame themselves for failing to provide care or treatment. Physicians should be alert to sense this reaction on the part of the relatives and should offer them an early appointment. Relatives who react in this way add to their own burdens and may make the patient discontented and distrustful. When physician is able to empathise effectively with families, to 'tune in' to their anguish, much of the difficult and demanding behaviour often exhibited by relatives diminishes.<sup>57</sup>

---

57. McGreehan & Warburton "How to help families cope with caring for elderly member"; Geriatrics; 33 (6): 99-106; 1978.

## **CHAPTER III**

# **CARE OF THE CANCER PATIENT**

Cancer is a social disease of tremendous impact. This killer disease is now a major problem. A cancer victim is not a person with a diseased body, but also an individual with family and friends, who has attitudes and aptitudes, interests and instincts, hopes and dreams of his own future and the future of his own family - all these are affected by the malady. This usual human problems are involved : fear of loosing a job, uncertainty of acceptance by ones own family and friends and concern about the fear of near and dear ones. These common problem are greatly intensified by the onset of cancer.<sup>1</sup>

---

1. Bhatt, U. Socio-economic Problems of Cancer Patients ; Bombay ; The Indian Cancer Society; 1963.

## PATIENT'S ATTITUDE TOWARDS DEATH

Any patient suffering from any kind of illness has his own fear about it. This fear is most prevalent among cancer patients. They mainly suffer from two kinds of fear - (a) the fear of cancer, and (b) the fear of hospitalization.<sup>2</sup> Before discussing how cancer patients cope with their disease, these two issues deserve some mention in order to appreciate and comprehend the impact of a life threatening illness like cancer can have on a patient and his family. *Fear of what cancer means.* Cancer is a particularly frightening disease because it is viewed as an illness with these three characteristics :

1. A cause that is unknown.
2. A treatment that is seen as generating great discomfort and incapacitation.
3. The outcome is uncertain and long-term survival chances far from sanguine.

Cancer is often viewed as a 'helpless disease'.<sup>3</sup> Treatment is seen as something that is done to a patient and for

- 
2. Pafferty, J.P. The psycho-social adjustment problem of the cancer patient. In Higby, D. J. (ed.) The Cancer Patient and Supportive Care ; Martimes Nijhoff Publication ; 1985.
  3. Greer, S. "The psychological dimension in Cancer treatment" Social Science & Medicine ; Vol. 18 ; No 4 ; pp. 345-349 ; 1984.

a patient with very little opportunity to actively assist the process. The specific fear that the diagnosis and treatment of cancer can elicit are numerous : fear of pain, fear of social isolation, immobility, physical restriction, etc.<sup>4</sup> Perhaps the chief fear of seriously ill cancer patient is that of emotional abandonment by the patient's doctor and family. Usually, this fear is not verbalised directly because it might generate anger, resentment and loss of future support. It is most often expressed indirectly as concern about being medically neglected, not receiving adequate nursing care or feeling neglected in some other manners by hospital staff.<sup>5</sup>

*The fear of hospitalisation.* The very act of being hospitalised often acts as a stress factor which is usually overlooked.<sup>6</sup> Being hospitalized is, for many people, like entering a foreign country. Hospital employees wear different clothes, speak an incomprehensible language and follow rules and procedures that are dramatically different from how most patients live. This is especially true for the patients

- 
4. Weisman, A.B. Coping with Cancer; Mc-Graw Hill ; New York ; 1979.
  5. Aharony, L.& Strausser, S. "Patient's satisfaction: what we know about and what we still need to explore"; Medical Care Review; Vol. 50; No.1; pp. 49-79; 1993.
  6. Ben-Sira, Z. "Chronic illness, stress & coping"; Social Science & Medicine; Vol. 18; No.9 ;pp. 725-736; 1984,



who occupy the lower rungs of the economic ladder. With a very faint exposure, they are more scared of being hospitalized than any well-off and educated people.<sup>7, 8</sup>

A brief note should be made concerning how hospitalised patients define their illness, for it often differs dramatically from how caregivers define it. Patients are often chiefly concerned with and define the seriousness of their illness by their immediate primary symptoms of pain, social incapacitation isolation, etc. Medical personnel are frequently more attentive to and concerned with the underlying pathology of the organised illness.<sup>9</sup> What this suggests is a difference in association and goals between caregivers and patient concerning what is of principal importance. The caregivers' recognition and appreciation of how the patient perceives his illness lessens the chance that the patients' concerns will go unmet, resulting in increased anxiety and apprehension<sup>10</sup>

- 
7. Minocha, A. Some Aspects of Social System of an Indian Hospital; Delhi ; Delhi University ; 1974.
  8. Oommen, T.K. Doctors & Nurses; Delhi ; Mcmillan ; 1978.
  9. Robinson, D The Process of Becoming Ill ; The Trinity Press; London ; 1971.
  10. Sommers & Sommers. Doctors, Patients and Health Care ; The Brookings Substitution; 1961.

## Coping With Death

The concept of coping as defined by Lazarus contains two functions, an external (problem-solving) one and an internal (regulatory or palliative) one.<sup>11</sup> The external function of coping is concerned with changing a situation that is stressful or problematic. This can be achieved by changing the reaction to a stress, e.g., seeking medical advice. The internal function of coping is aimed at reducing subjective emotional components of stress and maintaining a satisfactory internal state for processing information and action. The stress of confronting a life threatening illness like cancer generally involves both the coping functions. The style in which the patient copes with illness actively shapes the course of relationships with family members, physicians and other supportive resources.<sup>12</sup>

Is there a most correct or acceptable style of dying, or is there a 'best way' of coping with death? The initial response to this question must be another question : Best for whom? For health professionals? Health professionals seem to prefer people who cope with death quietly, cheerful-

- 
11. Lazarus, R.S. "Psychological stress & coping in adaptation and illness" ; International Journal of Psychiatry in Medicine ; 5 : 321 - 333; 1974.
  12. Molleman, E., et al. "The significance of doctor-patient relationship in coping with cancer"; Social Science and Medicine ; Vol. 18; No.6; pp.475. 1984.

ly and self-sufficiently. Or best for the society at large? The response might be then in terms of dying inexpensively, to reduce costs to taxpayers and strain on health facilities. Also dying with minimal disruption to others, so that the general stress level of community does not rise as a result of death.<sup>13</sup>

'Best' for family members?' The patient's style of coping with death should, one hopes, not be guilt inducing nor too disruptive of other tasks that need to be done. Remaining contracts should be rich, full and relaxed. And, if at all possible, financial costs should be covered by health insurance.

Even if we accept the definition of 'best' as meaning best for the needs and wants of the patient, we are still confronted with a complex situation. Each dying person is unique, both in what is brought into the situation from the past and in the nature of the immediate life-threatening situation itself. Thus, the style of coping with death is influenced by experiences, values and expectation of the fatally ill person.<sup>14</sup>

- 
13. Kalish, R.A. Coping with death. In Ahmed, P. (ed), Living & Dying with Cancer ; Elsevier ; New York ; 1981.
  14. Berman, S.H. & Wandersman, A. "Fear of cancer & knowledge of cancer : a review & proposes relevance to hazardous waste sites"; Social Science and Medicine; Vol.31; No.1; pp. 81-90; 1990.

The age of the person confronting death is certainly one major factor in the response to death. Younger people often believe that they have not been given their allocated time for living. They feel angry and cheated. Middle aged persons have many responsibilities and are often immersed in plans and projects that will now remain unfinished. In fact, the evidence is fairly consistent that old people are less fearful of their own deaths than are either middle-aged or younger individuals with the middle-aged probably being most anxious.<sup>15</sup>

Various aspects of the personal/social situation, such as demographic characteristics, social support and socio-economic status, are conceivably important factors associated with adaptation to cancer.<sup>16</sup> Social support has also been with adjustment to cancer. Consistent with Mechanic's statement that "the ability of persons to maintain psychological comfort will depend not only on the intrapsychic resources, but also - and perhaps more importantly - on the social supports, available or absent in the environment",<sup>17</sup> effec-

- 
15. Kalish, R.A. & Reynolds, D. Death & Ethnicity : A Psycho-Cultural Study ; Los Angeles, University of Southern California Press; 1976.
  16. Goldberg, R.J. & Cullen , L.O."Factors important to psycho-social adjustments to cancer" ; Social Science and Medicine; Vol. 20; No.8; pp.803-807; 1985.
  17. Mechanic, D. Social structure & personal adaptation : some neglected dimensions. In Coelho, C.V., Humburg, D.A., & Adams, J.E. (ed) : Coping & Adaptation; Basic Books ; New York ; 1974.

tive social support has been considered to be a crucial factor in the psychosocial adaptation during terminal illness.

### **Process of Coping**

When a patient comes to know that his illness is a terminal one, he goes through a number of stages to accept it.<sup>18</sup> Elizabeth Kubler - Ross has described these stages vividly.<sup>19</sup> During this process, a series of defensive measures are utilized to allow slower and less painful loosening of old ties and to adjust to the altered situation.

The first stage is that of *denial* and is characterised by patient's attempts to avoid the painful awareness of their terminal illnesses. In effect, a patient says, "I won't believe this is happening to me". This is usually a brief period in which the denial ebbs and flows and gradually replaced by awarenesses of the reality of the situation. In very few patients this psychological defense is persistently used, even until death.<sup>20</sup>

- 
18. Gross, T. "Emotional expression in cancer onset & progression" ; "Social Science and Medicine, Vol. 28; No. 12; pp. 1239-1248; 1989.
  19. Kubler-Ross, E, On Death & Dying ; London ; Macmillan ; 1969.
  20. Kastenbaum, R.J. Death, Society & Human Experience ; The C.V. Mosby Company ; 1987.

The patient's first reaction may be a temporary state of shock from which he recuperates gradually.<sup>21</sup> When his initial feelings of numbness begin to disappear and he can collect himself again, a person's usual response is, "No, it cannot be me". Since in our unconscious mind we are all immortal, it is almost inconceivable for us to acknowledge that we too have to face death. Depending very much on how a patient is told, how much time he has taken to gradually acknowledge the inevitable happening and how he has been prepared throughout life to cope with stressful situations, he will gradually drop his denial and use less radical defense mechanism.<sup>22</sup>

When the first stage of denial cannot be maintained any longer, it is replaced by feeling of anger, rage, envy and resentment. The next logical question is : "Why me" ? In contrast to the stage of denial, this *stage of anger* is very difficult to cope with from the point of view of family and staff. The reason for this is the fact that the anger is displaced in all directions and projected into the environment at times almost at random. The nurses are even more

- 
21. Koster, M.E.T.A. & Bergsma, J. "Problem & coping behaviour of facial cancer patients"; Social Science and Medicine; Vol. 30 ; No. 5 ; pp. 569-578 ; 1990.
  22. Karl. C.S. Mctress, E. S. & Mctress, J.F. Aging & Health : Biologic & Social Perspective ; California ; Addison - Wessby ; 1978.

often a target of their anger. Another reason for this anger is the loss of control over his life, which the patient used to enjoy before the diagnosis of the terminal illness.<sup>23</sup>

The third stage is that of *bargaining*. It is a psychological attempt to postpone the inevitable.<sup>24</sup> "If I don't do or think certain things, I will be spared". We all are familiar with this reaction when we observe children first demanding, then asking for a favour to their parents. The terminally ill patient uses the same manoeuvres. He knows, from past experience, that there is a slim chance that he may be rewarded for good behaviour and be granted a wish for special services. His wish is most always an extension of life, followed by the wish for a few days without pain or physical discomfort. Kubler-Ross mentioned of a patient who was an opera singer, with a distorting malignancy of her jaw and face who could no longer perform on the stage, asked "to perform just one more time".<sup>25</sup> Most promises are made with god and are usually kept a secret or mentioned between the lines. Many patients also promise to give parts of or their

---

23. Gotay, C.C. "Why me ? Attribution and adjustments by cancer patients and their mates at two stages in the disease process ; "Social Science and Medicine", Vol. 20:; No. 6 ; pp.825-831 ; 1985.

24. Lofland, L.H. The Craft of Dying : The Modern Face of Death ; Sage Publications ; 1978.

25. Kubler-Ross, E. Op.cit.

whole body "to science" if the doctors use their knowledge of science to extend their life.<sup>26</sup> Psychologically, promises may be associated with quiet guilt and it would therefore be helpful if such remarks by patients were not just brushed aside by the staff.

When the terminally ill patient can no longer deny his illness, when he is forced to undergo more surgery or hospitalization, when he begins to have more symptoms or becomes weaker and thinner, he cannot smile it off anymore. His numbness or stoicism, his anger and rage will soon be replaced with a *sense of great depression*.<sup>27</sup> It is the reaction most pervasive, the fear of loss.

The loss may have many facets. An opera singer responded to the required surgery for her face and removal of her teeth with shock, dismay and the deepest depression. But this is only one of the many losses that such a patient has to endure.<sup>28</sup>

With the extensive treatment and hospitalization, financial burdens are added. Little luxuries may not be afforded any more. It seems that such treatment and hospi-

---

26. Raven, R.W. The Dying Patient, London ; Pitman Medical; 1975.

27. Kubler-Ross, E. Op.cit.

28. Ibid.



talization cost in recent years have forced many patients to sell the only possessions they had, they were unable to keep a house which they built for their old age, unable to send a child through college and unable perhaps to make many dreams come true.<sup>29</sup>

There may be added loss of a job due to many absences or the inability to function and mothers and wives may have to become the breadwinners, thus depriving the children of the attention they previously had. When mothers are sick, the little ones may have to board out, adding to the sadness and guilt of the patient. An understanding person will have no difficulty in eliciting the cause of the depression and in alleviating some of the unrealistic guilt or shame which often accompanies the depression.<sup>30</sup>

A second type of depression is one which does not occur as a result of a part loss but is taking into account impending losses. If the patient is allowed to express his sorrow he will find an acceptance much easier. This second type of depression is usually a silent one in contrast to the first during which the patient has much to share and

---

29. Barton, D. Dying & Death; Baltimore; William K. Wilkins; 1977.

30. Brim, O.G. (ed.) Dying Patient; New York; Russell Sage Foundation; 1970.

requires many verbal interactions and often active intervention on the part of the people in many disciplines.<sup>31</sup>

If a patient has had enough time (i.e, not a sudden, unexpected death) and has been given some help in working through the previously described stage, he will reach a stage during which he is neither depressed nor angry about his fate. He will have been able to express his previous feelings, his envy for the living and the healthy, his anger at those who do not have to face their end so soon. He will have mourned the impending loss of so many meaningful people and places and he will contemplate his coming end with a certain degree of quiet expectation.<sup>32</sup> This is the stage of *acceptance*.

Acceptance should not be mistaken for a happy stage. It is almost void of feelings. It is as if the pain had gone, the struggle is over and then there comes a time for the final rest before the long journey.<sup>33</sup> This is also time during which the family needs usually more help, understanding and support than the patient himself.<sup>34</sup> While the

---

31. Kubler-Ross. E. Op.cit.

32. Kastenbaum, P Vitality of Death: Essays in Existential Psychology & Philosophy; Connecticut; Greenwood; 1971.

33. Marshall, J.R. The dying patient. In William, R. (ed.) Topics in Aging & Long-Term Care; Willian & Wilkins; 1981.

34. Labrccque, M.S. et al. "The impact of family presence on the physician-cancer patient interaction" ; Social Science & Medicine ; Vol. 33; No. 11; pp.1253-1261 ; 1991.

dying patient has found some peace and acceptance, his circle of interest diminishes. He wishes to be left alone or at least not stirred up by news and problems of the outside world. Visitors are often not desired and if they come, the patient is no longer in a talkative mood. He often requests limitations on the number of people and prefers short visits.<sup>35</sup> Communications then become more nonverbal than verbal.

There are few patients who fight to the end, who struggle and keep a hope that makes it almost impossible to reach this stage of acceptance. They are the ones who will say one day, "I just cannot make it anymore". The day they stop fighting, the fight is over.<sup>36</sup> The harder they struggle to avoid the inevitable death, the more they try to reach this final stage of acceptance with peace and dignity. If the doctors are unable to differentiate those two stages (which is, again, difficult), they do more harm than good to their patients and will make their dying a painful last experience.<sup>37</sup>

---

35. Brown ,E, L. Newer Dimensions of Patient Care.

36. Shelp. E.E. "Courage: a neglected virtue in the patient physician relationship" ; Social Science and Medicine ; Vol. 18; No.4; pp. 351-360; 1984.

37. Kubler-Ross, E. Op.cit.

These stages are meant to be neither comprehensive nor mutually exclusive. They may vary with most patients. Some persons may experience only a few of them, may pass through in different sequences.

It can be uniquely difficult to make good use of the time when there is little left, whether or not, options are further limited by illness and by treatment regimens.<sup>38</sup> Most people are so oriented to anticipating a future in mind that refocusing their thinking to a very brief future becomes an extremely difficult task. Nevertheless, it does happen : people confronting their own death frequently do become capable of focussing on the present and living in that present, not by excluding awareness of the future nor by denial of coming death but by having found an acceptance style of coping with death that permits significant attention to be given to what is available, rather than having all energy drained in attending to what will not be available.<sup>39</sup>

---

38. Chaturvedi, S.K. "What important for quality of life to Indians in relation to cancer; Social Science and Medicine; Vol. 33; No.1; pp.91-94; 1991.

39. Kubler-Ross, E. Op.cit.

## PHYSICIAN'S ATTITUDE TOWARDS THE ILLNESS

At a medical symposium, internists and surgeons specialising in oncology were asked to indicate who was the greatest source of distress for a patient after diagnosis and surgical treatment of cancer. According to the majority of respondents, the spouse was named most often on both counts. The physician was cited as fourth in importance in each case. When the same question was asked to a group of patient who had just received surgical treatment for cancer, their responses were just the opposite. The physician replaced the spouse in importance for both support and distress.<sup>40</sup>

This incidence clearly reflects a difference between the points of view of doctors and that of the patients regarding the process of treatment. The practice of "protecting" patients from learning about their diagnosis of cancer is rapidly disappearing.<sup>41</sup> Support for this change has been found in a variety of studies that have found patients to be dissatisfied with the information they re-

---

40. Bloom, J.R. "Cancer care providers and the medical care system, facilitators or inhibitors of patient coping respons? In Ahmed, P. (ed) Living & Dying with Cancer; Elsevier; New York; 1981.

41. Novack, D.H. et al; "Change in physician's attitude toward telling the cancer patient". Journal of American Medical Association; 41; 897-900; 1979.

ceive.<sup>42</sup> This expectation that the patient should be told has been accompanied by an emphasis on increasing the patient's role in the interaction,<sup>43</sup> by encouraging him to ask question or by encouraging physicians to involve patients in decision making.<sup>44</sup> But, again, the doctor need to know how much information should be conveyed to the patient at which stage. Sometimes patients make it clear that they are not ready to deal with the issues and yet from the beginning a major goal is taken on the doctor's part to encourage the patient to have input into treatment decisions.<sup>45</sup> This may not have a positive impact on the treatment of patient by creating an obstruction in the development of a healthy doctor-patient relationship.

Often mere willingness to discuss the possibility that a recommended treatment might cause side effects instills

- 
42. Blanchard, C.G, et at "Information & decision making preferences of hospitalised adult cancer patient"; Social Science and Medicine; Vol.27; No.11; pp.1139-1145; 1988.
  43. Levy, S.M. & Howard, J. Patient-centric technologies: a clinical-cultural perspective. In Milton, T., Green, C. & Meagher, R.(ed), Handbook of Clinical Health Psychology; Pleucian Press; New York; 1982.
  44. Illich, I. Medical Nemesis : The Exploration of Health; Random House ; New York; 1976.
  45. Cotanch, P.& Laszlo, J. Goals of patient versus goals of physician. In Laszlo.J. (ed) Physicians' Guide to Cancer Care; Mercel Deckker Inc.; 1986.

confidence in the candor of the physician.<sup>46</sup> It sets the stage for future honest communication and facilitates acceptance of other complications even those rarer ones that were perhaps not discussed. This type of climate creates a kind of trust that will go a long way towards defusing problem which are found to arise at home between visits to the doctor. The disparity between the goals of the patient and the physician may be in part related to a frequent clinical observation that with progressive illness the patient develops a shorter time frame for his concerns.

There seem to be three basic philosophies of intervention with the cancer patient. The first advocates providing service to everyone. The assumption does not seem to be warranted as many patients do well on their own without special intervention. Also, such an approach is generally not cost-effective.<sup>47</sup>

A second philosophy, often advocated by surgeons and oncologists, is to wait and see, also gets into serious emotional difficulty and then make a referral to a psychiatrist or social worker. The difficulty with this approach lies in the fact that people have to experience serious

---

46. Reddy, D.J. Cancer; Bombay; CTL; 1968.

47. Worden, J.W. Ways to improve coping with cancer. In Beck, L. et al (ed). The Cancer Patient : Illness and Recovery; Gustav Fischer Verlag; 1985

distress before referral is made and sometimes serious social and emotional difficulties do not come to the attention of medical personnel due to the press of time and the different focus on medical concerns.<sup>48</sup>

A third approach is an approach having its roots in preventive mental health. Doctors try to identify "in advance" those patients who are at highest risk for this type of dysphoria and distress in order to offer help before serious emotional disturbances and poor coping symptoms develop.<sup>49</sup>

The advantage of not offering intervention to everyone but trying to identify a specific target population are obvious, especially from an economic standpoint. But a far more important advantage is the humanistic goal of teaching people skills of coping and adaptation medical care but it provides patients with resources they can use in all areas of their lives, whatever the course of their cancer.

### **Coping With Stress**

The physician who specialises in the care of cancer patients is subject to frequent personal stress arising from

---

48. Ibid.

49. Ibid.



their interaction with their patient.<sup>50</sup> These stresses arise from the doctor's personality, his training and life experience in medicine, the conflict between the role of physician and clinical investigator and the inadequacies of the traditional contract (the doctor-patient relationship) in satisfying the needs of both doctor and patient in the circumstances where the patient has cancer.<sup>51</sup> The stress faced by health care professionals may be important not only because it presents a problem for the professionals themselves, but also because it contributes to the poor communication which presents a problem for patients and families.<sup>52</sup>

There have been several investigations which shed light on some of the stresses which are encountered by physicians caring for cancer patients.<sup>53</sup> Artiss and Levine, on the basis of their 'interaction with physicians in training

- 
50. Razavi, D. et al. "Immediate effectiveness of brief psychological training for health professional dealing with terminally ill cancer patients : a controlled study"; Social Science and Medicine; Vol. 27.; No.4; pp. 369-375; 1988.
  51. Higby, D.J. The doctor & the cancer patient : sources of physician's stress. In Higby, D.J. (ed). The Cancer Patient & Supportive Care ; Martinus Nijhoff Publishers; Boston ; 1985.
  52. Delvaux, N. et al. "Cancer Care : a stress for health professionals" ; Social Science and Medicine; Vol.27; No.2; pp. 159-166; 1983.
  53. Ullrich, A. & Fitzgerald, P. "Items experienced by physicians and nurses in the cancer ward" ; Social Science and Medicine; Vol. 31; No.9; pp. 1013-1022; 1990.

through a seminar designed to help them cope with cancer patients described several form of reactions to stress : anger towards staff physicians because they were such as "heartless", "callus" etc.; denial that there were any problems; verbal disapproval on disparagement of psychiatry; joking about situation with each other; or seeing "too busy" or "always forgetting" to attend the seminar.<sup>54</sup>

Not only is the communication between doctor and patient impaired by social reaction to stress, but in addition, there are different expectations on the part of the doctor and patient with respect to cancer.<sup>55</sup> The patient perceives the fact of having cancer as something which will be painful, will result in loss of body function, which will impair social relationships, etc. The physician, on the other hand, helped by depersonalising qualities of modern hospitals, sees the fears and concerns of the patient which are directed towards him as being inappropriate, since he cannot help and should be using his time for people he can help. The patient seeks relief of symptoms, anxiety and uncertainty whereas the physician seeks diagnosis, interven-

---

54. Artiss, K.L. & Levin, A.S. "Doctor patient relationship in severe illness : a seminar for oncology follows". New England Journal of Medicine; Vol. 288; No.23; pp. 1210-1214; 1973.

55. Chugha, B.R. Cancer & Its Cure ; Bombay ; The author ; 1949.

tion and disposition. Thus, it is apparent that the actual interaction between patient and physician when the patient has cancer, is a source of stress and frequently associated with avoidance behaviour in physician.

Coping with stress on part of the physician is a complex dynamic process.<sup>56</sup> Yancik studied coping with emotional distress and role fulfillment as two manifestations of occupational stress. Data were obtained from self-administered questionnaires completed at the work site by 43 (22-64 years old) staff member at three hospices. Results show that subjects call on different resources for coping with various selected problems. Internal resources as self-esteem and a sense of mastery were effective in sustaining subjects against the emotional distress that arouses in their work. External resources, help and support from others and cooperative efforts contributed to the subjects feeling of role fulfillment. It is concluded that special nature of hospice work requires a structural form of interaction among workers who perform similar functions.

### **Telling The Truth**

At a certain point of his treatment of a cancer patient, the doctor realizes that no matter how expertly

---

56. Lazarus, R.S. & Folkman, S. Stress, Appraisal & Coping; Springer; New York; 1984.

managed the therapy, the patient will die in weeks or months. They should realise that time needs to be set aside for a conference to discuss prognosis and care options as quickly as possible.<sup>57</sup>

Generally, it is the physician who controls the dissemination of the "official" information. When the physician first becomes aware of the limited life expectancy, he must decide how and when to talk to the patient and the family. This specific task and other dealings with the family are so discomfoting to many doctors that the interactions are often handled unskillfully. In preparation for such a conference it will help if the physician and the staff understand the social, emotional and spiritual impact of the disease on the family constitution. Knowing how the family has dealt with earlier crises will help to predict their reactions to this one.<sup>58</sup>

---

57. McCuen, G.E. & Boucher, T. Terminating Life : Conflict-  
ing values in health care; Wisconsin; G.E. McCuen;  
1986.

58. Amir, M. "Considerations guiding physicians when inform-  
ing the cancer patients"; Social Science and Medicine;  
Vol.24; No.9; pp. 741-748; 1987.

## FAMILY'S ATTITUDE TOWARDS THE PROBLEM

Like a pebble thrown into water, illness causes ever expanding circles, affecting not only the person who is ill but his family which is called upon to meet many of the emotional and physical costs of illness, his close relatives and friends.<sup>59</sup> It is frequently written that cancer is a 'family disease' and like other serious and prolonged illnesses, it is a source of severe stress that demands major adjustments, not only by the patient but by his family members too. While clinical concern about the harmful and stressful effects of cancer treatment on the family have increased, so has the recognition that although stressed and distressed themselves, the family is participating more and more integrally in the comprehensive care of the cancer patient.<sup>60</sup> Traditionally the patient's family was overlooked as a resource in the planned treatment process. They were asked to "wait outside", the patient was expected to keep the family informed. This concept is now as archaic as the passive patient.<sup>61</sup>

---

59. Field, M. Patients are People : A Medical - Social Approval to Prolonged Illness; Columbia University Press; 1952.

60. Balber, P. Reactions of patients & families : useful approaches, In Laszlo, J. (ed). Physician's Guide to Cancer Care Complications : Prevention & Management ; Marcel Dekker, Inc. ; New York ; 1986.

61. Rosenbaum, E. and Rosenbaum, I. A Comprehensive Guide for Cancer Patients and Their Families; Bull Publishing; Pals Alto; Calif.; 1980.

First of all, family support is now recognised as a critical factor in predicting how patients will cope with the treatment process. Second, how a cancer patient adjusts to and manages his treatment course is dependent, in part, on the behaviour of the individuals closest to him. Third, the nuclear family continues to remain the most important social support source for the patient and has most powerful effect on mediating and suffering the multiple stresses of cancer treatment. Finally, health professionals need the families' support as a necessary ally in cancer care.<sup>62</sup> Family members pressure the patient to seek out initial medical examinations for cancer treatment, they participate in the therapeutic decisions made by the patient, they provide the practical and financial assistance for patients to receive cancer therapy and they can provide caregivers the best information about the patient as an individual. If health professionals do not utilize this potential ally well, they will waste a valuable resource that can facilitate the patient's recovery.<sup>63</sup>

Family support, however, is not the same as family availability and the mere presence of a large and hovering

---

62. Rosen, B.K., Bost.L. & Aitken, P.W. Support services for hospitalised patient. In Lazlo, J. (ed); Physician's Guide to Cancer Care Complication; Mercel Deckker Inc.; 1986

63. Khanolkar, V.R. Look at Cancer ; Bombay ; ICRC ; 1958.

group of individuals in a waiting room does not necessarily mean access to helpful social resources on whom the patient and professional can rely in the treatment process.<sup>64</sup> A family can either facilitate or obstruct the cancer patient's efforts to master the task of coping with cancer. Therefore, knowing how to mobilise and strengthen the family's support potential is an effective preventive tool in cancer care.

#### **Complications In Family Support**

There is a strong clinical evidence that interpersonal relationships for the cancer patients may often act as a source of stress as well as a source of support. Social interaction between family members and cancer patients are often coloured with ambivalence and family members may have vast discrepancies between their outward behaviour and inner feelings.

Social support by families may create a process whereby cancer patients are victimised by ineffective efforts to help, such as the *overcompensating smoothers*.<sup>65</sup> When families react to cancer diagnosis, some of the behaviours can include both covert and overt hostility, depression, panic,

---

64. Koos, E.L. The Sociology of the Patient ; McGraw-Hill Book Company, Inc.; 1959.

65. Rosen, B.K., Bost, L. & Aitken. P.W. Op.cit.

guilt and the inability to resume normal activities. They tend to be too close, to pamper the patient, overwhelming him in an effort to ward off guilt feelings about their past relationships. This behaviour tends to increase the patient's depression as well as deplete the family.<sup>66</sup>

*The denying helpers.* There is a tendency for families to operate according to a set of rules designed to minimise discomfort and the discussion of true emotions between the cancer patient and his family is often very difficult. Families have a natural need to protect the patient from the realities of cancer and to feel it is essential to remain cheerful and optimistic. Yet while the negative feelings of anger, sadness and depression may be too difficult to express, this may result in family support problems by the 'denying helpers'.<sup>67</sup>

*The rejecting avoiders.* While most families initially mobilize around the cancer patient obtain services and treatment, some are temporarily immobilised and flounder and others may reject the patient and abandon him. There are families who are emotionally unsupportive and tend to evade, shun or neglect the patient either because they were never close, they fear catching cancer or they want to protect

---

66. Ibid.

67. Ibid.



themselves from hurt by giving the patient up at an early stage.<sup>68</sup>

Not every family can be open and loving to every cancer patient and it is difficult for staff to work with families when they have their own ideal preferences for family support.<sup>69</sup> It is impossible to penetrate such family system where offers to help were interpreted as intension by others and parental failure. For families with preexistent inter-generational problems, providing concrete services may develop a sense of trust and decrease family stress. Creative interventions for alternate forms of support may need to be the goal.<sup>70</sup>

What are the problems of greatest concern to the patient's family and how does it deal with them? No generalizations can fit all cases. Families are but a composite of different individuals with different reactions. What these reactions will be is determined by thier attitude to illness, the importance which the deprivations have to be endured.<sup>71</sup> Most important of all is the feeling they have

---

68. Ibid.

69. Hickey, C. (ed) Palliative Care of the Cancer Patient ; London ; Little Brown & Co. ; 1967.

70. Capra, L.G. The Care of the Patient ; Mcmillan ; 1986.

71. Bluglans, K. Care of the cancer patient's family. In Watson, M. (ed). Cancer Patient Care : Psychosocial Treatment Methods; The British Psychological Society; 1991.

about the patient, the place he holds in the family group, the outlook for the future and how far it is possible to maintain the patient's status in the group. Furthermore, as is true with the patient, the problem which confront them vary with the different stages of the illness, the degree to which it has progressed and the amount of incapacity it produces.<sup>72</sup>

The shock of discovery of terminal illness and its implications is as severe for the family members as it is for the patient.<sup>73</sup> The presence of a sick person in the home affects the life of the family, altering both its major aspects and the minutiae of everyday living.

If the patient is the man of the family and the breadwinner, the standards of living, plans for the future and the entire tenor of life may have to be changed. Curtailment of income over prolonged period of time, with no prospect of relief in sight, may impose hardships necessitating lowering of standards, readjustment in the pattern of living and the need for other member of the family to assure the responsibilities once borne by the patient.<sup>74</sup>

---

72. Field, M. Op.cit.

73. Schnaper, N. et al. Emotional support of the patient and his survivors. In Wiernik, P.H. (ed) Supportive Care of the Cancer Patient ; Futura Publishing Company Inc. ; 1983.

74. Vettese, J.M. Significant stressors that affect the family system. In Ahmed, P. (ed) Living & Dying with Cancer; Elsevier ; New York ; 1981.

If the patient is the mother, all the effects of the temporary dislocation of family life seen in acute illness are intensified and multiplied. Even when the father or one of the children is able to act as a mother substitute, the unusual pattern of living is often disrupted. What is more important is the change in the emotional tone of the home and the way in which all members of the family react to it.<sup>75</sup>

The children feel the effects of prolonged illness in the home both directly, and indirectly. Reduced income may mean abandonment of educational plans and consequent far reaching implications for future life. In addition to the economic repercussions, more subtle effects are of equal significance. The whole life of the family may revolve around the sick person. The attention his condition requires and the concern about his welfare may deprive the children of the care to which they have been accustomed and which is essential for their development. Their interests, their problems and joys which were of paramount importance to their parents may of necessity be relegated to a secondary place.<sup>76</sup>

---

75. Ibid.

76. Cassileth, B.R. & Hamilton, J.N. The family with cancer. I Cassileth, B.R. (ed). The Cancer Patient: Social and Medical Aspects of Care ; Lea & Febiger ; 1979.

Add to this anxiety, helplessness and frustration that accompany the witnessing of another's suffering in the face of one's inability to alleviate the pain, the fear of contagion or inherited disease. the threat of death frequently inherent in the diagnosis itself and in some measures, a picture of the emotional plight in which families may find themselves.<sup>77</sup> Sacrifices may be made willingly and gladly in the beginning, but as the stress of such demands continues over a long period of time the original concern for the welfare of the patient may be obscured and replaced by bitterness and resentment. Whereas in the beginning, the children identifying themselves with the patient's suffering, resented the illness, later they may come to resent the patient himself as well as the sacrifices his illness entails.<sup>78</sup>

The strain and stress that illness imposes are inevitably reflected in the way patient is treated by members of his family group.<sup>79</sup> Fearful of the illness and its implications, family members fight their natural desire to run away from day-to-day contact with it and inexorable emotional

---

77. Groeger, J.S. Critical Care of the Cancer Patient; Mosby Year Book Inc.; St. Louis; 1991.

78. Field, M. Op.cit.

79. Griffin, J. Nursing care of the critically ill patient. In Howland, W.S. & Carlon, G.C. (ed.). Critical Care of the Cancer Patient; Year Book Medical Publishers; Chicago; 1985.

strain it creates. Under pressure to do what they feel is expected of them, they are often overzealous in their efforts on the patient's behalf, suppressing what they really feel. When a person remains sick for a long time, his family in its concern about the illness tends to forget the person is sick. They see him surrounded by an assurance of "goodness" that may be completely different from what he actually is and what they know him to be.<sup>80</sup> We are all familiar with the sickroom voice, the sickroom manner and the inclination to protect the patient from any unpleasantness from the outside world. This creates an artificial atmosphere charged with tension of unrelenting effort to suppress the unconsidered word, the irritable reaction. Such protection often springs from a natural feeling that the patient is "too sick to be bothered". Well-meaning as such over-protectiveness may be, to the patient it means exclusion, for it cuts him off from the good and bad, and sorrows, that constitute everyday living. It serves as a denial of his rights as a family member.<sup>81</sup> The fact that he is a passive onlooker on the day-to-day life of the family group, acts as a constant inadequacy of his own usefulness, displacement and inadequacy. In

---

80. Higby, D.J. The care of the terminal patient. In Higby, D.J. (ed). Supportive Care in Cancer Therapy ; Martinus Nijhoff Publishers ; 1983.

81. Nealon, T.F. Management of the Patient with Cancer ; Philad.; Saunders ; 1966.

an effort to assert his importance, the patient may revert to a type of behavior which unless understood, may be difficult to cope with. He may complain or demand demonstrations of attention and affection, creating a situation fraught with danger both for himself and for all those around him.

In other instances, the over protectiveness may be but a way of controlling the sick person, the inclination to control being evoked by the patient's very helplessness. The net result is that the patient is robbed of his right to have a say in how his life, whatever remains of it, is to be lived. Such an exclusion and the feeling of rejection it can engender may will undermine the patient's will to live and, consequently, his response to medical treatment.

#### **Reaction Of The Family To Hospitalisation**

Time may come when the demands of the patient's condition make continued care in the home impractical and his removal to the hospital the only means of securing the necessary medical care.

The meaning of hospitalisation to family members can be best understood if we keep in mind the community's attitude towards hospitalisation in general and on admission to a hospital for "terminal illness" in particular. In the past, patients entered such hospitals to die.<sup>82</sup> Community atti-

---

82. Chatterji, K.K. "Study of Cancer in India" ; Indian Medical Gazette ; Vol. LXI, No. 8, August, 1926.

tudes change slowly and relations still react with fear, anxiety and often guilt to the implication that in arranging for hospitalisation they are in reality "putting the risk person away". There are instances where the feeling is so intense that relatives resist taking such a step, thus depriving the patient of whatever benefits he might derive from hospital care. At other times, the decision may be arrived at only after a long and painful struggle and only when circumstances leave no alternative.<sup>83</sup>

Despite the difficulties in caring for a sick person in the home, his removal does not eliminate problems for his family. It merely shifts the focus of their concern. The whole routine of family living may become centered on hospital visiting hours requiring adjustments in their accustomed routine which may not come easily.

It frequently happens that both the patient and members of the family are aware of the nature of the illness, but do not dare to speak of it openly because each tries to shield the other. When they are together during visiting hours they try to be cheerful and keep away from discussing what is really troubling them so as to spare each other's feelings. How much this restraint costs them is evidenced by the fact

---

83. Freedman, T.G. The role of the family therapist. In Cassileth, B.R. & Cassileth, P.A. (ed). Clinical Care of the Terminal Cancer Patient ; Lea & Febiger ; Philadelphia ; 1982.

that often both the patients and the relatives seek out the social worker following visiting hours in order to discuss their doubts, misgivings and fears as the only means of release from the tension under which they labour.<sup>84</sup>

Family members, as they are tied to the patient emotionally, react to the same fears as does the patient. Let us take the diagnosis of cancer, for example. Even though an attempt is made by the doctor to keep the knowledge of the diagnosis from the patient, family members are usually told the nature of the illness. This means when subjected to questioning by the patient, they are forced to be secretive and evasive, fearful lest in an unguarded moment they may let the patient learn what they know. Under the stress of their own anxiety, they react with tension, but also to learn how to handle the patient's questions.<sup>85</sup>

#### **Family Members Need Help**

Recognising that the attitude of family members is an important element, facilitating or retarding the patient's progress, it devolves upon those concerned with his care to help them handle some of these problems so that they may find release and not to be forced to vent their feelings

---

84. Tinker, J. & Rapin, M. Care of the Critically Ill Patients; Spinger Verlag ; 1982.

85. Feigenburg. L. Terminal Care : Friendship contracts with dying cancer patients; N.Y.; Brunner/Mazel; 1980.



upon the patient. Experience has shown that the same methods which have proved effective in helping the patient can be applied as successfully in dealing with members of his family.<sup>86</sup> As with the patient, working with family members implies a willingness to recognise and help with the problems exist. They need sustained help, recognition of the burden they are called upon to carry and an opportunity to voice their frustration and grievances. The best results are obtained with inclusion, not exclusions, of family members in planning for the patient's care. With an opportunity to participate actively in the therapeutic measures instituted by the medical team on the patient's behalf, they can become understanding, sympathetic and useful adjuncts in treatment. Unfortunately, however, the busy routine of a hospital provides but small opportunity for such active working together. Relatives feel, and rightly so, that the patient's physician is their most reliable source of information. In reality, however, relation seldom succeed in seeing the doctor and often find it difficult to understand the implications of the patient's illness or to obtain reliable information about his physical condition.

---

86. Jones, E.G. Cancer : Its Causes, Symptoms & Treatment; B. Jain Publishers Pvt. Ltd.; New Delhi; 1991.

## **CHAPTER IV**

### **CHILDREN WITH CANCER**

Death is a tragic event. It becomes more tragic when a young one faces his death much before it is expected. The number of children dying of cancer each year is not negligible. Children, as patient are expected to develop different kind of interaction pattern with doctors than their aged counterparts. Family members, especially, parents become an integral part of this doctor-patient relationship. So, in this chapter, I prefer to discuss about the doctor's interaction with terminally ill children taking into account the parents mostly.

## PATIENT'S ATTITUDE TOWARDS DEATH

The majority of authors are in agreement that the older child with a fatal prognosis, especially the adolescent, is aware of and anxious about the potential outcome of his illness.<sup>1</sup> For the fatally ill child under 5, it is generally agreed that anxiety taken the form of separation, loneliness and fear of abandonment. The disagreement arise with the age group in between, the child aged from 6 to about 10. There are two avenues of thought regarding the level of awareness in children in this age group. The first is that the fatally ill child under 10 lacks the intellectual ability to formulate a concept of death and therefore is not aware of his own impending death. If the adult does not discuss the seriousness of his illness with the child, the child is thought to experience little or no anxiety related to the illness.<sup>2,3</sup> The second avenue of thought is that many of the fatally ill children in the 6 to 10 years age group, if not aware at a conceptual level of their own impending death, are aware at least that something very

---

1. Spinetta, J.J. "The dying child's awareness of death : a review"; Psychological Bulletin; 81:256; 1974.
2. Evans, A.E. & Edin, S. "If a Child Must die"; New England Journal of Medicine; 278: 138; 1968.
3. Yudkin, S. "Children & Death", Lancet; 1:37; 1967.

serious is happening to them.<sup>4,5,6</sup> Both groups support their conclusions with examples, the latter group far outweighing the former in depth and extent of observations.

The discovery of death for the child is often a very private, secret experience of great importance, to be shared with playmates, but only cautiously alluded to in talk with adults. Considering the fact, that it is not generally discussed in some societies, it is amazing that children all over the world, work out similar theories about its nature and have very much the same responses to it.<sup>7</sup>

As the child's ego capacity expands, the view on death changes. Most observers in the field feel there are essentially three phases : under fives have the idea that death is reversible, not final and is seen as a departure or sleep. From five to eight or nine, death becomes personified, and, is associated with aggressive events, contingent

- 
4. Bluebond-Langer, H. Meanings of death to children. In Feifel, H. (ed). New Meanings of Death; New York; Mc-Graw Hill Book Co.; 1977.
  5. Burton, L. Tolerating the intolerable : the problems facing parents and children following diagnosis. In Burton, L. (ed). Care of the Child Facing Death; Boston; Routledge & Kegan Paul; 1974.
  6. Eason, W.M. The Dying Child : The management of the child or adolescent who is dying; Springfield; Charles Thomas Publisher; 1970.
  7. Oremland, E. and Oremland, J.D. (ed.). The Effects of Hospitalisation on Children: Models for their care; Charles C. Thomas Publisher; 1973.

upon the hostile action of others. After eight or nine, death is seen as a process dependent on natural laws.<sup>8</sup>

It has been seen that fatally ill child chooses whether or not to talk about his illness based on past and present experience within the family regarding openness of communication about the illness. Each choice may be viewed as a different style of coping. The choice for silence can lead to exercise denial and avoidance, place distance between the child and his sources of support and lead to feeling of rejection and isolation. A forced openness in such a family might appear to the child as an even worse alternative than his suffering in silence. In contrast, a choice for open discussion, stemming from the sincere attempts of family members to communicate concern and support allows overt expression of feelings. Such expression of a child's fear relative to the illness can lead to a mutual support among family members helping the child achieve a balanced adaptive equilibrium.<sup>9</sup>

- 
8. Piaget, J. "The stages of the intellectual development of the child"; Bulletine of the Menninger Clinic; 26: 120-128; 1962.
  9. Spinetta, J.J. Communication pattern in families dealing with life-threatening illness. In Sahler, O. (ed). The Child & Death; The C.V. Morby Company; 1978.

## **Coping With The Terminal Illness**

Although childhood cancer is a shared stress to which families develop coordinated responses, the illness affects the child differently than it does other family members. Research with children and adolescents with cancer brought out the following stresses that youngsters identify.

At the diagnostic stage and immediately thereafter children experience stress in understanding the seriousness of the situation and in dealing with uncertainty. How do children become aware that they are in a serious situation, that they have a condition they ought to worry about? Sometimes parents or staff members tell them directly. Sometimes the child draws a conclusion using many cues (such as parental distress) and reading between the lines of what is said directly and what is whispered out of earshot.<sup>10</sup>

Of all the coping strategies used by children with cancer, information seeking and denial seem to be the most common.<sup>11, 12</sup> Information seeking, is an attempt to manage

- 
10. Chesler, M.A. & Barbarin, O.A. Childhood Cancer and the Family: Meeting the challenge of stress and support; Breennor/Mazel Publishers; New York; 1987.
  11. Zeltzer, L. Chronic illness in the adolescent. In Sahler, J. (ed.). Topics in Adolescent Medicine; New York; Grunne & Stratton; 1978.
  12. Koocher, G. & O. Malley, J. The Damocles Syndrome : Psychological Consequences of Surviving Childhood Cancer; New York; McGraw-Hill; 1981.

stress by cognitive mastery, by learning enough about it to establish a sense of intellectual control and by being able to convey the nature of illness to others. Denial as a coping strategy involves the avoidance of information or experience that may unnecessarily increase one's anxiety about the illness. Both strategies represent efforts to deal with information and its emotional meaning. Although each has the potential to help the child respond positively to the stress of the illness and treatment, overuse or extreme form of each strategy have negative potential. Information seeking may lead to understanding but information overload may lead to a lack of attention to feelings that accompany facts. Denial may prevent great anxiety and permit the youngster to continue to live normally, but its overuse may lead to a premature cessation of caution and medical compliance.<sup>13</sup>

As treatment progresses, the seriousness of the situation may be brought home to the child by drastic medical procedure. Surgery, chemotherapy, radiation, repeated hospitalisation, tests and injections -- all debilitate the

---

13. Katz. E. & Jay, J. "Psychological aspects of cancer in children, adolescent and their families"; Clinical Psychology Review; 4:525-542; 1984.



child physically and mentally.<sup>14</sup> Children cope with this situation by using self-control procedures that minimise anxiety, pain and discomfort.<sup>15,16</sup> It has been found that for children, changes in their appearances are even more troublesome than the pains of treatment. Loss of hair and consequent baldness generally are more traumatic for girls than for boys and for older children than for younger children.<sup>17</sup> In addition to prolonged discomfort, frequent hospitalisations or confinement at home often lead to social isolation. Although most children with cancer experience a great deal of attention at first, some feel forgotten and eventually isolated, over time. This may lead to hopelessness and despair.<sup>18</sup>

- 
14. Zeltzer, L. et al. "Psychosocial effects of illness in adolescence, Part II : Impact of illness on crucial issues and coping styles"; Journal of Pediatrics; 97: 132-138; 1980.
  15. Katz, E. et al. Assessment & management of pediatric pain. In Herson, M.; Eisler, R. & Miller, P (ed). Progress in Behaviour Modification & Therapy, New York; Academic Press; 1984.
  16. Jay, S. & Elliot, C. Psychological Intervention for Pain in Pediatric Cancer Patients. In Humphrey, G. et al (ed). Pediatric Oncology; Boston; Martinus Nijhoff; 1983.
  17. Farrell, F & Hutter, J. "Living until death : adolescents with cancer"; Health & Social Work; 1980; 5:35-38.
  18. Nelcamp. V. "Into the light"; Cincinnati Horizons; 1980; 9(4): 13-17; 49-50.

As the amount of time spent in treatment increases, children inevitably experience the death of other children whom they have be-friended. These deaths bring home very clearly the life-threatening nature of their own illness. One young girl was devastated when another young girl with whom she shared a hospital room died. She had hoped and believed earnestly that they would survive the illness together. The fragility of her own life became apparent when she realised that death could affect her as well.<sup>19</sup> In addition to adapting to the disease and its treatments, children with cancer also experience stress arising from relationships with the staff members and medical personnel. They expect the physicians to be open, honest, non-judgemental and respectful and to include them in the formulation of treatment plans. When physicians are distant from and lack communication with young patients, ill-children may feel like non-persons.

As youngsters and their parents try to deal with or to discuss the illness with one another, they sometimes discover that they have quite different coping strategies. Parents may want to discuss issues with their children that the children do not wish to discuss, or vice-versa. Some young

---

19. Pendelton, E. Too Old to Cry... Too Young to Die; Nashville; Tenn; Thomas Nelson; 1980.

people with cancer also desire to protect their parents. Perhaps out of guilt for what their parents are going through, or perhaps just because they can see how upset their parents are, youngsters may try to shield them from some of the things they themselves worry about.<sup>20</sup>

In addition to dealing in new way with one's parents, youngsters with cancer recognise that their illness has an effect on their younger brothers and sisters. Comments from ill youngsters often confirm many parents' report that their brothers and sisters feel left out, get less attention and feel jealous. But there are different pictures also. Some children with cancer are moved by their siblings' deep caring and concern and ways in which they are confronted by their brothers' or sisters' reactions. This is especially characteristic of relationships with older siblings, who sometimes adopt a parental role towards the child with cancer.<sup>21</sup>

Just as parents must decide what to tell their children about the diagnosis, youngsters with cancer must decide if, when and how to share this information with their friends. How do friends react? According to the ill children, some

---

20. Orr, D & et al. "Adolescents with cancer report their psychological needs", Journal of Psychosocial Oncology; 1984, 2 (2); 47-59.

21. Farrell, F. & Hutter, J. Op.cit.

friends are scared, run away and back off, but some are supportive and helpful.<sup>22</sup> When loss of opportunities for social interaction with peers is severe, it is experienced as a major deprivation that multiplies other stresses of illness. When positive interaction with peers occurs, it helps ease the stress of coping with the illness and renews youngsters' adaptive capacities. Not only is it helpful to have friends who will reach out, but again it is part of the ill child's responsibility (and therefore the parents' responsibility as well) to reach out to friends and to create opportunities for positive peer interaction. If youngsters with cancer are awkward about relating to former peers and unsure how much to share about their illness, so are their peers.<sup>23</sup>

#### **PHYSICIAN'S ATTITUDE TOWARDS THE PATIENT**

Most lay persons believe that physicians understand the great mysteries of life. Some patients perceive physicians as being omnipotent, capable of relieving all pain, curing all illness and even preventing death. If death does occur,

---

22. Burton, L. The Family Life of Sick Children; Boston; Routledge & Kegan Paul; 1975.

23. Koocher, G. The Crisis of Survival. In Christ, A & Flomenhaft, K. (ed). Childhood Cancer : Impact on the Family; New York.

many bereaved survivors expect physicians to maintain emotional control and serve as pillars of strength for them.<sup>24</sup> The death of a child causes additional problems for the doctors as well because children are expected to be healthy, resilient and growing not deteriorating and dying like old people.

### **Coping With Stress**

Just like patient, physician also suffer from a number of stresses and develops mechanism for coping with these stresses. Many physicians, in an attempt to fulfill the role they perceive for themselves, unconsciously depersonalise their patients. If the patient is not a person, then the patient's death is not relevant. Thus the physician avoid thinking of their own limitations either as physician or as mortals. However, when this type of defense mechanism is used, the result for the physician and the patient is less than satisfactory.<sup>25</sup>

- 
24. Koenig, H.M. Reflections of a Pediatric Cancer Specialist. In Spinetta, J.J. & Deasy - Spinetta, P (ed). Living with Childhood Cancer; The C.V. Mosby Company; 1981.
  25. Lansdown, R. & Goldman, A. Children with Cancer. In Watson, M. (ed). Cancer Patient Care : Psychosocial Treatment Methods; The British Psychological Society; 1991.

One way of understanding this situation is to divide the problems associated with care into three time periods, each having its particular difficulty.<sup>26</sup>

The first is the *period of impact*. Being the first to know the diagnosis and prognosis when life is threatened, the pediatrician is the first to feel the impact of the tragedy. Telling the parents is difficult. The disclosure to the parents that their child has a condition that might prove fatal usually triggers a series of reactions that include shock, disbelief in the diagnosis, disbelief in the prognosis, anger, guilt, acceptance and anticipatory mourning. In order to clarify the communication, both parents should be told at the same time if at all possible. It is not unusual for parents to find this event more overwhelming than the actual death, depending on how much anticipatory mourning could be accomplished. Parents occasionally blame the physician as an omnipotent, malevolent person who could change the diagnosis and prognosis if he wished to do so. Although parental feelings of anger and failure may be projected onto the pediatrician, most parents find it difficult to be angry with the person in whom they must put their

---

26. Schowalter, J.F. The reactions of caregivers dealing with fatally ill children and their families. In Sahler, O.J.Z. (ed), The Child, & Death; The C.V. Mosby Company; 1978.

faith for good care and they therefore, displace their hostility onto other caregivers, spouses or other relatives, neighbours and so on.<sup>27</sup>

It is generally accepted that parents should know the facts of the case. But it is difficult to know how much the child should be told. Obviously, hope should never be completely withdrawn from anyone. Most fatally ill pediatric patients do not ask whether they will die, but must know that something terrible is wrong with them. In fact, once parents know the prognosis, their reactions to the child change so dramatically that it is impossible for the child not to realise that something very worrisome is occurring.<sup>28</sup>

The second phase of case may be termed as the *period of battle* and consists of the time of management until the child is in the extreme stage. These periods, of course, are not as clearly demarcated in practice as on paper and a number of emotions, such as denial, grief, guilt and anger are common to all three periods.<sup>29</sup>

Along with anger, guilt is ubiquitous when one is working with a dying child. Parents must be assured and

---

27. Ibid.

28. Ibid.

29. Ibid.

reassured that their child's illness is not their fault. Guilt often leads to a variety of reactions that cause problems.<sup>30</sup>

The third and final phase of care is the *period of defeat*. This includes the terminal phase of treatment, the death and the period of contact with the family thereafter.<sup>31</sup>

During this terminal phase, the reaction of physicians towards children that is most frequently noted in the literature is withdrawal. Although withdrawal is a natural part of anticipatory mourning and the patient may exhibit it as well, staff withdrawal should be neither abrupt nor extensive. Physician's withdrawal from the patient is often accompanied by withdrawal from the family as well at the time they need support most. It is important for all staff to follow the old adage that the fewer the treatments available to the physician, the more the physician must be available.<sup>32</sup>

Following a death, there may be a feeling of relief as well as defeat, especially, if the child has suffered for a long time. It is common for the physician to withdraw, but

---

30. Ibid.

31. Ibid.

32. Ibid.



it is crucial that the family not be abandoned. Physician's presence and willingness to listen are usually more important than what is said. Often parents complain that once their child has died, the physician forget about them and their child. Contact in the following weeks or months by the physician, psychiatrist social worker, psychologist to see how the parents and siblings are reacting to the death is seldom done but very useful.<sup>33</sup>

#### **FAMILY'S ATTITUDE TOWARDS THE CHILDHOOD CANCER**

The family is the society's primary unit for intimate social interaction, the setting most appropriate for sharing intense feelings. When childhood cancer impact upon individuals, it is the family in which deepest relationships and fullest expressions of feelings are experienced.

#### **Coping With Stress**

Parents of children with cancer undergo a series of personal and social stresses that are set in motion by this serious and chronic childhood illness. They include :

- i) *Intellectual stress*, which is created by massive amounts of technical information about the disease and

---

33. Ibid.

treatments and by the unfamiliar culture of medical system.

- ii) *Instrumental stress*, which is created by the myriad of new daily practical tasks involved in maintaining a home, family and work life in the midst of the medical crisis.
- iii) *Interpersonal stress*, which is created by the escalating needs of all family members and the changing sets of relations with old and new friends and with service providers.
- iv) *Emotional stress*, which is created by the psychological and often physical consequences of fear, distress and loss of sleep and energy.
- v) *Existential stress*, which is created by confusion about the meaning and order of life challenged by "unjust" pain and terror for a child.<sup>34</sup>

Stresses experienced by parents of children with cancer are often rooted in relationships with people with whom they interact regularly. These other people may be of 'direct' stress if they place inappropriate pressures or demands on parents or fail to provide legitimately requested assistance or people may be of 'indirect' stress if they even unwill-

---

34. Chesler, M.A. & Barbarin, O.A. Op.cit.

ingly become an additional source of concern for parents who wish to be primarily or solely concerned with their ill child.

Parents seldom experienced difficulty telling their spouses about the illness, because both parents generally were on hand during the diagnostic conference. But regardless of the specific individual role they assume vis-a-vis the medical system and the ill child, they now have a new situation to deal with together. Whereas parents generally report that their spouse is the most helpful person in their attempt to deal with the experience of childhood cancer, many also report added stress from their spouse's reaction to the disease and its treatment.<sup>35</sup>

The role of the marital sub-system is to provide for the intimacy needs of the adult family members for closeness, emotional support, sexual activity and psychological refuge. The stress of childhood cancer may divert attention from marital consideration, leaving spouses few opportunities for intimacy, support and enjoyment. Under the pressure of fear and pain, some spouses may focus their pain or

---

35. Spinetta, J. Op.cit.

anger on each other.<sup>36, 37</sup> Although marital relations are not usually weakened or destroyed by the stress of childhood cancer, pre-illness difficulties are often exacerbated.<sup>38</sup> Some parents of children with cancer feel that the struggle with the illness leads to improvements in the quality of family life. The view of stress as a common problem that can be solved through common effort helps overcome loneliness and may lead to increased interdependence and teamwork.<sup>39</sup>

The experience of childhood cancer bring many practical changes in family life. For instance, the jobs of caring for the ill child and of transporting the child for clinic treatment or hospitalisation often force parents to reduce or alter their responsibilities as homemakers or wage earners. Some fathers cut back on the amount of time spent at work in order to perform family chores or to spend more time at hospital and mothers often cut out or cut back from full-

- 
36. Kaplan, D. et al. "Family mediation of stress". Social Work; Vol.18; No.4; pp.60-69; 1973.
  37. Marcus, L. "Pattern of coping in families of psychotic children"; American Journal of Orthopsychiatry; Vol.47; 338-399; 1977.
  38. Frauz, "When your Child Has A Life Terminating Illness"; Washington D.C.; Association for the Care of Children's Health ; 1983.
  39. Cook,J. "Influence of gender on the problems of parents of fatally ill children" ; Journal of Psychological Oncology; Vol. 2; No.1, pp.71-91; 1984.

time employment in order to be available to care for the ill child.<sup>40</sup>

The difficulty of achieving a balance between change and continuity is exacerbated when families lack sufficient resources to handle all the jobs involved. Time and energy are often at a premium and parents, especially, face the problem of whether and how to renegotiate their work roles and their involvement in home management and child care. Flexibility in changing parental tasks may not come without emotional costs in the sibling subsystem as well as in the marital subsystem. As mother's and father's roles shift to accommodate the ill child's regimen, siblings may have to adapt to new found distance from mother and interdependence with father.<sup>41,42</sup>

It is sometimes hard to tell a child with cancer about the illness because parents are concerned about the child's reaction. Negative reactions on the child's part put additional stress in the parents' already burdened situation. Even, however positive the child's adjustment to the disease, treatment and new or altered life situations, the child's reaction often creates stress for parents.<sup>43</sup>

---

40. Ibid.

41. Featherstone, H. "A Difference in the Family"; New York; Penguin; 1981.

42. Burton, L. Op.cit.

43. Spinetta, J. Disease-related communication : how to tell. In Kellerman, J. (ed) Psychological Aspects of Childhood Cancer ; Springfield ; Charles C. Thomas ; 1980.

The reactions of the ill child's siblings often are quite stressful for the parents. It has been noted that siblings feel left out of new family development and changing roles and many become deeply upset. They see their mothers as over-protective and over-indulgent of their ill sibling. So, they express their feelings in ways that draw parents' attention and concern.<sup>44</sup> Siblings often identify one another and link their fate with one another's experiences. Some siblings may even think that they caused the illness, perhaps by being too rough with their brother or sister. Moreover, if one sibling gets ill, the other may expect to get ill as well. Under these circumstances, it is no surprise to find that the physically normal children are jealous of their ill sibling.<sup>45</sup> There are also numerous examples for siblings who play positive roles in the family as safety valves or alarm bells, wherein they draw their parents' attention to these overreactions.<sup>46</sup> Typically older siblings are especially helpful, whereas younger siblings

---

44. Spinetta, J. et al, Emotional Aspects of Childhood Cancer and Leukemia : A Handbook for Parents ; San Diego ; Leukemia Society of America ; 1976.

45. Hewett, S. & Newson, J. The Family & The Handicapped Child ; Chicago ; Aldine ; 1970.

46. Cairns, N. et al. "Adaptation of siblings to childhood malignancy"; Journal of Pediatrics; Vol.45; No.3; pp.484-487; 1970.

are a major cause of worry.<sup>47</sup> In addition to intrafamily dynamics, siblings experience stress from the world outside home. As they go to school to play with their friends, many siblings are torn between this loyalty to the ill child and the desire to avoid stigma. As siblings encounter and report these issues, parents find them to be new sources of stress.<sup>48</sup>

The grandparents of the child with cancer may become another source of stress for the parents. When grandparents respond by needing help and attention, instead of providing it, they further stress the family's resources. Stress emanating from parents' relations with the child's grandparents is partly rooted in the pain that the illness creates for grandparents and partly in the negative ways some grandparents relate to the parents.<sup>49, 50</sup>

Coping with friends and community members increase in importance when a family experiences a crisis such as childhood cancer. For some parents stress is associated with

---

47. Burton, L. Op.cit.

48. Gorgan, J. et. al. "Impact of children cancer on siblings; Health & Social Work; No.2; pp.45-57; 1977.

49. McCollum, A. Coping with Prolonged Health Impairment in Your Child; Boston; Little Brown; 1975.

50. Binger, C. et al. "Childhood leukemia : emotional impact on the patient and family"; New England Journal of Medicine; Vol. 260; pp. 414-418; 1969.

friends' responses and reactions also. The experience of serious illness itself is often isolating for parents as they feel no one else knows or can appreciate what is happening to them. Friends who advertantly confirm these feelings add to the stress and trauma of the entire illness experiences.<sup>51</sup> The family must decide how open or private it wants to be in its contact with others. For their part, friends may not know what to say or do or how to be helpful to the family. Because the demands of caring for a child with a chronic illness such as cancer may exceed the family's resources, outside help is often required. Assistance may be hard to get and some person outside the family may react with indifference or insensitivity.<sup>52</sup>

Not all parents and families experience these personnel and social stresses in the same way or to the same degree. A variety of personal and family background factors are responsible for this variation in the experience of social stress.

### **Patient And Family**

Parents have the awesome responsibility of preparing children for a successful adult life. Basic child-rearing

---

51. Burton, L. Op.cit.

52. Chesler, M.A. & Barbarin, O.A. Op.cit.



tasks involve the selection of developmentally appropriate standards and the application of discipline, so that the child acquires approved attitudes and skills. The typical child-rearing process is complicated by illness and treatment, pressures to treat the child in a special way, and reactions of others to the child and family.

Childhood cancer increases the complexity of the child-rearing process. The child's physical and emotional condition and parental uncertainty about the future may produce confusion on how to administer discipline. Moreover, treatment and its side effects may interfere with normal maturation processes.<sup>53</sup> Parents face a dilemma in simultaneously treating their child normally and acknowledging the child's special condition. While seeking to protect their child, and to adjust hope and expectations for the child's future in terms of the illness, parents must stimulate the child to achieve his potential and to live as normal a life as possible -- now and in the future.<sup>54, 55</sup>

---

53. Comaroff, J. & Maguire, P. "Ambiguity & the search for meaning : childhood leukemia in the modern classical context"; Social Science and Medicine; 1981; 15B; 115-123.

54. Burton, L. Op.cit.

55. Koocher, G. & O'Malley, J. Op.cit.

Deciding when and how to discipline an ill child is a significant problem for many parents, as is the maintenance of family routines and household chores. Discipline is not an abstract problem but relates to other child-rearing issues and ultimately to parents' definitions and goals for a normal life for their child. A concern for effective discipline often involves parents' fear of spoiling their child or their experience that their child is becoming spoilt.<sup>56</sup> The potential for spoiling may be created by others outside the immediate family, by relatives or neighbours who, overcome with grief and concern, constantly pamper and over react to the child's imagined or real discomfort or shortened life span. Parents' inability to ward off or correct neighbour's and relatives' behaviour contributes to this problem. When parents do not know enough about their child's medical conditions, they are especially unable to know what standards they should establish or encourage. In some cases, conversation with the medical staff can provide such information and direction.<sup>57</sup>

---

56. Lawrence, S. "Results : Candelighers discipline questionnaire"; Candblightingems National News-letter; 1978; 2(2); 2.

57. "The chronically Ill Child & Family in the Community" Washington D.C. Association for the Care of Children's Health; 1982.

## Telling The Child With Cancer

A unique child rearing dilemma that parents of ill children face involves the need to decide what and how to tell the child with cancer about the illness. There are two widely known different approaches to "telling" the child : the protective approach may be of constructive use for a short while, eventually the pretense fails and awareness generally is inevitable. Studies show that parents with more other children tell the ill child significantly more about the disease and treatment than do parents with fewer or no other children.<sup>58</sup> If there are older siblings in the family, parents may share more information with these siblings simply because they are responsible family members, perhaps themselves "old enough to know" and to be of assistance in the caregiving process. Once explanations are made to siblings, parents can expect that siblings might tell or leak that information to the ill child. Thus, they may be more willing or forced to share more information about the disease or reasons for treatment with the ill child.<sup>59</sup>

---

58. Slavin, L. et. al. "Communication of the cancer diagnosis to pediatric patients : impact on long-term adjustment"; American Journal of Psychiatry; 1982; 139 (2); 179-183.

59. Bluebond-Langer, M. The Private World of Dying Children; Princeton; Princeton University Press; 1978.

In some cases, parents are not able to control what their child is told about the disease, especially as their child interacts with other ill children or with other social groups. Not only does sibling structure play a key role in the telling process, information shared with grandparents or other relatives or conversations between relatives and the ill child, may cause the child to raise questions that require more parental disclosure. Thus, decisions to tell the child about their medical condition cannot be isolated from what is told to or known by their family and community. "Telling" is not only a child rearing issue, but a lifestyle issue for both parents and children.<sup>60</sup>

#### **Preparing A Child For Death**

For parents of children who die, unique child-rearing issues develop. Foremost among these are the way in which parents talk about or prepare terminally ill children for death. Most of the parents are honest and direct with their children. While they encourages the child to have hope, they were ready to face together the reality that the child was going to die. In addition to being honest with their children about impending death, parents tried to pacify

---

60. Glasser, B. & Strauss, A. Awareness of Dying; Chicago; Aldine; 1965.

their children's fears by telling them that they would be going to heaven and would no longer be in pain. Some parents on the other hand denied the seriousness of their child's condition or did not know that their child's illness was a terminal one until shortly before the child's death. These parents generally did not prepare their children for what lay ahead.<sup>61</sup>

It appears that the age of the child, as well as the degree to which the parents themselves prepare for their child's death are key variable in determining how parents of children with childhood cancer deal with this issue. Sometimes older siblings, with or without their parents' knowledge, also play critical roles in teaching terminally ill children how to behave and in preparing them for death.<sup>62</sup>

#### **Physician And The Patient's Family**

The relationship between medical professionals and parents concerned with childhood cancer is delicate. It begins in moments of great tension and anxiety and proceeds through a period of uncertainty and physical as well as emotional pain. Regardless of the eventual outcome, par-

---

61. Chesler, M.A. & Barbarin, O.A. Op.cit.

62. Ibid.

ents and professionals are bonded by the child's illness, caught in an ongoing relationship defined by the child's progress. The quality of this relationship is crucial to the comfort of both the family and the professional. A poor relationship can make doctors' work even tougher; a good relationship can provide medical team members rewarding moments of intimacy and collaboration. A good relationship with the staff influences the way in which patients and family members cope with illness.<sup>63</sup>

Parents identify following dimensions of their interaction with the medical staff, indicating both the content of problems and characteristics of a high-quality relationship.<sup>64, 65</sup>

A number of scholars suggest that many parents respond to the intellectual stress of childhood cancer by seeking information and understanding of the disease and its treat-

- 
63. Adams, D. Childhood Malignancy : The Psychosocial Care of The Child & His Family; Springfield; Charles C. Thomas; 1979.
  64. Mechanic, D. "Influence of mothers on their children's health attitudes and behaviours"; Pediatrics; 1964; 33; 444-453.
  65. DiMatteo, M. & Hays, R. "The social significance of patient's perception of physician conduct. A study of patient satisfaction in a family practice centre". Journal of Community Health; 1980; 6; 18-34.

ments.<sup>66, 67</sup> The amount of medical information physicians share is not the only issue parents identify in characterising effective communication : The extent to which the staff is open and clear in communicating about non-medical matters, such as personal, familial and school issues are also important.<sup>68</sup> Sometimes it is difficult for parents' to ask staff members all the questions they have, especially when the questions focus on non-medical issues. Aside from feeling worried, ignorant and intimated the parents' sense of parental competence may be eroded if they repeatedly need to seek expert opinion in the day to day care of their ill child. As a result, many parents stop looking for open staff communication and stop asking their deeply felt questions.<sup>69</sup>

Another dimension affecting staff-parent relationships is 'the quality of social and emotional contact' between parents and physicians. Some parents identify the importance of warm, caring and sensitive doctors. When the

- 
66. Lazarus; P. Psychological Stress and Coping Process; New York; McGraw Hill; 1966.
  67. Futterman, E. & Hoffman, I. Crisis and adaptation in the families of fatally ill children. In Anthony, J. & Koupernick, C. (eds). The child in His Family; The impact of death & disease; Vol.2; New York; Wiley; 1973.
  68. Binger, C. et.al. Op.cit.
  69. Halpern, R. "Physician-parent communication in the diagnosis of child handicap : A brief review"; Children's Health Care; 1984; 12 (4); 170-173.

quality of interpersonal relationship is judged as poor, the family typically perceives staff rudeness and lack of sensitivity to their emotional stress.<sup>70</sup> Research on the doctor-patient relationship affirms that many doctors have difficulty expressing care and warmth in such relations.<sup>71</sup> With regard to the particularly potent issues of childhood illness, the physician's typical (and perhaps self-protective) pattern of emotional distance may clash with parent's emotional needs.<sup>72</sup> Sometimes this relationship is also affected due to the specific character of the medical bureaucracy. Parents report that at times the medical care organisation marches right over their needs and feelings.<sup>73</sup>

Of all the factors in parent-child-staff interactions, the source of parents' strongest feelings (both positive and negative) relate to the ways physician deal with their children. Staff who behave in an engaging, warm, caring way

- 
70. Sabbeth, B. "Understanding the impact of the chronic childhood illness on families"; Pediatric Clinics of North America; 1954; 31 (1); 47-58.
  71. Cassileth, B. & Hamilton, J. The family with cancer. In Cassileth, B. (ed). The Cancer Patient : Social & Medical Aspects of Care; Lea and Febiger; Philadelphia; 1979.
  72. Meadow, R. "Parental response to medical ambiguities of congenital deafness". Journal of Health and Social Behaviour; 1982; 6 (4) : 6.
  73. Wilson, B. "Pediatric cancer hospital lobby and waiting rooms"; Candlelighters Foundation Quarterly Newsletter; 1982; 6 (4) : 6.



with the child, usually are able to establish a meaningful relationship with the family. However, parents do not expect the staff to cater to every whim and fancy of the child. In fact, parents respect for the ability of the physician to strike a balance between empathy with the child's condition and the control of the child's behaviour.<sup>74</sup>

The typically passive and powerless position of patient undoubtedly influences parents' concern about their own involvement in the case of their children. Several important questions have been raised about the model of medical practice that concentrate so much power in physician and unnecessarily strips patients of some of their most important resources - self-esteem, coherence, assertive posture toward the illness and so on.<sup>75,76</sup> If problems of patient loss of control and learned helplessness are typical of doctor-patient relationships, they are even more problematic for parents who are worried about their fragile and vulnerable children. Parents wish to maintain their parental role,

---

74. Vernick, J. Meaningful communication with the fatally ill child. In Anthony, J. & Koupernick, C. (ed). The Child in His Family : The impact of disease & death; Vol.2; John Wiley & Sons; 1973.

75. Antonovsky, A Health, Stress & Coping; San Francisco; Jossey-Bass; 1980.

76. Taylor, S. "Hospital patient behaviour : Reactance, helplessness or control?"; Journal of Social Issues; 1979; 25 (1); 156-154.

expecting and needing to be actively involved in protecting and caring for their children. Several authors agree that active parental participation in the care of children with cancer may help relieve parents feelings of guilty, helplessness and impending loss. Moreover, they may help ease the staff's burden and prevent them from making medical mistakes. Many parents feel that medical care organisation exhibits ambivalence, if not resistance, to active parent involvement in their children's treatment.<sup>77, 78, 79, 80</sup>

---

77. Adams, B. Op.cit.

78. Richmond, J. & Weisman, H. "Psychologic aspects of management of children with malignant disease"; American Journal of Disease of Children; 1953; 89; 42-47.

79. Hamovitch, M. The Parent & the Fatally Ill Child; Duranti; Calif.; City of Hope Medical Centre, 1964.

80. Futterman, E. & Hoffman, I. Crisis and adaptation in the families of fatally ill children. In Anthony, S. & Koupernick, C. (ed). The Child in His Family : The Impact of Disease and Death; Vol.2; Johan Wiley and Sons; 1973.

## **CHAPTER V**

## **CONCLUSION**

The demarcating line between sociology of profession and sociology of medicine is very fine. Most of the studies straddle both these sub-discipline of sociology. Scholarly works done on doctor-patient relationship demonstrate the close linkages between the two specializations. This can be gauged from researches in this field, particularly with reference to doctor's attitude towards patients, his preferred role relations with patients, his preferential treatment to privileged patients and his problems and difficulties with the sick in general.<sup>1</sup>

Regarding doctors' attitude towards patients, Oommen finds that most of the doctors tend to view patient not as a person but as a bundle of clinical of symptoms. More importantly, Oommen observes that majority of the doctor in public hospitals do not consider the welfare of the patients as their most important role obligation.<sup>2</sup>

Similarly, Madan finds in his study of the apex institution that doctors do not seem to want to spend more time on patient care but on research.<sup>3</sup> Comparative studies of institutional doctors and private practitioners, however,

- 
1. Sharma, S.L. (1987) Trends in the study of medical profession in India. In Lal, S.K. & Chandani, A. (ed). Medical Care : Readings in Medical Sociology; Jainsons Publications; New Delhi.
  2. Oommen, T.K. (1978) Doctors & Nurses; A Study in Occupational Structure; Delhi; Macmillan.
  3. Madan, T.N. (1977) "Towards a humanised medicine"; The Indian Journal of Medical Education; January-June.

suggest that private practitioners show greater warmth in their dealings with patients<sup>4</sup> and that they combine physical care along with psychological and emotional care of their patients.<sup>5</sup>

Regarding doctors' preferred role relations with patients a number of researchers find that doctors' subscribe to Parsons' affective -- neutrality prescription, prefer as they do to avoid emotional involvement with patients.<sup>6, 7, 8, 9</sup> Some studies have advanced evidence suggestive of doctors' discriminatory dealings with patients on accounts of kinship considerations, patients' socio-economic status, power positions, sex, etc.<sup>10, 11, 12</sup>

- 
4. Chandani, A. (1985) The Medical Profession : A sociological Exploration; Jainsons Publications; New Delhi.
  5. Ramanamma, A. & Bambawale, U. "Occupational attitude of physicians"; Sociological Bulletin; Sept.; 1978.
  6. Mathur, I. Interrelations in an Organisation; Alok Publisher; Jaipur; 1975.
  7. Advani, M. Doctor-Patient Relationship in Indian Hospitals; Sanghi Prakashan; Jaipur; 1980.
  8. Chandani, A. Op.cit.
  9. Ramanamma, A. & Bambawale, U. Op.cit.
  10. Mathur, I. Op.cit.
  11. Oommen, T.K. Op.cit.
  12. Sribastava, A.L. Impersonality in the hospital : A sociological study based on the attitude of doctor-patient and intermediary staff; Interdiscipline; Spring; 1975.

I decided to confine my study within the pattern of interaction between the doctor and the terminally ill patient. But while going through source materials, I realised that the relationship between the doctor and terminally ill patient is totally different from the doctor-patient relationship we usually refer to. In the later case, patients get back their health after treatment and in most instances they do not need the help of their family members to the extent a terminally ill patient does. In the non-terminal case, the doctor-patient relationship includes family members also. In this case, the doctor-patient relationship takes the shape of a triangle where all the three points i.e., doctor, patient and family have reciprocal relationship with each other. I have discussed this interaction between doctor, terminally ill patient and his family in three different chapters taking into consideration three different kinds of terminally ill patients.

Because of their naturally reduced physical ability due to old age, geriatric patients are dependent on others. If any more disability or disease adds to it, it is the direct caregiver who becomes more important for the patient than the doctor who visits the patient for a specific period of time. In a country like ours, where traditional family

members take up the responsibilities of caring for the aged, this always leaves different kinds of impact on different members. There is no time limit for providing this care. It may need longer time than the family actually expected. This may ultimately lead to financial problem. Most of the families of our own country take up these burdens and go through it silently. It often happens that a family is unable to provide a particular kind of care prescribed by the doctor to the patient due to their lack of resources. A compassionate doctor can be of real help to the family in caring for their aged members.

My second category of terminal patients are those who are suffering from cancer. In case of geriatric patients, the patients themselves were aware of their age and the approaching death. But cancer is blind to age. Cancer patients can be of any age, starting from children, upto the aged. Age of the terminally ill patient becomes an important factor while the doctor is interacting with them. Most of the cancer patients suddenly realise that their days are numbered now onwards. Facing one's own death is very difficult and requires help from the doctors as well as from the family members. It is the doctor who should import the bad news of the patient's terminal illness to him and his fami-

ly. This is because it is he who can then suggest the steps to follow in an informed fashion. Even for breaking this news, a healthy relationship between the doctor, patient and his family is a must. The doctor can speak about this hard reality only if the patient and his family faces it with courage and keeps faith in doctor. The patient and his family also can face the situation with steadiness when the doctor is friendly and encourage interaction. The quality of patient care thus depends on the interaction between doctor, patient and his family.

The patient undergoes a tremendous tension after knowing about his terminal illness. The family's normal function gets obstructed. Caring for the ill member becomes the priority of the family. Sometimes the nature of illness requires the patient to be hospitalized. This often puts the family in greater difficulties. Often they feel guilty for not been able to provide the required care to the patient. Financial scarcity makes the situation worse. In this situation the family also requires help from the doctors and others. Sympathetic and amiable doctor can help the family members and make them of more use in the caregiving process of the patient. Here also we can see that family becomes inseparable from the treatment process and the doctor-patient relationship.



I took children with cancer as third and last category of terminally ill patients because of two reasons. Firstly, children are supposed to have started their lives. But childhood cancer turns them into a unique kind of patient. Usually children are guided by their parents at this stage. So, it is parents rather than the children who play the main role in decision-making. This is expected to give the doctor-patient relationship a different colour.

Secondly, in case of other terminal patients, family members also take part in the treatment process. But a child is such a member of family whose death is expected to affect all the other members very deeply. How family members deal with these children with cancer is another point of interest for me.

Regarding the first issue, I found that the typically passive and powerless position of children with cancer undoubtedly influences parents concern about their own involvement in the care of their children. Disclosing the truth to the parents of fatally ill child is very painful for the doctor. It becomes easier when the parents have faith in the doctor and act rationally. In case of other terminally ill patients, they are also given the news of their terminal illness. But conveying the same becomes more

troublesome in the case of children with cancer. Doctors and parents get confused whether the child will be able to bear the shock or not. Some patients are so young that they do not understand the concept of death properly. In these cases family, especially parents, become most important in the treatment process of the children with cancer.

Childhood cancer affects the family more than any other cases. In other cases of terminal illness, other family members try to adjust with the approaching death of the sick one. But for childhood cancer, it becomes difficult on the parents part to make others understand the reality they face. Parents always try to hide the truth from the siblings' of the dying child. This puts the parents in a big dilemma. Their duty is bifurcated between preparing one child for death and the other for life. Even when the siblings come to know, they also try to share all the familial responsibilities and help their parents in providing care to the dying child. The sick child, also, as he gets detached from the outer world because of his sickness, starts depending upon his parents and siblings more and more. In this case also, family is just inseparable from the patient. Doctor, patient and family - all these three are dependent on each other for providing proper care to the patient.

So far we have seen few sociologists dealing with different aspects of doctor-patient relationship. But the family was not taken into consideration in their perspective. Family was taken for granted to be there to provide required care for the patient. In my work, I tried to bring out this unattended issue to light. I went through different kinds of literature to find out how family members deal with the patient and doctor on the one hand and with their own internal problems in the other. I feel as the patient needs doctor's help for regaining his lost health, the same way the families also need professional help from time to time while providing care to a terminally ill patient.

The ways in which a society copes with major events of a person's life, viz., birth, illness and death, are central to the beliefs and practices of that society and also bear a close relationship to its other major social, economic and cultural institutions. In particular the treatment of those who are temporarily or permanently dependent on others is a revealing indicator of the social values lying behind the allocation of material and non-material resources. This means that the knowledge and practices of the members of any society about how to promote, maintain and restore health will be related to and vary with three major facets: the

familial or kinship structures and the associated gender order ; the specifics of the economic system and the associated social and economic classes therein ; and the structures of political governance.<sup>13</sup>

In my work, I have dealt with the first aspect, i.e., the family. In our society, the family still performs the role of the primary caregiver to the patients. The whole family take part directly or indirectly in the care giving process. Sometimes close relatives and friends are also included. This is in contrast with developed countries. In those societies, care is mostly provided by various caregiving organisations, like hospice, along with the family.

Though in our society all the family members take part in the care giving process, it is mainly the women who take the direct burden of the job. And if it is necessary, then women are compelled to leave their job and look after the ill person, while men continue to be the bread-earners of the family. In this respect, western countries also act in the same way.

This indicates that the pattern of health care is manifestation of the social structure of particular society. In our country the family takes the burden of patient care.

---

13. Stacey, M. (1988), The Sociology of Health and Healing; Unwin Hyman Ltd.

But in developed societies the family structure is not pressured in the same way for providing patient care. Our social values also contribute to the situation. Hospitalisation, and especially dying in the hospital has always been looked down upon which is completely different from the western countries. But slow development of hospice programmes reflects that our society is also changing.

The existing health care system in our society exhibits a heavy bias towards a cure orientation. Physicians are thought to diagnose and treat disease and to expect cure rates as a consequence. Not much emphasis is placed on the management of patients who have diseases that cannot be cured. But, if care is perceived as the only acceptable goal of medical care, then chronic degenerative, eventually fatal disease is a fact that cannot be acknowledged.

Hospice is a programme of care oriented to meeting the needs of those patients who cannot realistically expect to be cured and whose needs are primarily for comfort and relief for the limited time of life they are expected to have. It is focussing on the quantity of living remaining for those who have minimal quantities of time left.

Since quality is such a personal matter and of individual life-styles, the hospice is very much a need-oriented

programme of care in which the dominant priority is that the patient and the family have primary role both in defining their needs and in being participants in the process by which they will be treated. What is appropriate in such circumstances is what the patient and the family find comforting and supportive in all areas of existence- physical, emotional, social, spiritual, financial. Because patients and families under stress cannot be expected to exercise the best judgement and because families may be facing the most serious illness they have ever experienced cannot be expected to be knowledgeable in how to handle it, hospice programmes are prepared to provide the professional and personal resources necessary to meet needs in all these areas. The goal of such care in hospices is not simply symptom control (i.e. keeping the patient physically comfortable). The focus of such care is palliation, i.e. assisting the patient to live in relative comfort and as painlessly as possible, until the day he dies. The goal of this sort of care is to help the patient to continue life as near to the usual manner as possible- at work, being with the family, doing whatever is especially significant before the close of life, feeling a part of ongoing life even as the patient is concluding his own.

These are some of the aspects I wanted to deal with in my work. I could not go deeper due to time constraints. People usually go to the general practitioner first. If the condition requires, then GP refers the patient to the specialist. This happens with most of the terminal patients. It is expected that the treatment process of the specialist will be somewhat different from that of the GP. I intended to check this variation in the process of patient care but without success.

My other point of interest was to see whether the difference in family structure contributes significantly to the quality of patient care or not. Joint families consist of more family members than nuclear families. It is expected that a patient in the joint family will receive more attention than in a nuclear family. On the other hand, there is a possibility of difference in opinion regarding the process of patient care in the joint family as the number of people taking part in decision making is larger. But in a nuclear family, only a few, may be only one person takes the decision. This aspect also remained untouched in my work.

I could not include another category of terminally ill patients, i.e., AIDS patients. Lay people, even the doctors are scared of contaminating AIDS as it is still incurable. Once a patient is found to be affected with AIDS, the whole

society tries to avoid him. So, AIDS patients are supposed to face completely different kind of 'interaction with their doctors and receive different kind of care from his family. It would be really interesting to know about this. The literature on AIDS patients is very skimpy in India which leaves a lot of room for further detailed study.