

DEATH, DYING AND NEAR DEATH EXPERIENCE **Preliminary report on surveying the need and developing the method**

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SUMMARY

Psychology of deaths due to acute medical emergencies is under-researched. Most studies till now have concentrated on extended-death situations like malignancy. This open pilot study of twenty five patients examines the psychological state of patients during a life threatening acute medical illness (Group A, ten patients) and of those who survive such an experience (Group B, fifteen patients). The study finds psychological exploration both possible and necessary if carried out in a discreet manner. Salient features of the interview technique are discussed. The study finds out whether patients are aware of the possibility of terminality. The psychological disturbances manifest and nature of care expected are also discussed. Near Death Experiences of those who acknowledge their occurrence are reported. Some nuances of thanatological research are high-lighted: What are the abilities needed in an interviewer? Can such exploration increase psychological distress in a patient already prone to it because of serious medical sickness? What impact such research can have on the interviewer himself? The paper answers some of these common questions while developing the method of thanatological study in acute medical death-situations.

Introduction

Scientific enquiry into death is a relatively recent phenomenon. The psychiatrist's role in the terminal patient traces its history to the last three quarters of a century.

Treatment of the dying keeping his psychological needs in mind gained attention (Hackett and Weisman 1962) as did Hospice care (Krant 1981). Use of treatment modalities in terminal patients like psychotherapy (Leshan and Leshan 1961, Cramond 1970, Stedeford 1979), Behaviour Therapy (Whitman and Lukes

1975) and psychopharmacologic agents (Goldberg et al. 1973) were studied. Counter-transference attitudes of health personnel dealing with the dying (Joseph 1962, Hicks and Daniels 1968) as well as when, what and how to disclose (AitkenSwan and Easson 1959; Oken 1961, Weisman 1967) occupied the attention of other researchers. Kubler-Ross epoch making work (1969, 1974, 1975) served as a launching pad, as though, for a global upsurge in thanatological research. Near Death Experiences or NDEs also occupied the attention of quite a few others. (Moody 1975, Sabom 1982).

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Most of the studies (a number of them cannot be quoted for exigencies of space) have evaluated dying as a process extended over a period of time, for example, following the diagnosis of malignancy through the resultant morbidity to eventual death. Deaths due to acute life-threatening medical emergencies has escaped the attention of researchers, barring a few, like Levinson (1972) who discussed psychological state of patients facing sudden death, Hackett & Cassem (1972) who examined the psychology of cardiac arrest, and Bruhn et al. (1974) who evaluated psychological predictors of sudden death in cardiac patients. This, however, is a miniscule minority, probably for pragmatic reasons. The equation needs to be set right. Moreover death and dying has escaped the attention of researchers in India, in this age of the *thanatologic imperative* (Kothari and Mehta 1986) and in a country which not without reason can boast of a great philosophical tradition on the subject, right from the Vedas to Sri Aurobindo (Kamath 1978). The present effort may be considered one in the direction of setting the equation right.

Aims of the Study

1. Is it possible to study the psychology of death and dying in a general medical set-up?
2. Whether there is a need to do so?
3. How does one go about it?
4. Are psychiatric disturbances manifest by such patients?
5. Are Near Death Experiences (NDEs) reported in those who recover?
6. What are the needs and expectations of such patients?

Material and Methods

A total of 25 patients (Group A, 10, and, Group B, 15) from the General Med-

ical Ward administering both emergency and ongoing care in a teaching general hospital in Greater Bombay were included in this open pilot study. Their ages ranged from 12 to 61 years. The sample was made up predominantly by the age groups 16-30 years (56%) and 31-45 years (28%).

Group A (10 patients - 7 male and, 3 female) was seen when acutely sick medically and emergency life-sustaining procedures were being administered. Group A thus consists of seriously sick patients with a definite mortality risk.

Group B (15 patients - 9 male, 6 female) consisted of patients who had been through a life threatening medical illness and were now in the recovery phase. They came from either the ICCU or Intensive Nephrology Care Unit.

Interview Technique

All patients were first screened on the weekly rounds with the Physician-In-Charge and the resident staff. They were then interviewed by one of the authors having post-graduate qualification in psychiatry (ARS). The Mental Status Examination of all patients was done. The interview schedule was semistructured, being conducted in 1-6 sessions. Open ended questions were usually asked. Rarely were leading questions used because of their psychologically disturbing potential. This, rather than asking 'Do you think your sickness can result in something serious? May be... death?' the question put was, 'What do you feel can be the outcome of your present sickness?'

If the question was parried, one or two discreet questions put were, 'You know, being in a hospital with lots of doctors and nurses around and so many tubes being used on a person can cause anxiety. How does that affect you?' If still there was

no answer, a comment was made like, 'It appears you are satisfied with what is being done for you. We are happy you are confident of a smooth recovery?' From either of the comments, the patient broke his initial reserve and became communicative.

The interview itself had to be discreet because of the sensitive nature of the subject tackled. Also there was the continuous need to avoid arousing undue anxiety in patients, already over-burdened with the distress consequent to physical morbidity and even in relatives, and the ward-staff. No misplaced zeal need be used in any psychological investigation that adversely affects the emotional equilibrium of the seriously sick and their relatives. A firm commitment to this effect from the psychiatric side is a must, whether asked for or not. This tends to keep over-enthusiasm in check and zealousness tempered, while the genuine keenness of research is never compromised.

Results and Discussion

I. *The Sample*: Most Group A patients developed their sickness less than three months prior to hospitalization (60%) while Group B was represented, 73%, by those who developed their sickness more than three months prior to hospitalization. Group A, thus, represented patients who had fallen sick relatively recently (average duration 10 days) while Group B consisted of those who had symptoms for a longer period (average duration 160 days). Majority of Group A patients were seen 24 hours - 14 days of developing acute symptoms (80%). Group B patients were seen 8 days - 30 days following recovery of the acute episode (87%).

Thus the acutely sick were seen during their acute phase and the recovering patient in a reasonable time following the

acute phase and during their active recovery and rehabilitative period. The sample may, therefore, be considered fairly representative of the phenomenon studied.

Table 1
Diagnostic Break-up, Group A (N = 10)

| Diagnosis | Expired | Recovered | Total |
|------------------------|---------|-----------|-------|
| Fulminant Pneumonia | 2 | 1 | 3 |
| Advanced Tuberculosis | 1 | 1 | 2 |
| Hepatic Encephalopathy | 2 | 0 | 2 |
| Acute Renal failure | 1 | 2 | 3 |
| | 6 | 4 | 10 |

Table 2
Diagnostic Break-up, Group B (N = 15)

| Diagnosis | Male | Female | Total |
|---|------|--------|-------|
| Myocardial infarction and/or Ischaemia | 5 | 3 | 8 |
| Acute Renal failure in a patient with chronic renal failure | 3 | 4 | 7 |
| | 8 | 7 | 15 |

Comment: All patients needed emergency resuscitation measures and had survived.

II. *Diagnosis*: Table 1 gives the diagnostic break-up in Group A. The common life threatening sicknesses were Fulminant Pneumonia, Advanced Tuberculosis, Hepatic Encephalopathy and Acute Renal Failure. Six of these patients expired and four recovered.

Table 2 shows the diagnostic break-up in Group B. Myocardial Infarction and/or Ischaemia, and Acute Renal Failure were patients with Chronic Renal Failure are represented here. The diagnoses represent acute life threatening medical situations commonly encountered in a general medical ward.

III. Mental Status Examination:

Table 3
Group A: Mental Status Examination (N = 10)

| Item | No. | % |
|-------------------------------|-----|-----|
| Clouding of Consciousness | 10 | 100 |
| Delirium | 6 | 60 |
| Coma | 5 | 50 |
| Anxiety symptoms | 4 | 40 |
| Paranoid ideation | 3 | 30 |
| Depressive symptoms | 2 | 20 |
| Conversion Symptoms | 1 | 10 |
| Obsessive Compulsive Symptoms | 1 | 10 |

Note: More than one symptom was often present in the same patient.

Table 3 shows Mental Status Examination (MSE) results in Group A. Clouding of consciousness was present in all patients at some time or other. But this did not preclude further MSE. 50% went with coma and 60% had episodes of delirium, either preceding or succeeding the MSE. Lack of communicativeness (3 pts.), lack of personal hygiene (4 pts.) and incontinence (2 pts.) were the usual accompaniments of disturbed consciousness.

Terror with florid paranoid ideation (3 pts.); hallucinations (visual 2 pts; auditory 1 pt.); depressed mood (2 pts.); crying spells, guilt feelings, suicidal ideation (1 pt.); anxiety (4 pts.); somatic preoccupation (5 pts.); conversion symptoms (1 pt.); and compulsive symptoms (1 pt.) were also seen.

Orientation to time, place, or person was disturbed in seven out of ten patients. Memory appeared disturbed in five, immediate (5 pts.), recent (5 pts.) and past (2 pts.). Intelligence was affected in two patients.

Anxiety, Paranoid ideation, Depressed mood, Conversion symptoms and Obsessive compulsive symptoms were present and seemed to be exacerbation of basic personality characteristics.

Group A, thus, consisted of acute medical emergencies who progressively lapsed into disorganized states of the mind. This is especially true of those who subsequently expired (60%). These patients were reasonably young and the duration of morbidity was quite short. Thus, acute medical emergencies may leave little time for psychological understanding or for the relatives to cope with the probability of death in a family. It differs considerably from an extended death situation like malignancy. Follow up of close relatives of such patients needs further study. Important areas could be the repercussions of lack of time for psychological rehabilitation, or the time to say good-bye. Also worth exploration would be how patients and their relatives compress the stages of dying in the short time at their disposal, how they succeed and where they fail, and the sequelae of either.

Table 4 shows mental status examination in Group B. Almost all patients were eager to establish communication. Only 3 patients showed mild clouding of consciousness. No perceptual or cognitive disturbances were noted; neither were Insight of judgement impaired.

Table 4
Group B: Mental Status Examination (N = 15)

| Item | No. | % |
|----------------------------------|-----|----|
| Clouding of Consciousness (mild) | 3 | 20 |
| Anxiety Symptoms | 8 | 53 |
| Depressive Symptoms | 3 | 20 |
| Indifference | 2 | 13 |
| Psychologically normal | 2 | 13 |

Note: Symptoms overlap in some patients.

Anxiety symptoms were manifest in eight patients of Group B. They were apprehensive about the sickness, were afraid it was severe and would seriously cripple their day to day activities (although the

medical opinion warranted such a conclusion in only four such cases). They complained of difficulty in getting sleep (8 pts.), tremulousness (7 pts.), palpitations (6 pts.), and fear of fresh acute episode of their sickness. They occasionally showed clinging behaviour (4 pts.) and asked for repeated reassurance from medical staff and relatives (6 pts.). They had occasional spell of crying (3 pts.) with sulking behaviour (4 pts.) and irritability (6 pts.). Some complained of fleeting suicidal thought (2 pts.) All patients were anxious about the future welfare of their family members.

Three patients showed depressed mood. They felt life was not worth living (3 pts.), it would be better to die (3 pts.), and after-life would be better (2 pts.). They felt guilty of insufficient provision for family members (2pts.), prayed for a miracle to cure their sickness (2 pts.), prayed that life be prolonged to carry out pressing business and family duties (2 pts.).

Two patients appeared indifferent to the severity of their sickness. They maintained a resigned attitude, appeared to take excessive interest in religion and had faith of tiding over their present crisis. They however also complained of petty inconsistencies in the behaviour of relatives and medical staff. Two patients appeared to take the experience with minimal of psychological symptoms. Group B patients showed a keen desire to talk and unburden themselves, but this need was not met by either the staff or the relatives.

IV. Psychiatric Disturbances: Anxiety was the predominant symptom in both Groups A and B (Table 3 and 4). This is understandable due to an experience which is felt so near death. Lot of this anxiety centered around the future course and outcome of the illness which almost no pa-

tient knew for sure. This is probably due to an honest doubt in the physicians' mind whether such knowledge can have its own psychological repercussions. Anxiety (53%) and Depressive (20%) were seen as clinically diagnosable disease entities in Group B patients (Table 3).

Terror with paranoid ideation where manifest (Table 3) involved persecutory delusions about relatives and medical staff. Those patients who showed no abnormality (Table 4) seemed to have both an element of faith and awareness of practicalities. They had had fleeting anxiety and depressive symptoms. They felt grateful for the support of atleast one significant relative, of religious scriptures, and the ward-staff in their crisis.

V. Awareness of Terminality: 60% patients in both Group A and B were aware of the possibility of terminality (Table 5). The similarity in both groups is striking and needs further study. As at present, it appeared more a manifestation of sickness severity rather than a premonition.

Table 5
Aware of Possibility of Terminality in both Groups A and B (N = 25)

| Item | Group A (N = 10) | | Group B (N = 15) | | Total | |
|---------------------------------------|------------------|-----|------------------|-----|-------|----|
| | No. | % | No. | % | No. | % |
| Aware of possibility of terminality | 6 | 60* | 9 | 60* | 15 | 60 |
| Unaware of possibility of Terminality | 4 | 40 | 6 | 40 | 10 | 40 |

*Note: 60% of both Groups A and B were aware of the possibility of terminality.

VI. Near Death Experience (NDE): Table 6 shows NDEs. 10 patients out of 19 replied in the affirmative when questioned for it. Their experiences are mainly 'Intense Darkness' (3 patients) and 'Total

Silence' (3 patients). Other items were bright lights, receding into the background, vision of Christ and vision of Yama.

Table 6
Near Death Experience (NDE)
(N = 10, Group A 2, Group B 8)

| Item | No. | % |
|--|-----|----|
| Feeling of intense darkness | 3 | 30 |
| Feeling of total silence | 3 | 30 |
| Feeling of bright light and exploding firecrackers | 1 | ~* |
| Feeling of receding into the background to become a dot | 1 | - |
| Vision of tall grey haired bearded man with flowing robes standing with open arms (identification as Christ) | 1 | - |
| Vision of a burly individual riding a bull (identified as Yama deva) | 1 | - |

*Denotes irrelevance of % statistics here because of small sample.

VII. *Nature of Care Asked for:* Almost all patients asked for prompt relief from pain and discomfort (84%) and distress free digestive and evacuative functioning (84%). They wanted reassurance that they would improve (60%) and asked for a painless end if it became inevitable (36%). They liked cheerfulness in medical staff (80%), appreciated competence in symptom relief (88%) and singled out individual staff members for accolades (76%) and brick-bats (56%). They disapproved of anger in staff-members (72%), neglect (52%), evasive answers (40%) or false reassurances (32%). These items show that patients were keenly aware of what went on in their environment.

It was not always that detailed talk or reassurance was asked for. Often patients appreciated acks like a warm greeting, a gentle touch of comfort, a helping hand in

getting up from bed, an allowing of the doctor's hand to be clasped, an opportunity to cry or touch the feet. A regular, brief, cheerful visit was better appreciated than a prolonged, irregular one. Patients disliked caring persons who avoided eye-contact either while talking to them or even passing them by.

In most cases that survived, patients were grateful to recount the heroic measures carried out. But many were equally expectant that care of a significant intensity would still be continued.

A word or two about patients' over-zealous methods at rehabilitation also reveals another aspect of the nature of care these patients need. This applies particularly to patients physically restricted during their rehabilitation, especially the myocardial infarction patients of Group B. While on Occupational Therapy, they sometimes over-stretched themselves when unobserved.

Sexual needs were again a neglected area of counselling. At least two patients of infarction confided they masturbated in hospital without knowledge of the medical staff. They were too embarrassed to ask for advice. A straight forward approach to counselling about sex or masturbation in recuperating infarct patients is therefore necessary. Although the number is small (i.e. 3 out of 9 cardiac patients), these are sensitive areas. Patients may be unable to reveal them, yet it may be the need of quite a few. Further study of factors which help and/or hinder rehabilitation and how the caring team could by simple and straight forward explanation help in dispelling doubts and fears would be worthwhile.

VIII. *Comments on the Interview Session & Techniques:* The authors found that initial resistance to being interviewed was born out of a great need to deny. Any de-

nial, by both patients and relatives, seems to serve an important social function (Beilen 1981). It maintains the semblance of a relationship based on hope and courage. Where denial was an important defense, the interview was conducted in short sessions, in as less glum a manner as possible. The manner of the interview was such as to instil cordiality. It involved, amongst other things, listening to the difficulties of being in a general medical ward. It also meant passing on relevant information to the ward staff for necessary action. The interviewer thus became something of a liaison worker here.

All of us have a rather strong inner resistance to letting dying persons say what's on their minds (Cassem and Stewart 1975), because it increases our own death-anxiety in turn. This applies to medical men as well as relatives. But practically every empirical study in this field has emphasised the ability to listen over the ability to say something (ibid). The patient does not only want answers to his questions. He often wants a receptive, knowing and caring situation. In the bargain, he is ready to offer the researchers any number of enlightening answers to *his* questions. Probably, Saunders summed it up beautifully when she said, "The real question is not, 'What do you tell your patients?' but rather, 'what do you let your patients tell you?'" (Saunders 1969).

It is difficult to resist the experience of being carried away by certain emotions in thanatological research. This is the universal experience of most such researchers. This again is a reality every researcher in this field must be ready to accept. In fact if he does not do so, it is only a measure of his denial, or lack of awareness.

As Kubler-Ross (1975) so succinctly put it, "Each encounter with death is an invitation for growth".

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