

## TERMINAL CARE — WHAT THE CARERS THINK

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### SYNOPSIS

In preparing for a seminar aimed at carers for the dying in Singapore, a questionnaire was sent to those who registered for the meeting. The questionnaire was designed to allow participants to reflect on their own deaths and to determine how carers rated the present care for the dying in Singapore.

Of the 118 participants who answered the questionnaire 81% had had actual involvement with the terminally ill in the previous twelve months. 31% were doctors, 36% nurses, 10% spiritual advisors, 10% social workers, 13% others. 71% would like to die at home and 61% would like their whole family present. 70% believed in a life after death. 28% feared death itself but 71% feared the dying process. 96% felt that the present services for the terminally ill in Singapore are inadequate. Neglected areas were emotional support of the dying (82%), emotional support of the families affected (64%), physical care (68%), pain control (48%), financial assistance (21%).

87% of the 111 who evaluated the seminar would like future seminars. Requested teaching sessions were those on: pain control (65%), psychological aspects (64%), their role in care of terminally ill (53%). 13% would like more meetings within their own specialty while 71% would like to meet as a multi-disciplinary group.

**INTRODUCTION**

The Singapore Medical Association Seminar on Multidisciplinary Approach to Terminal Care, held on 31st August 1985, was aimed at those involved in terminal care in their professions. A total of about 1870 notification forms were sent and 204 registered for the seminar. Though this constitutes only 11% of all those notified, the response is relatively encouraging in view of the taboo attached to the topic for discussion. All registrants and panel speakers received survey form (1). 120 survey forms were returned, that is, only 59% responded to this self-administered survey which attempted to ascertain the carers' perception on death and terminal care in Singapore.

Participants were requested to fill an evaluation form at the end of the Seminar (2).

**I FINDINGS OF THE SURVEY**

The first question was to allow those who had reservations in answering further questions to return the rest of the form unanswered. Only 2 out of 120 participants ticked this box. However, due to the high non-response rate among those notified, these 2 may represent only the "tip of the iceberg".

**Profile of our participants**

Among the 118 who answered the questionnaire, 81% had had actual involvement with the terminally ill within the past one year. Their roles with the dying were that of a doctor (31%), nurse (36%), spiritual advisor (10%), social worker (10%) and others (13%).

**(1) Reflecting on my own death**

"Where would you like to die?"  
84 (71%) would like to die at home.  
"Who would you like to be with?"  
72 (61%) prefer to be with their whole family.

**Life after death?**

"Do you believe in life after death?"  
70% responded positively,  
15% were not sure,  
15% denied its existence.

Cross-tabulation of the carer's role with acceptance of a life-after-death was as follows:-

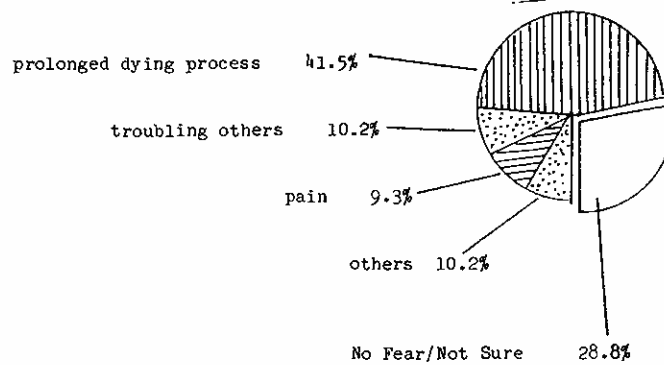
24 of 37 doctors	(65%)
30 of 43 nurses	(70%)
11 of 12 spiritual advisors	(92%)
7 of 12 social workers	(58%)
11 of 14 "others"	(79%)

Surprisingly even one of the spiritual advisors did not believe in life-after-death.

**Fear(s) surrounding my own death**

"Are you afraid of the after life?" 11% answered YES  
"Are you afraid of death?" 28% answered YES  
"Which of the following do you fear most about the dying process?" 71% ticked one of the 4 boxes provided  
(Refer to Figure 1 for details)

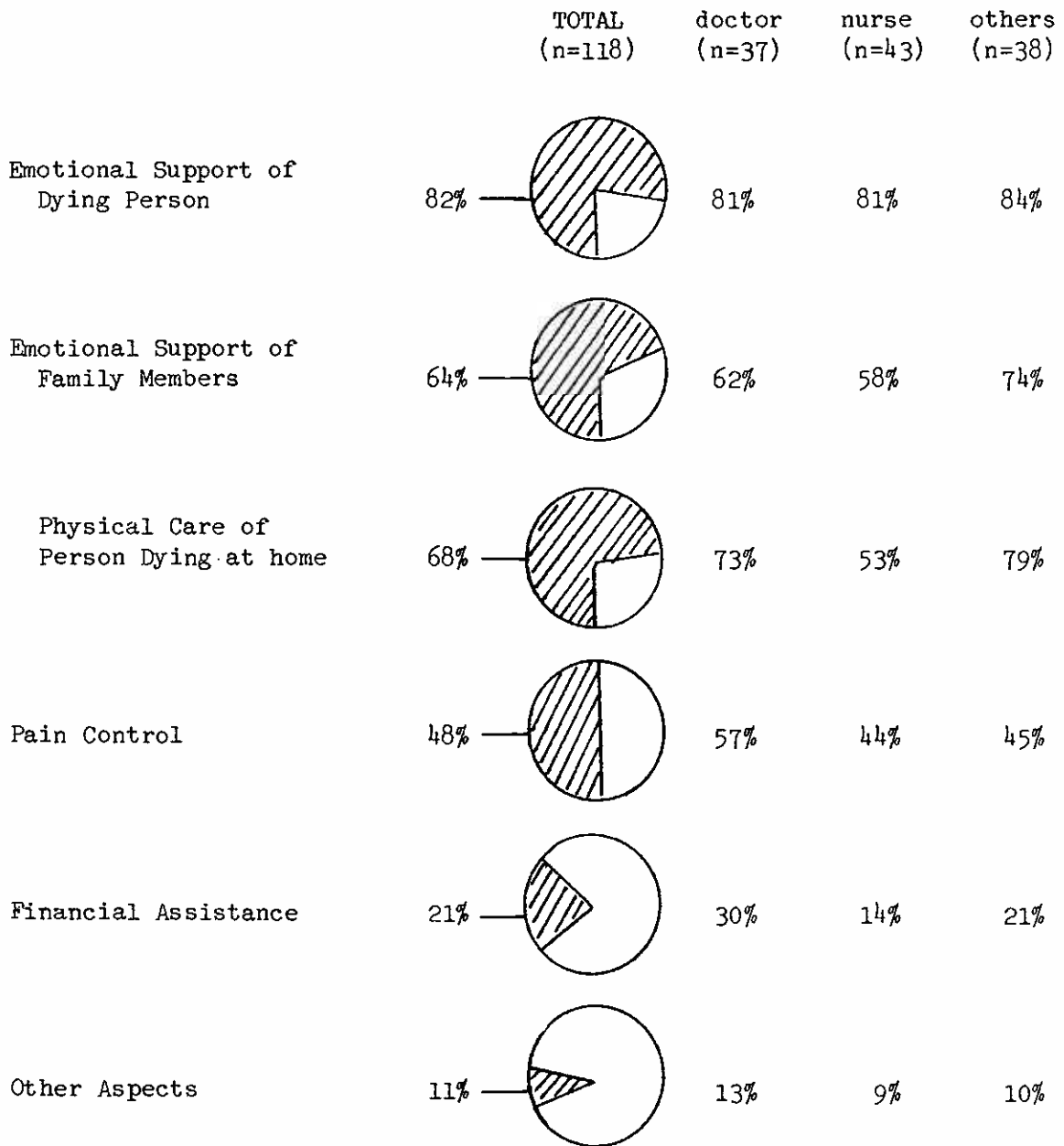
**Figure 1: Which of the following do you fear most about the dying process? (N = 118, present study)**



**Personal Fears vs Carers' Role in Terminal Care**

ROLE	FEARS				Role Total
	No %	Other fears	Prolonged dying process	No Fear or not sure	
Doctor	No %	10 27.0	14 37.8	13 35.1	37 31.4
Nurse	No %	11 25.6	23 53.5	9 20.9	43 36.4
Spiritual advisor	No %	5 41.7	3 25.0	4 33.3	12 10.2
Social worker	No %	5 41.7	3 25.0	4 33.3	12 10.2
Others	No %	4 28.6	6 42.9	4 28.6	14 11.9
COLUMN TOTAL	No %	35 29.7	49 41.5	34 28.8	118 100.0

Figure 2. Perceived-Neglect in Terminal Care vs Personal Role in Terminal Care (Present study)



(2) Present provision for the dying in Singapore

"Do you think dying is adequately provided for in Singapore?" 96% answered NO. They were asked to indicate which areas were being neglected. Cross-tabulation of their role with their perceived-neglect is found in Figure 2. 95% of the 118 carers considered care of the dying the joint responsibility of the medical team and the family.

(3) Further comments for carers

Additional comments were given by about half of the 118 carers. Among this half, they mentioned specifically the need to consider: euthanasia or related ethical issues (10%), special educational provision for carers (10%), hospice, special center or special team (20%), the spiritual aspect of life and death (20%).

Those who did not give additional comment did not differ much in their role in terminal care compared

with those who gave additional comments. No further comments were given by 51% of the doctors, 65% of the nurses, 47% of the others (chi-sq p = 2379; not stat. sig.).

II Findings of seminar evaluation

Of the 157 who attended the seminar, 111 (70%) returned the evaluation forms. Assessment of the professional categories of this group and those who participated in the survey indicates that the nurses were most responsive. (Table 1). The status of the 46 who attended but did not evaluate the seminar is not available.

69-97% found the 4 topics covered and the general discussion useful. 87% would like to attend related seminars in the near future. 71% would like to meet as a multidisciplinary group while only 13% would like to meet with only their own speciality. Cross-tabulation of their other requests with their professional categories show that 50% to 76% would like to learn

**TABLE 1: DISTRIBUTION OF CARERS AT DIFFERENT STAGES OF SMA SEMINAR ON TERMINAL CARE (PRESENT STUDY)**

	SMA* or doctors	Nurses	Social worker or clergy	Others	(Total)
Notified	1670	100	100	—	(1870)
Returned SQ	37	43	24	14	(120)
Evaluated S	18	72	10	11	(111)

SQ = Survey Questionnaire

\*SMA = Members of Singapore Medical Association

S = Seminar

**TABLE 2: REQUESTS BY PARTICIPANTS FOR FUTURE MEETINGS DURING SMA SEMINAR (PRESENT STUDY)**

	pain control	psycho. aspect	role in terminal care
Doctors (n = 18)	56%	50%	50%
Nurses (n = 72)	67%	64%	54%
Others (n = 21)	67%	76%	52%
Total (n = 111)	65%	64%	53%

more about 3 specific aspects of terminal care, (Table 2, chi-sq tests on all did not indicate statistical significance), i.e. pain control, psychological aspects and their own role in terminal care.

## DISCUSSION

Locally, there are at least 14 publications on death, euthanasia and terminal care (1-14). Most of them are short review articles, editorials or personal opinions. One was written by a lawyer (2). Based on these published opinions, there seems to be a need for a special team to handle the medical, legal, social, psychological, spiritual and other needs of the terminally ill in order to ensure a dignified dying process, which is not prolonged unnecessarily. On the other hand, carers and the affected community need to be educated on the accepted approach to this very complex, yet inevitable, process of being alive (for some).

While the published opinions are mostly against euthanasia (6, 7, 10, 11, 14) there is already evidence that euthanasia by omission or commission may be on the increase (2, 8, 15). Theoretically, medical advances can allow terminal patients to die comfortably (10, 11, 15) and this has been achieved in the hospice movement (4, 15, 16). In practice, there appears to be a gap between what is available and what is accessible for terminal care in Singapore. Three terminal cancer patients were described to be suffering from intractable pain (1, 8). One of them pleaded for voluntary euthanasia in vain and committed suicide (8). They probably represent many more terminal patients, cancerous or otherwise, who may benefit from efforts to bridge this gap (4, 15).

Most Singapore families are housed in high-rise flats (10, 11) and there is an increasing trend towards women joining the work-force. Thus, there is an increasing scarcity of female carers. The health-care service-utilization trend is a mixture of the scientific with the non-scientific, with a high tendency towards doctor-hopping (1).

Specialists in the community and hospital settings, who may not be suitable for terminal care, are often approached.

## LOCAL STATISTICS

As pointed out during the SMA seminar (15), the total number of deaths per year in Singapore has been increasing steadily from 10,178 in 1962 to 12,896 in 1982. The crude mortality rate for cancer, is also increasing. A special kind of care is often required in such cases because of a prolonged dying process. The proportion of deaths occurring away from private residences, has increased in all ethnic groups (from 1962 to 1982): 26% to 40% for Malays, 54% to 65% for Chinese, 66% to 71% for Indians, 54% to 74% for Others. Most of these deaths occurred in acute hospitals.

In 1983, 4,520 of all the 13,321 deaths occurred in those below 60 years (17). 2,628 of the total deaths were from those who were married and below 60 years. 2,911 died from malignant neoplasm, of which 1,047 were below 60 years old. Deaths not occurring at home continued to be high (63%), with a similar pattern of distribution for the four ethnic groups as in 1982.

## CONCLUSION AND RECOMMENDATIONS

Despite the high non-response rates in the present study, it has identified;

- (1) the presence of a group of carers who feel that terminal care services in Singapore is grossly inadequate. This perception may explain why they themselves also harbour fear(s) towards death and the dying process.
- (2) the desire among these carers to be more equipped for terminal care in the near future.

In conclusion, we recommend regarding terminal care in Singapore, the initiation of:-

- (1) Initial training (preferably overseas) of key personnel, in the newer approach to terminal care and support of carers.
- (2) Teaching at undergraduate and postgraduate levels, including multidisciplinary sessions.
- (3) Research into the specific needs of Singaporeans, especially at the cultural, spiritual and emotional levels.

The introduction of hospice care extended to the whole community, would not only incorporate the 3 recommendations, but would bring the holistic caring approach so that Singaporeans could live in peace until they die (15).

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