

Attitudes of Japanese Physiotherapists towards Death and Terminal Illness

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Abstract. A preliminary study was carried out by means of a three-part questionnaire to determine attitudes of 146 physiotherapy clinicians in Yamaguchi Prefecture, Japan, towards death and terminal illness. This self-administered postal survey was cross-sectional. Results indicated that there was little discernible difference in the response to the questions among the subgroups *vis-à-vis* gender and years of professional practice. Topics of death and terminal illness were found to have been subjects that were relatively openly discussed in the respondents' families. The majority of the respondents desired "dignified death" for themselves and to be informed of their condition if they became terminally ill. Although they were willing to treat persons with terminal illness, the respondents were psychologically uncomfortable in the situation, and the majority of them seemed to lack sufficient knowledge and, therefore, necessary execution skills to provide the necessary psychological support when subjected to such a situation. Therefore, education and training of physiotherapists enabling them to professionally confront persons with terminal illness would be of significant value if introduced into the physiotherapy curricula.

Key words: Attitude, Death and terminal illness, Physiotherapist

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INTRODUCTION

Due to the recent advancement of gene analysis technology, elucidation of the causes and pathophysiology of so-called intractable diseases has progressed, and the development of their treatments is being actively pursued¹⁾. This trend has diversified into many fields of medicine and has led to an increase in treatment options particularly in the practice of dealing with malignant neoplastic diseases, one of the leading causes of death in Japan. Because of such progress in medical science we have an increase in a number of persons who are surviving the ordeal of life threatening diseases or conditions, together with the possible resultant

physical or psychological consequences. With these advances in medical science, physiotherapists increasingly have to treat persons who are facing life-threatening conditions including those receiving palliative care. However, persons generally referred to physiotherapy overwhelmingly consist of those who can be expected to attain a considerable amount of functional recovery. Treating such clients from a vigorous mental and physical get-well aspect will generally be sufficient for a physiotherapist. However, when confronted with a terminally ill client, a physiotherapist may well portray anxiety or be incapable of coping with such a situation. This may result in an inappropriate treatment and, therefore, possibly add to a client's

anxiety about his/her condition when approached by a physiotherapist with such an attitude, when, as a healthcare professional, he/she is expected to provide quality treatment²⁾.

There is a paucity of physiotherapy literature concerning attitudes towards death and terminal illness with regard to Japanese physiotherapy clinicians. Therefore, the purpose of this preliminary study was two-fold: 1) to gain knowledge on views and attitudes of Japanese physiotherapists when treating critically ill and terminally ill persons; and 2) to contrast the findings of this study with those of a former study by Luttkicken et al. in the United States of America (USA)³⁾. The findings from this study will help to contribute to our knowledge on the trend of attitudes of Japanese physiotherapists towards persons with terminal illness. Development in this research area will possibly necessitate the need for further education of physiotherapists in this field, and this will prove to be a valuable attribute to their training and, consequently, to the quality of life of terminally ill persons⁴⁾.

METHODS

Instrumentation

A self-administered questionnaire survey consisting of two parts was selected as the appropriate tool for data collection. Part 1 of the questionnaire consisted of a total of 10 questions, the first seven of which were originally developed by Edwin S. Shneidman⁵⁾, and the latter three originally formulated by Carolyn A. Luttkicken³⁾. The first four questions related specifically to the individual's feelings about dying (Table 2), and questions 5, 6 and 7 were aimed at eliciting physiotherapists' thoughts on the influence of psychological factors concerning death, as well as their reactions towards terminal illness (Table 3). The last three questions focused directly on client care (Table 4). In answer to each of the 10 questions, the respondents were asked to choose one out of several choices.

Part 2 of the postal survey sought background and demographic information on the respondents in which they were asked about their gender and years of professional practice.

Participants and procedures

The original English version of the ten questions

for Part 1 was translated into Japanese by the authors. Following this, the physiotherapists at Kaga Onsen Hospital, Department of Physical Therapy critically examined the questionnaire for its wording and phrasing.

Three hundred and thirty-two respondents were selected from a convenience sample of physiotherapists practising in Yamaguchi Prefecture. Because of the relatively small number of physiotherapists making up the total membership in the prefecture, almost all of the members were selected from the 2006 membership directory of the Yamaguchi Physical Therapy Association. Persons excluded from this study were those who were involved in teaching and research, were inactive at the time of the survey, were employed in local government offices or were employed part-time. The surveys took approximately 30 min to complete and were mailed to all of the respondents with a letter of explanation concerning the purpose of the study, together with a stamped-addressed return envelope. The instructions to respondents included a guarantee of confidentiality, the need to respond to every statement and the absence of a right or wrong answer, and that the questionnaires would remain anonymous.

The study was carried out in June and July of 2006, and the time period required for return of the survey to the investigators was within three weeks of receiving the mailed questionnaire. No reminder, by telephone or otherwise, was necessary. Approval by the research ethics board for this type of survey was not mandatory at the location of the principal investigator.

Statistics

Responses to the questionnaires were coded and entered into a data file using *Microsoft Excel 2001*. A descriptive summary and frequency analysis were performed for all of the items. In order to examine whether an individual respondent's background would have any influence on the answers, the chi-square test was used. Probability values of <0.05 were considered statistically significant.

RESULTS

A total of 162 questionnaires were received, but usable returns amounted to 146, resulting in a return rate of 44.0%. The reason for the elimination of 16 of these returned questionnaires was due to

Table 1. Respondents' background

Professional practice (years)	Men No. (%)	Women No. (%)	Total No. (%)
<5	32 (24.0)	28 (19.2)	63 (43.2)
5–10	28 (19.2)	16 (11.0)	44 (30.1)
10–15	6 (4.1)	10 (6.8)	16 (11.0)
15–20	5 (3.4)	4 (2.7)	9 (6.2)
>20	10 (6.8)	4 (2.7)	14 (9.6)
Total	84 (57.5)	62 (42.5)	146 (100)

incomplete responses on the part of the respondents to some of the questions. Table 1 presents the respondents' characteristics.

The chi-square test yielded no significant differences among the subgroups that were categorised according to gender and years of professional practice. Results of the responses to the questions of the survey are presented in Tables 2, 3 and 4.

DISCUSSION

Relatively few differences existed among the subgroups of the Yamaguchi physiotherapists in response to the questions on death and dying. However, there were some discernible variations among the subgroups and also between the results of the current study and those of the one carried out in the USA³.

Personal feelings towards death

Approximately half of the respondents answered *openly* to the question on *When you were a child, how was death talked about in your family?*, while slightly over only one third (36.5%) of the physiotherapists in the USA study did³. Thus, it appears that talking about death and dying is currently relatively open among households in Yamaguchi Prefecture, Japan. However, in general, death and dying still appear to be talked about with a hushed reticence in most advanced societies, and the Japanese society is no exception. Historically speaking in Japan, caring for the sick, elderly and the dying at home used to be the normal practice. Thus, attitudes of the Japanese people towards death were instilled through this practice with the accompanying familiarity of caring for the dying (usually senior) family members at home. Therefore, the necessity for education on death and

dying for the remaining family members was unwarranted. Today, with the tabooing of death and the majority (approx. 80%) of Japanese people presently dying in hospitals and institutions there is hardly any opportunity to be educated on this subject while living in a highly industrialized society⁶. Death is, in fact, hidden from the public eye. However, since death education advocated by Deeken⁶ in the late 1980's has slowly garnered the attention of the Japanese people, talk about death and dying has become increasingly more open. If we look at death from a different perspective, we are, in fact, inundated with death, which is vividly demonstrated through computer games and films depicting violent death, together with constant coverage of murders and suicides by the media. Consequently, death is regarded as something virtual, which is seen in present-day society as a growing problem especially in the case of its influence on the younger generation^{7, 8}.

Misguided images of death and dying held by the present-day younger generation may be to their disadvantage if they, as potential physiotherapists, are confronted with the current education and training of physiotherapists. In one survey conducted in 2005 approximately 60 per cent of physiotherapy educators stated a necessity for death education to be incorporated into the study programme⁹. Through increasing students' awareness of this issue educational effects can be maximized with a focus on the affective aspect of their learning⁹.

For more than half of the respondents their personal attitudes towards death were influenced by the death of someone close to them, which is a universal emotional reaction of individuals regardless of differences in culture. However, one in four physiotherapists in the USA study stated that religious education had had an impact on their

Table 2. Personal feelings towards death

	Men n=84	Women n=62
<i>When you were a child, how was death talked about in your family?</i>		
1) Openly	34 (40.5)	31 (50.0)
2) With some sense of discomfort	10 (11.9)	6 (9.7)
3) Only when necessary and then with an attempt to exclude the children	16 (19.0)	13 (21.0)
4) As though it were a taboo subject	3 (3.6)	1 (1.6)
5) Never recall any discussion	21 (25.0)	11 (17.7)
<i>Which of the following most influenced your present attitudes towards death?</i>		
1) Death of someone close	46 (54.8)	40 (64.5)
2) Specific reading	6 (7.1)	2 (3.2)
3) Religious upbringing	2 (2.4)	4 (6.5)
4) Introspection and meditation	2 (2.4)	0 (0.0)
5) Ritual (e.g., funerals)	7 (8.3)	1 (1.6)
6) TV, radio, or motion pictures	7 (8.3)	6 (9.7)
7) Longevity of my family	4 (4.8)	4 (6.5)
8) My health or physical condition	4 (4.8)	1 (1.6)
9) Other (specify)	6 (7.1)	4 (4.8)
<i>What does death mean to you?</i>		
1) The end; the final process of life	38 (45.2)	20 (32.3)
2) The beginning of a life after death; a transition, a new beginning	3 (3.6)	6 (9.7)
3) A joining of a spirit with a universal cosmic consciousness	5 (6.0)	1 (1.6)
4) A kind of endless sleep; rest and peace	13 (15.5)	5 (24.2)
5) Termination of this earthly life, but with survival of the spirit	6 (7.1)	11 (17.7)
6) Don't know	16 (19.0)	7 (11.3)
7) Other (specify)	3 (3.6)	2 (3.2)
<i>If you had a choice, what kind of death would you prefer?</i>		
1) Tragic, violent death	0 (0.0)	4 (3.2)
2) Sudden, but not violent death	13 (15.5)	4 (3.2)
3) Quiet, dignified death	49 (58.3)	43 (69.4)
4) Death in the line of duty	1 (1.2)	1 (1.6)
5) Death after a great achievement	1 (1.2)	1 (1.6)
6) Suicide	0 (0.0)	0 (0.0)
7) Homicide victim	0 (0.0)	0 (0.0)
8) There is no "appropriate" kind of death	8 (9.5)	3 (4.8)
9) Other (specify)	12 (14.3)	6 (9.7)

Figures in parenthesis denote percentage.

personal attitudes towards death³⁾, while only 4.1 per cent of the respondents in this study cited religious education as being an influencing factor in this regard, which may be a reflection of a lack of religious education in contemporary Japanese society.

The answer *the end* was the response given to *meaning of death* by approximately 40 per cent of

the Japanese respondents. In the USA study 27 per cent of the physiotherapists believed that *This earthly life is terminated, but with survival of the spirit* and 16.5 per cent believed in *the beginning of a life after death*³⁾. This fact, again, may reflect on an education based on Christian faith in the USA.

The answer *quiet, dignified death* was the choice given by the majority of the respondents when they

Table 3. Responses concerning reactions to terminal illness

	Men n=84	Women n=62	Professional practice (years)				
			<5 n=63	5–10 n=44	10–15 n=16	15–20 n=9	>20 n=14
<i>To what extent do you believe that psychological factors can influence (or even cause) death?</i>							
1) I firmly believe they can	25 (29.8)	21 (33.9)	23 (36.5)	13 (29.5)	3 (18.8)	4 (44.4)	1 (7.1)
2) I tend to believe they can	46 (54.8)	31 (33.9)	32 (50.8)	25 (56.8)	9 (56.3)	4 (44.4)	9 (64.3)
3) I am undecided, or don't know	10 (11.9)	8 (12.9)	6 (9.5)	4 (9.1)	4 (25.0)	1 (11.1)	3 (21.4)
4) I doubt that they can	3 (3.6)	2 (3.2)	2 (3.2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (7.1)
<i>If your physician knew that you had a terminal disease and a limited time to live, would you want him to tell you?</i>							
1) Yes	59 (70.2)	47 (75.8)	47 (74.6)	35 (79.5)	10 (62.5)	8 (88.9)	6 (42.9)
2) No	7 (8.3)	1 (1.6)	1 (1.6)	4 (9.1)	0 (0.0)	0 (0.0)	3 (21.4)
3) It would depend on the circumstances	18 (21.4)	14 (22.6)	15 (23.8)	5 (11.4)	6 (37.5)	1 (11.1)	5 (35.7)
<i>What effort do you believe ought to be made to keep a seriously ill person alive?</i>							
1) All possible effort: transplants, kidney dialysis, etc.	2 (2.4)	1 (1.6)	2 (3.2)	1 (2.3)	0 (0.0)	0 (0.0)	0 (0.0)
2) Efforts that are reasonable for that person's age, physical condition, mental condition, and pain	49 (58.3)	47 (75.8)	45 (71.4)	28 (63.6)	10 (62.5)	5 (55.6)	8 (57.1)
3) After reasonable care has been given, a person ought to be permitted to die a natural death	26 (31.0)	12 (19.4)	13 (20.6)	11 (25.0)	5 (31.3)	3 (33.3)	6 (42.9)
4) An elderly person should not be kept alive by elaborate artificial means	7 (8.3)	2 (3.2)	3 (4.8)	4 (9.1)	1 (6.3)	1 (11.1)	0 (0.0)

Figures in parenthesis denote percentage.

were asked about their preference of how they wished to face death. This finding implies that the physiotherapists in Yamaguchi Prefecture attached a high value to a *noble* death; i.e. they would rather begin a quiet journey to the next world while having no regrets or causing any inconvenience to anyone when their death was inevitable.

Approximately 12 per cent of the respondents chose *sudden, but not violent death* in answer to the question on the preference for their own death. This response may reflect their own personal fear of facing death over an extended period of time or from their personal experience of having been called upon to treat persons who have been subjected to *heroic efforts* to prolong their life and are, therefore, aware of the resulting low quality of life that must be endured by such persons following their survival. This point of view seemed more prevalent in the American survey with the percentage of their answers to the above question amounting to 36.5³⁾. Four women respondents preferred *tragic, violent death*, while no American counterpart stated this preference³⁾. It is uncertain

of whether or not this finding implies multifaceted personal attitudes towards death among Japanese women.

The answer *There is no "appropriate" kind of death* was chosen by approximately 12 per cent of the respondents. This finding may be based on the notion that *A patient's death signifies defeat for healthcare professionals*, or death is too sad to contemplate for the majority of the respondents who were young.

Responses concerning reactions to terminal illness

Approximately one third of the respondents firmly believed *psychological factors can influence death*, while approximately half of those in the USA study did³⁾. However, if one adds 53 per cent of the Yamaguchi physiotherapists who *tended to believe* this, then the percentage of the believers amounts to 84. Thus, we can conclude that the majority of the respondents are generally aware of the effect of psychological factors influencing death, which is proof of people today being cognizant of these factors to a considerable degree regarding health

Table 4. Responses to questions concerning care of terminally ill persons

	Men n=84	Women n=62	Professional practice (years)				
			<5 n=63	5–10 n=44	10–15 n=16	15–20 n=9	>20 n=14
<i>When you are asked to treat a terminally ill person, how do you usually feel about treating him/her as compared to persons without terminal illnesses?</i>							
1) Feel different with most terminally ill persons and avoid treating if possible	2 (2.4)	2 (3.2)	1 (1.6)	2 (4.5)	1 (6.3)	0 (0.0)	0 (0.0)
2) Feel different but willing to treat	16 (19.0)	13 (21.0)	8 (12.7)	9 (20.5)	5 (31.3)	2 (22.2)	5 (35.7)
3) Feel different but willing to treat and give any needed psychological support	36 (42.9)	37 (59.7)	42 (66.7)	15 (34.1)	7 (43.8)	5 (55.6)	4 (28.6)
4) Feel no different	30 (35.7)	10 (16.1)	12 (19.0)	18 (40.9)	3 (18.8)	2 (22.2)	5 (35.7)
<i>How do you usually feel about discussing death or the person's illness with the person?</i>							
1) It is not my role to discuss	10 (11.9)	3 (4.8)	1 (1.6)	4 (9.1)	0 (0.0)	1 (11.1)	6 (42.9)
2) I try to avoid talk about death because I feel uncomfortable	13 (15.5)	10 (16.1)	15 (23.8)	5 (11.4)	1 (6.3)	2 (22.2)	1 (7.1)
3) I am willing to discuss death with the person, but I don't actively encourage it	30 (35.7)	27 (43.5)	22 (34.9)	21 (47.7)	10 (62.5)	2 (22.2)	2 (14.3)
4) I actively encourage the person to discuss his feelings of death with me	5 (6.0)	1 (1.6)	4 (6.3)	2 (4.5)	0 (0.0)	0 (0.0)	1 (7.1)
5) I don't think I have sufficient training to discuss death	26 (31.0)	21 (33.9)	21 (33.3)	12 (27.3)	5 (31.3)	4 (44.4)	4 (28.6)
<i>Did your formal physiotherapy education include information on how to handle a person's feelings of death?</i>							
1) Included a great deal of information on how to handle person's feelings of death	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
2) Included sufficient information on handling death	8 (9.5)	7 (11.3)	7 (11.1)	4 (9.1)	2 (12.5)	1 (11.1)	0 (0.0)
3) Included very little information on handling death	49 (58.3)	42 (67.7)	45 (71.4)	26 (59.1)	10 (62.5)	5 (55.6)	6 (42.9)
4) Did not deal with death at all	27 (32.1)	13 (21.0)	11 (17.5)	14 (31.8)	4 (25.0)	3 (33.3)	8 (57.1)

Figures in parenthesis denote percentage.

and illness. The findings for this question for the American study were not much different from that of the current Japanese study except that the numbers of the American physiotherapists who *firmly believed* and *tended to believe* were reversed³⁾.

Three quarter of the respondents in this study *wished to be informed if they had a terminal illness and a limited time to live*, while 83 per cent of the USA study did so³⁾. However, there are presently only 40 per cent of physicians in Japan who would inform persons with advanced cancer of such a fact¹⁰⁾. In other words, the majority of physicians still equate terminal illness with death. In 2002 the definition for palliative care changed from *care of clients who no longer respond to treatment with the aim of a cure* to that of *an approach of improving the quality of life of clients and their family who are*

faced with life-threatening diseases or conditions by means of prevention, assessment and control of pain and care of other physical, sociopsychological and spiritual problems. However, if one considers the situation as it presents itself today the above definition may still remain idealistic.

In response to *What effort do you believe ought to be made to keep a seriously ill person alive?* two-thirds of the respondents chose *efforts that are reasonable for that person's age, physical condition, mental condition, and pain*, with the respondents in the USA study showing a similar tendency³⁾. Nowadays the life of terminally ill persons can be lengthened by means of advanced medical technology. However, even though increased awareness of palliative care has increased in the mind of healthcare professionals in Japan, controversy still ensues on whether or not to extend

the life of terminally ill persons. The respondents of this study seem to be possibly circumventing excessive technological intervention in the case of terminally ill persons.

A study by Lutticken, et al. revealed that only 7.3 per cent of American nurses believed *all possible effort must be made to keep a seriously ill person alive*, and not one American physiotherapists who did so³⁾. By quoting Golub and Reznikoff¹¹⁾, Lutticken, et al. asserted the following as one possible explanation for this small disparity between the two professional groups: nurses may have more experience with actual deaths of clients and, therefore, are more often placed in situations involving moral and ethical decisions concerning the preservation of life³⁾, while physiotherapists rarely have the opportunity to do so. The majority of the respondents in the current study seemed to have had less of a need to comply with the above statement *all possible effort must be made to keep seriously ill person alive* compared to that of the American nurses³⁾.

Responses to questions concerning care of terminally ill persons

The answer *feel different* was the response in this study given to *When you are asked to treat a terminally ill person, how do you usually feel about treating him/her as compared to persons without terminal diseases?*, which was almost a match to that of the USA study (70% vs. 84%³⁾). This question referring to physiotherapy for terminally ill persons may have been rare 32 years ago even in USA. This finding suggests that the majority of physiotherapists would *feel uncomfortable* treating dying persons, but be *willing to provide treatment and any needed psychological support*. However, the response *feel no different* amounted to approximately three times greater than that given by the American respondents (27.3% vs. 10.4%³⁾).

Approximately 90 per cent of the respondents did not receive any education on death and dying according to this study, which is reflected in the answer that only 4.1 per cent of them would *actively encourage the person to discuss his feelings of death with them*. Therefore, the majority of the respondents may be engaged in avoidance behaviour in diverse ways²⁾. Since treatment measures for dying persons provided by healthcare professionals are dependent largely on the attitudes of both the dying person and the healthcare

professional²⁾, introducing physical care, together with a psychological approach, to dying persons into the physiotherapy curricula may alleviate the present lack of preparedness on the part of physiotherapists treating persons who are terminally ill.

Approximately half of the Yamaguchi physiotherapists with more than 20 years of professional experience seemed to think that it was not their role to *discuss death or the person's illness with them*. This may be due to the fact that the philosophy of the physiotherapists differs according to the length of their professional experience¹²⁾. Another explanation may be that they consider discussion of death and dying with the person who is terminally ill beyond their responsibility and scope of their professional practice as a physiotherapist; or, it may result from a legacy of their being trained as physiotherapists when the perception towards death and dying in their field of practice was inconsequential. Whatever the reason, this finding is of little consequence in this study because the number of respondents with more than 20 years' experience was only 14; but, as health professionals, it is our responsibility to treat the client as a whole person, not just as a condition or disease.

Establishment of a healthy professionalism in physiotherapy in regards to the quality of life of persons with terminal illness will be conducive to awareness of using the acquired skills and development of new skills. Kübler-Ross advocates that the goal of healthcare professionals is not to educate a professional to care for dying persons, but to train hospital personnel so that they can comfortably face the dying person and implement measures for the solution of problems associated with it²⁾. As physiotherapists are having increasing opportunities to perceive and understand their own feelings towards death and the necessary training to understand and respond to such feelings of the terminally-ill, they will be better prepared, in the future, to assume newer and active roles in the treatment of these persons.

Limitations

One limitation of this study was that the physiotherapists from only one out of the 47 prefectures in Japan were represented, so the survey results are not necessarily representative of physiotherapists throughout Japan. In addition, the

study of Lutticken, et al. that was used as a comparison to this preliminary study, was carried out 32 years ago, but, in spite of this time lag, the authors still consider it relevant as a comparison for their present study.

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