



Excerpts
From



Japan Society for Dying with Dignity Newsletter

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As of September 1, 2013, JSDD has 125,484 members.

Contents:

- Research on Terminal Stage of life Awareness -1-
- Graph of Terminal Stage of Life National Awareness of Research Results -3-
- Commentary: Research Results Reveal Major Issues -4-
- Movement in Legislation -6-
- Living Will Workshop of Japan~In Search of New Structure -6-
- From One Telephone Call -8-

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Research on Terminal Stage of Life Awareness reported by Ministry of Health, Labor and Welfare

Terminal Stage of Life National Awareness: 70% in support of Advance Healthcare Directive (Living Will); only 3% in Writing

Ministry of Health, Labor and Welfare recently finished compiling a summary of its research on national awareness regarding terminal stage of life conducted every five years (2013). Although 70% of respondents were in support of having an advance healthcare directive (living will) in preparation for when one is not capable of making his or her own healthcare decisions, more than 50% were against legalizing the directive so that he or she can be treated in accordance with his or her own directive.

A questionnaire was sent to the following demographics; unfortunately, the response rate was only 37%:

5,000 general citizens, of which 2,197 responded
3,300 physicians, of which 921 responded
4,300 nurses, of which 1,434 responded
2,000 care givers, of which 880 responded

Comparisons cannot be made between this study and previous ones since not only was the name of the research changed from “National Awareness on Terminally Ill Stage Medical Treatments” to “Awareness on End of Life Medical Care,” there have been some changes in the contents of the questionnaire. In this

study, the questions were much more specific and concrete, e.g., asking about particular treatments considered unnecessary if diagnosed with terminal stage cancer, heart disease or traffic accident, and where they would like to spend their last days.

Necessary, but Have Not Prepared

In this study, the term, “living will” was purposely not used in the questionnaire, but questions referred to a written document you prepare in advance to choose preferred medical treatments you would like to receive (or not receive) if you are in a situation which precludes you to make your own decisions. In response, 70% of general citizens supported such document, and 2% were against it. 73% of physicians, 85% of nurses and 84% of care givers were in support of it. In the 2008 study, the questionnaire asked whether there is a need for living wills, and 62% of respondents answered yes. In 2003, 59% were in support of it, and in 1998, only 48%. The trend is clear that the number of supporters has been increasing over time. For some reason, when asked if they have prepared such document, only 3% answered ‘yes’ (5% of physicians, and 4% of nurses and care givers.) It is clear that people acknowledge the need for it, but have not made the step to actually prepare it.

Precaution against Legalization

The questionnaire included a question, “Do you support legal endorsement of medical treatments you would like to receive or refuse in accordance with what is stated in your directive?” to which only 22% general citizens answered yes (16% physicians). On the other hand, over half of the general respondents, 53% (and 71% physicians!), answered negatively, such as “unnecessary” or “should not be legalized.” In the 2008 study, those who were in support of the living will were asked the question; “Should it be legalized or should the ultimate decision be left to the physician and family without legalizing it?” Only 34% said it should be legalized, while 37% in 2003 and 49% in 1998. The trend clearly indicates that for some reason, the support for legalization of the living will has been decreasing.

Refusal to Administer Cardio Pulmonary Resuscitation and Artificial Respiration

In this study, more specific questions regarding types of medical treatments people preferred based on illness. The following are some examples of questions and responses from this study:

Question: If you are diagnosed with terminal stage cancer and have difficulty eating and breathing, but have no pain and the mentally unchanged, what types of medical treatments would you refuse?

72% Stomach tube feeding
69% Cardio pulmonary resuscitation
67% Artificial respiration
63% Nasal tube feeding

Question: What types of medical treatments would you refuse if you could no longer drink from your mouth?

24% Antibiotics for pneumonia
22% Intravenous therapy

Responses were similar when asked the same question but in a situation of having advanced stage dementia and you need assistance just to get around.

In a situation of being in vegetative state for more than six months from traffic accident and being tube fed, 27% actually wanted to receive antibiotics for pneumonia, but a very low percentage of people wanted artificial respiration and cardio pulmonary resuscitation, 9% and 11% respectively.

Attitudes of Healthcare Providers Lagging

Healthcare providers were asked the question, “Do you have sufficient communications with patients in dying process and their families regarding their treatments?” 43% of physicians responded with “yes, sufficiently;” 29% responded with “somewhat;” and 6% admitted that they do not. There seems to be a lack of communication between patients and physicians in many cases.

To the question, “Do you refer to the guidelines issued by the Ministry of Health, Labor and Welfare on decision process regarding medical care for terminal illnesses?” 20% said “yes,” 23% said “no,” and 34% said they did not know about the guidelines. The question, “Do you refer to guidelines issued by relevant medical associations?” received a 23% “no” and 31% “do not know about the guidelines.” Surprisingly, it is clear that these guidelines are not well known or recognized among the physicians.

Terminal Stage of Life National Awareness of Research Results (graph)

(1) Legalization of medical directive for treatments

Do you support legal endorsement of medical treatments you would like to receive or refuse in accordance with what is stated in your directive?

Answers:

1	support legalization	2	legalization unnecessary	3	should not legalize
4	don't know	5	no answer		

(General population: 2,179 respondents)



(Physicians: 921 respondents)



(2) General population’s medical treatment wishes

What types of medical treatments would you want to receive if you had advanced stage dementia and need assistance just to get around?

Answers:

1	would like to receive	2	do not wish to receive	3	don't know
4	no answer				

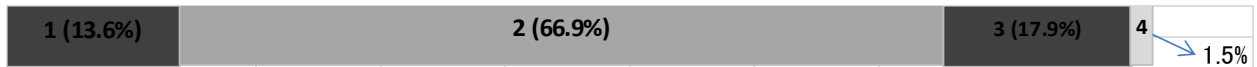
Antibiotics/IV for pneumonia:



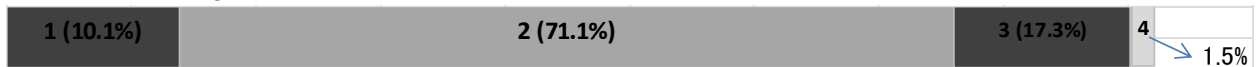
IV treatment when no longer able to drink from the mouth:



Stomach tube feeding during vegetative state (central IV feeding):



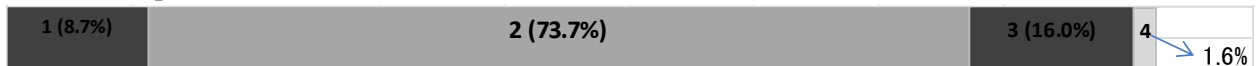
Nasal tube feeding:



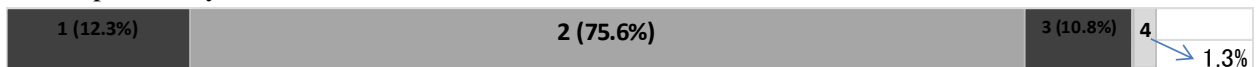
Stomach tube feeding:



Artificial respiration:



Cardio pulmonary resuscitation:



Commentary: Research Results Reveal Major Issues

-----What the Terminal stage of your life and Living Will Should Look Like-----

The major challenge of the recent awareness research on terminal stage healthcare conducted by the Ministry of Health, Labor and Welfare was to figure out its implications as a “stand alone” study since the contents of the questionnaire differed so much from the previous studies which had been conducted every

five years to make any kind of comparison. Nonetheless, the results of this study carry just as much importance to JSDD as the previous.

The biggest issue we see is the fact that despite 70% of general citizens supporting the concept of advance healthcare directive, i.e., the living will, only 3% of them actually have prepared documents. Currently, JSDD has about 125,000 members, which is only .6% of the national population over the age of 70. This indicates that there is a great potential for JSDD to increase its membership with more effective and larger scale publicity and advertisement.

Advance Healthcare Directive: Still not a Well-Known Phenomenon

Even a bigger challenge is the legalization of the living will. JSDD has worked very hard for the movement which it believes is absolutely necessary to honor patient self-determination. The fact that an increasing number of the population, over half, believes it is unnecessary (43%) or it should not be legalized (11%) is not only shocking, but devastating to our organization. How should we deal with this hard fact?

When 70% of the population responded that if diagnosed as terminally ill, they did not wish to have cardio pulmonary resuscitation, artificial respiration or tube feeding, there is a strong indication that they recognize the significance of advance healthcare directive. However, the fact that only 3% of them actually have it suggests the possibility that people simply are unaware or do not understand the full concept of advance healthcare directive or the living will.

Furthermore, what is exceptionally perplexing is the fact that the number of physicians who oppose legalization of the living will increased to 71%. The proposed bill includes a liability exemption clause to protect them from legal prosecutions when patients die as a consequence of physicians honoring their living wills. Why anyone would oppose something that protects them is mystery.

Unclear Intent behind the Questions

To make any sense out of these results, we are inclined to make two assumptions. 1) The concept of the living will is still not well-known among the general population. 2) Most physicians do not clearly understand the meaning, the process, or the significance of legalizing the living will.

The changes in the way questions were worded in this study compared to previous ones is also a concern. Take a look at a couple of examples:

What do you think about preparing in advance a document expressing your desire to refuse any life prolonging measures in case of situations in which you are suffering from an incurable illness or at a terminal stage of your life? (Previous Studies)



How do you feel about preparing in advance a document depicting which treatments you would refuse for situations in which you lack mental ability to make such decisions on your own? (This Study)

The previous questions used terms such as “incurable” and “terminal stage” which limited circumstances under which a document expressing your wishes for dignified death was needed. The questions in this study avoided these terms to cover a wider range of circumstances under which a pre-written document may be required. Therefore, the new questions were worded in such a way that respondents could have interpreted them differently which led to differences in their responses.

In any case, this study revealed the fact that many people do seek palliative treatments and do not wish for life prolonging measures at terminal stage of life. JSDD will continue to work towards making it common knowledge that the living will is an effective and useful tool to make dignified death a reality for those who wish.

Movement in Legislation: Diet Members Coalition for Dying with Dignity (DMCDD)

DMCDD Members Seeking Legalization Slightly Decreases

At the House of Councilors election held in July, DMCDD (headed by Mr. Teruhiko Mashiko) lost five diet members from 125 to 120. Mr. Taro Asou, the Finance Minister, was elected as the chief advisor, and Ms. Akiko Santo, ex-Vice President of the House of Councilors was elected as an advisor.

Soon after the election, DMCDD lost 34 members; however, nine new members were elected including Mr. Yuuya Niwa, ex-Minister of Health, Labor and Welfare. Also due to the efforts made by JSDD staff, the number of House of Representatives members were increased to 86, with a total of 120 DMCDD members.

In July 2009, the leading party shifted from the Liberal Democratic Party to the Democratic Party, then back to the Liberal Democratic Party/Komeito Party in December last year when the Democratic Party was defeated in the House of Representatives election. These frequent changes of power in the government caused changes in DMCDD membership, some first timers. Unfortunately, this led to some previously held discussions to start from scratch. Despite this seemingly stagnant situation, Prime Minister Abe exhibited a positive posture by stating, “I want a system in which a patient is not forced to accept life prolonging measures against his/her will, while a physician is able to care for his/her patients with confidence and peace of mind.”

We believe that the Abe Administration will remain in power with stability and will soon reopen discussions in order to make immense strides towards legalization of living will.

Living Will Workshop of Japan - In Search of New Structure -

The Living Will Workshop of Japan inaugural meeting was successfully held on June 9, 2013 and was reported in the last issue of JSDD Newsletter #150 (July 1). We decided to revisit the meaning of this completely new form of workshop among healthcare providers, patients and families.

Recent films about end of life such as “Ending Note” and “Last Trust” have shown popularity; book stores display topics of gentle death and terminal stage of life all over the counters. This “End of Life” boom in Japan is likely a direct reflection of 30 million people now reaching over the age of 65, a quarter of the entire population of Japan.

JSDD President and Chairman of the Living Will Workshop of Japan, Dr. Iwao, founded this workshop because he felt the need for comprehensive meetings in view of this current trend to openly discuss death with dignity and living will.

Death of a human being should not only be discussed from a physician’s point of view. Patients’ wishes, families’ confusion and agony are important factors when discussing one person’s death. Care givers and social workers who closely work with and care for their patients are all involved and play a role in the dying process of a beloved human being. Each has its own perspective and issues which must be discussed and resolved together. There are not many forums where everyone in the group can discuss a topic so openly with an equal weight regardless of occupation or social stature.

Scope of Discussions beyond JSDD Policies

Even with the basic conditions of dignified death clearly defined; being incurable and at terminal stage while fully depending on life sustaining measures, the decision is tough to make depending on type of illness and patient medical history. In reality, families’ wishes and confusion seem to heavily influence the decision to administer life prolonging measures when the time comes. In order to fully honor the patient living will, all of these issues must be addressed and taken into consideration.

One of the main challenges ahead is to determine in depth what terminal stage really looks like depending on the illness or situation: dementia, cancer, persistent vegetative state, senility, or emergency rescue from an accident. This will require a lot of research and data gathering from people who work in these scenes on a daily basis. At the same time, only when we have a clear understanding of what the families go through and what challenges they face, can we begin to discuss what dignified death and living will should be in Japan. Focusing on resolving issues at hand should help us establish a new form of dignified death. Therefore, the workshop is not the place for doctors to present their accomplishments, but a new ground where medical care and patient welfare issues are presented openly and thoroughly and resolved from all aspects.

There is a plethora of topics that need to be discussed, for instance, what percentage of physicians actually honor their patients’ living will while the living will is still in the process of being recognized in legislature; views regarding life prolonging measures for the disabled; the need for a proxy when a patient with a living will loses consciousness; where to draw the line between dignified death and euthanasia.

The topic of the second workshop on November 23 will be “dementia.” The living will of a patient with dementia is valid as long as it was prepared while the patient was still mentally competent. What is the definition of mental competency? Can family members interpret the intent of a patient? How do we know if the intent of the dementia patient hasn’t changed since he/she was in good health? There are many questions to be answered.

Although the workshop is collocated with JSDD headquarters, it is important that the discussions of the workshop are open and develop beyond the limitations set by JSDD policies.

From One Telephone Call - Dementia -

How many phone calls does JSDD Headquarters receive on a daily basis? Let's say 100 calls a day. That's still 15 calls every hour. Of course, we take calls of people wanting to become members or report a change of address. Every once in a while, we receive calls similar to the following: It was a man 60-70 years of age. He articulately explained his situation. "My mother wanted to die with dignity, so she became a member; however, her dementia has advanced in the last two years, and she is now hospitalized. She is receiving life prolonging measures such as IV therapy. I want them to stop, but found out that she had not been paying her JSDD membership fees. What should we do?"

We checked her records and found out that her fees had not been paid for the last two years. JSDD policy is that membership becomes invalid after three years of no payment, assuming the loss of interest in dying with dignity. She did not pay for two years, so her membership should still be valid.

Is it enough to simply follow the manual instructions?

The man continued, "In other words, we can assume that she has no intentions of canceling her membership?"

We hesitate to say, "No, she does not."

According to our policy, she is still a valid member, but there is no way to confirm whether she still intends to keep her living will valid. Her lack of payment could have been a deliberate decision on her part to no longer keeping her living will valid or due to dementia.

When we explained our position, the man said, "You are right. We don't know if she still have the same intent. Let me think about this some more," and hung up the phone.

What is her intent?

We never met him, but for every family member such as this man, the stories are very deep and serious because they are family matter-very personal. When we face reality and the current system, we are sometimes at a loss. There is only so much this organization can do, but we must take each case with the utmost sincerity and integrity.

Here is another example.

A clerk from a law firm representing a legal guardian called us. The question was if it is possible to cancel his client's JSDD membership because he is suffering from dementia. Our response was, "It is not a problem to withdraw JSDD membership at any time, but can you prove that he wants to withdraw?" His response was, "Our client does not possess the mental capacity to express his intent, so no, it is not

possible.” We responded with, “Again, members can withdraw at any time, but we need confirmation from the member about the decision.” He said, “I will have to talk to the lawyer.”

There is no way to confirm the current intent of the person when he or she is in vegetative state or advanced stage of dementia. If we simply follow the manual instructions and organization policy, the answer is easy; “yes, we will start the withdrawal procedure.” We are in no position to read into someone’s mind when that person is no longer capable of communicating his/her mind. All we could do was to imagine what this old patient looked like on the other side of the phone.